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Center

Free Research-based resources from the MSKTC to support individuals with

Traumatic Brain Injury

Edition 11
July 2023

www.MSKTC.org/TBI

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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®). The Center is funded by the U.S. Department of Health and Human Services (HHS), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) under grant number 90DPKT0009. To learn more, visit **http://www.msktc.org**

About the Model Systems Program

The Traumatic Brain Injury Model System (TBIMS) Program is funded by NIDILRR in the U.S. Department of Health and Human Services. The TBIMS began in 1987 and continues its mission to improve care and outcomes for individuals with TBI. Currently there are 16 TBIMS centers, each providing a multidisciplinary system of rehabilitation care, including emergency medical, acute medical, and post-acute services. In addition to providing direct services, these centers play a pivotal role in building the national capacity for high-quality treatment and research serving persons with TBI, their families, and the communities in which they reside. To learn more, visit **https://msktc.org/tbi/model-system-centers**.

Traumatic Brain Injury Model Systems

2017–2022 Funding Cycle

Alabama
UAB Traumatic Brain Injury Model System
University of Alabama at Birmingham, Birmingham, AL

Colorado
The Rocky Mountain Regional Brain Injury System
Craig Hospital, Englewood, CO

Indiana
Rehabilitation Hospital of Indiana Traumatic Brain Injury Model System
Indiana University School of Medicine, Indianapolis, IN

Massachusetts
Spaulding-Harvard Traumatic Brain Injury Model System
Spaulding Rehabilitation Hospital, Boston, MA

Michigan
Southeastern Michigan Traumatic Brain Injury Model System
Wayne State University, Detroit, MI

Minnesota
Mayo Clinic Traumatic Brain Injury Model System
Mayo Clinic, Rochester, MN

New Jersey
JFK Johnson Rehabilitation Institute
JFK Johnson/JFK Neuroscience Institute, Edison, NJ

Northern New Jersey Traumatic Brain Injury System
Kessler Institute for Rehabilitation, West Orange, NJ

New York
New York Traumatic Brain Injury Model System
Mount Sinai School of Medicine, New York, NY

Rusk Rehabilitation Traumatic Brain Injury Model System
Rusk Institute of Rehabilitation Medicine, New York, NY

Ohio
Ohio Regional Traumatic Brain Injury Model System
Ohio Valley Center for Brain Injury Prevention and Rehabilitation, Columbus, OH

Pennsylvania
Moss Traumatic Brain Injury Model System
Albert Einstein Healthcare Network, Philadelphia, PA

Texas
The Texas TBI Model System of TIRR
TIRR Memorial Hermann, Houston, TX
North Texas Traumatic Brain Injury Model System
Baylor Institute for Rehabilitation/University of Texas Southwestern, Dallas, TX

Virginia
Virginia Commonwealth Traumatic Brain Injury Model System
Virginia Commonwealth University, Richmond, VA

Washington
University of Washington Traumatic Brain Injury Model System
University of Washington, Seattle, WA

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, Independent Living, and Rehabilitation Research.

https://www.tbindsc.org/

Contents

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**.

TBI Factsheets

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

TBI Infocomics

The MSKTC translates contents from the consumer factsheets and presents them in a comic-styled storyboard format

TBI Audio Factsheet

The MSKTC narrates the consumer factsheets to develop audio factsheets to enhance user accessibility.

TBI Videos

The MSKTC works with researchers and consumers to develop 10- to 20-minute films and shorter video clips illustrating TBI Model System research and clinical practice in action and providing practice tips to people with TBI.

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 develops Hot Topic Modules, which are 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, Independent Living, and Rehabilitation Research (NIDILRR). Those reviews offer timely summaries of newly released Model System research studies using lay language for easy access.

TBI Database

The MSKTC maintains a database of nearly 900 TBI citations and abstracts of studies funded by NIDILRR.

Opportunities to Participate in MSKTC Activities

Engaging people with lived experience in our work helps make the MSKTC resources more useful. 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** or call 202-403-5600.

Collection of Traumatic Brain Injury Factsheets Offered by the MSKTC

This section contains TBI factsheets offered by the MSKTC. These and other resources are available at no charge on **www.MSKTC.org/TBI**.

Volume 1: Factsheets Developed 2007–2012

- Couples' Relationships After Traumatic Brain Injury
- Depression After Traumatic Brain Injury
- Driving After Traumatic Brain Injury
- Fatigue and Traumatic Brain Injury
- Returning to School After Traumatic Brain Injury
- Sexuality After Traumatic Brain Injury
- Sleep and Traumatic Brain Injury

Volume 2: Factsheets Developed 2012–2021

- A Family Caregiver Guide to Selecting Rehabilitation Programs for Persons with Disorders of Consciousness (DoC)
- Alcohol Use After Traumatic Brain Injury
- Balance Problems After Traumatic Brain Injury
- Changes in Emotion After Traumatic Brain Injury
- Cognitive Problems After Traumatic Brain Injury Memory and Moderate to Severe Traumatic Brain Injury
- Concussion Recovery
- Facts About the Vegetative and Minimally Conscious States After Severe Brain Injury
- Headaches After Traumatic Brain Injury
- Loss of Smell or Taste After Traumatic Brain Injury
- Memory and Moderate to Severe Traumatic Brain Injury
- Parenting with a TBI
- Seizures and Traumatic Brain Injury
- Severe Traumatic Brain Injury: What to Expect in the Trauma Center, Hospital, and Beyond
- Social Skills After Traumatic Brain Injury
- Spasticity and Traumatic Brain Injury
- Staying Healthy After TBI
- Stress Management for Caregivers of Individuals with Traumatic Brain Injury
- Traumatic Brain Injury and Acute Inpatient Rehabilitation
- Traumatic Brain Injury and Chronic Pain: Part 1
- Traumatic Brain Injury and Chronic Pain: Part 2
- Understanding Behavior Changes After Moderate to Severe Traumatic Brain Injury
- Understanding and Coping With Irritability, Anger, and Aggression After TBI
- Understanding Traumatic Brain Injury (4 Part Series)
- Vision Problems After Traumatic Brain Injury (TBI)
- Voting Tips for People Living With Traumatic Brain Injury

Volume 1:
Factsheets Developed 2007–2012

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

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 neurotransmitters) 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 specialized 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 physiatrists—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

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

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

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.

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*
- State Vocational Rehabilitation Offices. *www.jan.wvu.edu*
- Association for Driver Rehabilitation Specialists. *www.driver-ed.org*
- National Mobility Equipment Dealers Association. *www.nmeda.org*

Reference

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

Disclaimer

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Source

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Authorship

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

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.
- **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.

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

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

National Association of Special Education Teachers.
www.naset.org/traumaticbraininj2.0.html

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

National Longitudinal Transition Study 2.
www.nlts2.org/index.html

Pacer Center.
www.pacer.org

The National Center on Secondary Education and Transition.
www.ncset.org

Reference

Keyser-Marcus, L., Briel, L., Sherron-Targett, P., Yasuda, S., Johnson, S., Wehman, P. (2002). Enhancing the Schooling of Students with Traumatic Brain Injury. *Teaching Exceptional Children*, v34 n4 p 62-67.

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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

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.

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.

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.

- 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.

- 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

- 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

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

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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*
- University of Maryland Sleep Hygiene: Helpful Hints to Help You Sleep. *http://www.umm.edu/sleep/sleep_hyg.htm*
- *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.

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

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).*

Volume 2:
Factsheets Developed 2012–2022

A Family Caregiver Guide to Selecting Rehabilitation Programs for Persons With Disorders of Consciousness (DoC)

January 2023 https://msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains the medical and rehabilitation care needs of persons with disorders of consciousness (DoC). It discusses the questions to ask when searching for the right program for your loved one with a DoC.

Background and Overview

This factsheet is intended for use by family caregivers of persons with DoC**.** This may include family members, partners, friends, or other caregivers. A person with DoC is not aware of their own self or surroundings. They can't stay awake or interact with others. DoCs include coma, unresponsive wakefulness syndrome (also called the vegetative state), and the minimally conscious state. A detailed description of these conditions and the recovery that follows can be found at https://msktc.org/tbi/factsheets/facts-about-vegetative-and-minimally-conscious-states-after-severe-brain-injury.

After a severe traumatic brain injury (TBI), a person may have a DoC that lasts a long time. If your loved one has a DoC but is ready to leave the hospital or acute care unit, they will still need close monitoring and expert care. As a family caregiver, you are an important part of the care team. Family caregivers should be involved in all phases of care and discharge planning.

Persons with DoC may benefit from rehabilitation, also sometimes called rehab. But, not all rehab programs are a good fit for persons with DoC. Some programs don't have the skilled staff, knowledge, or services needed to provide quality care to your loved one. A lack of expertise may lead to inappropriate care decisions and poor outcomes.

A group of expert clinicians and researchers from the American Congress of Rehabilitation Medicine and the TBI Model Systems specializing in DoC developed recommendations for programs that provide rehab to persons with DoC. The recommendations are based on evidence from research, best practices, and expert agreement. They may help you learn what is needed to best manage your loved one's care needs. This factsheet can help you find the right rehab program for your loved one with a DoC. It can help you figure out whether a specific program may meet your loved one's needs. The sections that follow cover the topics: Rehab Program Staff, Rehab Program Goals, Caregiver Training and Support, and Getting Ready for the Next Level of Care.

I. Rehab Program Staff

The care team should include experts from a range of healthcare specialties. A doctor (internist, hospitalist, or attending physician) should be on-site at least 5 days a week. When they aren't on-site, there should be an on-call

The Traumatic Brain Injury Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See https://msktc.org/tbi/model-system-centers for more information).

provider available to care for patients. For patients on ventilators, a pulmonologist (lung specialist) should also be available on-site. The program should have a way to get timely consults from experts who are not on-site. The care team on site should also include (but may not be limited to):

- A rehab physician
- A nurse
- A respiratory therapist
- A nutritionist
- A physical therapist
- An occupational therapist
- A speech-language pathologist
- A neuropsychologist or a psychologist
- A case manager or social worker
- A spiritual support person

II. Rehab Program Goals

The program should focus on overall goals of evaluating level of consciousness, promoting health and well-being, enhancing recovery, and monitoring for changes in level of function. Family caregivers should be involved in all phases of rehab goal setting.

A. Evaluation

To determine level of consciousness in patients with DoC, programs should use procedures designed for persons with DoC and recommended in clinical practice guidelines. There are rating scales designed to determine a person's level of consciousness. Current guidelines recommend using rating scales repeatedly over a period of days or weeks to establish a correct DoC diagnosis.

Family caregivers may want to ask:

1. ***Will the evaluation process include rating scales designed for persons with DoC? If so, how often will they be given?***

Recommended rating scales include:

- The Coma Recovery Scale-Revised (CRS-R)
- The Sensory Stimulation Assessment Measure (SSAM)
- Wessex Head Injury Matrix (WHIM)
- The Sensory Modality Assessment and Rehabilitation Technique (SMART)
- The Western Neuro Sensory Stimulation Profile (WNSSP)
- Disorder of Consciousness Scale (DoCS-25)

If rating scales are used, the evaluation should be repeated to avoid misdiagnosis.

2. ***What types of behaviors are evaluated by rating scales for persons with DoC?***

- The ability to stay awake, pay attention, and follow directions (cognitive function)
- The ability to understand and communicate in any way possible (language function)
- The ability to move the body (motor function)
- The ability to see, hear, and feel (sensory function)
- The way the environment affects behavior (noise, temperature, lighting, time of day)

3. ***What other information and tests will the program use to determine level of consciousness?***

The program should also use information from other sources to help determine level of consciousness. This includes results from recent tests of the brain, such as CT scans, MRIs, and EEGs.

B. Promoting Health and Well-Being

The program should use procedures to help maintain your loved one's general health, address problems that may arise, and promote overall health and well-being.

Strategies to Maintain General Health

The following procedures can help maintain overall health and level of function:

- Repeated evaluation of the lungs, skin, bones, muscles, bowel, bladder, and sleep pattern.
- Ongoing review of medicines. Medicines should be reviewed often. The program should take steps to reduce or stop medicines that can cause drowsiness and slow recovery.
- The program should review patients' care routines and body systems on a regular basis. This can help to quickly find and treat common problems such as infections, seizures, or hydrocephalus (a build-up of fluid on the brain).
- The program should have procedures (e.g., positioning schedules, passive range of motion) to help prevent problems that can occur due to lack of movement.
- The program should have procedures in place to quickly transfer patients to a nearby hospital for emergency care when needed.

C. Enhancing Recovery

While medicines, environmental management strategies, and assistive technologies may help support recovery, no treatment can cure a DoC. Treatment strategies may focus on:

- Staying awake during the day and sleeping through the night
- Reducing physical discomfort and distraction
- Moving around and performing self-care tasks (brushing their hair and teeth, washing their face, eating)
- Communicating (talking, writing, or use of gestures)
- Initiating and maintaining social interactions

Family caregivers may want to ask:

1. ***What medicines does the program use to improve a patient's ability to stay awake and respond to directions and questions?***

- Amantadine hydrochloride can speed up the recovery process when given between 4 and 16 weeks after TBI in persons with DoCs. Clinical practice guidelines suggest that the program should consider this medicine unless your loved one's doctor thinks they should not take it based on medical reasons.
- Zolpidem may improve alertness and behavioral responsiveness in a small percentage of persons with DoCs. The program may consider this medicine unless your loved one's doctor thinks they should not take it based on medical reasons.
- When medicines are recommended, ask about the expected benefits and potential side effects. You may also want to ask how your loved one's doctor will know the medicine is working.

2. What steps does the program take to provide a safe, comfortable environment and reduce physical discomfort and distraction?

The program should change the patient's environment to help with rehab efforts. For example, the program can:

- Make sure your loved one is positioned comfortably in the bed or wheelchair
- Reduce bright lights and distracting noises
- Make sure the room is not too hot or cold
- Remove splints, braces, or other physical restraints that may make it hard to move

3. What types of technologies do you use to help with communication and make it easier to initiate and maintain social interaction?

Programs should have a process in place to find out if an assistive device may help your loved one. Programs should also have a process to help select the best device based on your loved one's needs and abilities. Such devices may be high tech or low tech. Examples include:

- Switches and touch pads
- Picture or letter boards
- iPads and tablets
- Paper and pencil or dry-erase boards
- Eye-tracking systems (computer systems that track eye movements to assist with communication and environmental control)

D. Monitoring for Changes in Level of Function

The program should have a doctor or other provider on staff with relevant knowledge, training, and experience to determine and communicate information about a person's level of consciousness and potential for recovery. The DoC practice guidelines include factors that have been used to predict recovery. You can find a family-friendly version of these guidelines at: https://www.aan.com/Guidelines/home/GuidelineDetail/926.

The program should monitor your loved one's response to treatment efforts and progress over time. The program should also monitor program performance and your needs as a family caregiver.

Family caregivers may want to ask:

1. How and when will information about my loved one's diagnosis and potential for recovery be shared with the family?

- Shortly after admission to the program, a care plan meeting should be held to provide information about your loved one's current level of consciousness, rehab goals and expected length of stay in the program.
- Discussions should address the questions and outcomes that you feel are most important.
- The program should give you updates any time there is a change in your loved one's clinical status that results in a change in the treatment plan or rehab goals.
- The program should give you clinical information in language that is easy to understand.

2. How will you know if the treatment efforts are working?

- The program can use the rating scales specially designed for persons with DoC (CRS-R, SSAM, etc.) to monitor treatment response and progress over time.
- The care team should meet regularly to consider whether changes in the treatment plan are needed.

3. How does the program evaluate its success overall? Does the program have reports they can share?

You may be able to obtain information about the outcome measures used and program performance. Examples include:

- Scores or information about the program's performance on behavior rating scales
- Benchmarks or criteria used to determine the length of stay in the program
- Data or information about overall program performance
- Data about how many DoC patients were admitted to the program in the last year and where they were discharged to
- Information about how the program meets family caregivers' needs

4. What type of education and training activities are provided for staff involved in the care of persons with DoC?

The program should provide ongoing education and training for staff to help make sure they are skilled in evaluating, treating and measuring changes over time.

III. Information, Training and Support Services for Family Caregivers

The program should provide tailored education, hands-on training, and individual or group support to family caregivers. The program should also offer guidance to help family caregivers deal with ethical questions that may come up during treatment.

Family caregivers may want to ask:

1. Are educational materials and hands-on training available to family caregivers?

The program should address:

- Tools and resources to improve your knowledge about DoC and common care needs
- Financial matters related to insurance and long-term care planning
- Hands-on training so you can understand and take part in in everyday care when needed. This may include how to perform basic stretching, turning, and positioning; and how to interact with your loved one.

2. What kind of social, financial, and legal support services are available through the program? Is there someone available who I can talk to about finding community-based programs and resources?

The program should provide support services to family caregivers. This should include information and help finding:

- Community-based social support services, programs, and resources
- State and community-based agencies to help with legal and financial needs

3. Who do I talk to if I have concerns about the care my loved one is getting and the providers responsible for administering care?

The program should have a process in place to help family caregivers if concerns or differences in opinion arise with the care plan, treatment team, or program.

IV. Getting Ready for Your Loved One's Move to the Next Level of Care (Facility or Home)

The care team should help you understand why your loved one may need a transition to a different level of care (more or less intensive care setting). They should also talk to you about the options that may be available.

Family caregivers may want to ask:

1. How often will the team meet with the family to talk about progress, future care needs, and discharge options?

Periodic meetings should be held with the team and family caregivers to discuss your loved one's care plan, progress, transition, and discharge options.

2. How will program staff know when my loved one is ready to move to the next level of care?

- Your loved one may eventually be ready to take part in rehab activities that require more active participation. This may be the case if they improve in their ability to communicate clearly and interact with others.
- Sometimes results from assessment and treatment suggest that a patient may not improve or may improve more slowly. In this case, a move to a less intensive setting with a focus on maintaining general health, supporting slow recovery where possible, and maximizing quality of life may be best.

3. When it is time to move to the next level of care, what information should be passed on to other health care providers and family caregivers to support ongoing care needs?

Information that can help support the next level of care includes:

- Current level of consciousness.
- Level of help needed to take care of basic care needs. This includes the number of people and hours needed to help with eating, using the toilet, and grooming. This also includes level of supervision needed to keep your loved one safe.
- Likelihood of further improvement in physical and mental abilities.
- Active health problems and treatments.
- Current medicines.
- Equipment needs.
- Caregiver education and training needs.
- Recommendations for follow-up (when, where, who).

More Resources on Severe TBI and DoCs

American Congress of Rehabilitation Medicine. (n.d.). *Publications.* https://acrm.org/publications/

CARF International. (2022). *CARF® accreditation focuses on quality, results.* http://www.carf.org/home/. This website includes consumer resources that may help you assess the quality of a program's services and decide if any given rehab program is a good fit for those with severe TBI.

Giacino, J. T., Katz, D. I., Schiff, N. D., Whyte, J., Ashman, E. J., Ashwal, S., Barbano, R., Hammond, F. M., Laureys, S., Ling, G. S. F., Nakase-Richardson, R., Seel, R. T., Yablon, S., Getchius, T. S. D., Gronseth, G. S., & Armstrong, M. J. (2018, August 8). Practice guideline update recommendations summary: Disorders of consciousness. *Archives of Physical Medicine and Rehabilitation (99)*9, P1699–1709. https://doi.org/10.1016/j.apmr.2018.07.001. Factsheet for family caregivers that includes a summary of practice recommendations for diagnosing and providing care to persons with DoCs. These guidelines include factors that have been used to predict recovery.

Model Systems Knowledge Translation Center. (2017). *Severe traumatic brain injury.* https://msktc.org/tbi/factsheets/Severe-Traumatic-Brain-Injury. Consumer factsheet about what to expect for your loved one’s care in the first days and weeks after the injury. Also includes suggested questions to ask, information about care options, and tips on how you can help support your loved one’s recovery.

Model Systems Knowledge Translation Center. (2020). *Facts about the vegetative and minimally conscious states after severe brain injury.* https://msktc.org/tbi/factsheets/facts-about-vegetative-and-minimally-conscious-states-after-severe-brain-injury. Booklet designed for families that describes each of the DoCs that can occur after brain injury. Also includes information about patterns of recovery, moving to different levels of care and advice on what to look for when choosing a place of care for your loved one.

Authorship

A Family Caregiver Guide to Rehabilitation Programs for Persons With Disorders of Consciousness (DoC) was developed by Amy Shapiro-Rosenbaum, PhD; Susan Johnson, MA, CCC-SLP, CCM; Flora Hammond, MD; Brian D. Greenwald, MD; Brooke Murtaugh, OTD, OTR/L, CBIST; and Joseph Giacino, PhD in collaboration with the Model Systems Knowledge Translation Center. All authors are affiliated with the Brain Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine while Amy Shapiro-Rosenbaum, Flora Hammond, Brian D. Greenwald, and Joseph Giacino are also affiliated with the Traumatic Brain Injury Model Systems.

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider about specific medical concerns or treatment. The contents of this fact sheet were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90DPTB0011, 90DP0082, and 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

Additional Notice: This information should not be interpreted as a clinical practice guideline. Statements or opinions expressed in this document reflect the views of the contributors and do not reflect the official policy of ACRM, unless otherwise noted.

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Alcohol Use After Traumatic Brain Injury

January 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet describes negative effects that may occur from alcohol use after a TBI. See pages 3 & 4 for suggestions on how to reduce or stop drinking.

Introduction

Alcohol and traumatic brain injury (TBI) are closely related. Up to 50% of adults with TBI were drinking more alcohol than is recommended before they were injured. People who were over age 60 when they had their TBI were less likely to drink too much before their injury, but those who did had worse outcomes. Although many people initially drink less after a TBI, starting to drink again increases their chances of having worse outcomes. By 2 years after injury, we find that more than 40% start drinking again.

After a TBI, many people are more sensitive to alcohol. Drinking raises their risk of getting injured again. It also makes cognitive (thinking) problems worse and increases the risk of emotional problems such as depression. Drinking can also get in the way of TBI recovery. For these reasons, doctors urge people with TBI not to drink. Not drinking can prevent further injury to the brain and promote healing.

Facts about TBI and alcohol

Alcohol and TBI recovery

- TBI recovery goes on for a lot longer than we used to think was possible. Most people see improvements for many years after injury.
- Drinking can slow down or stop TBI recovery.
- Not drinking gives the brain the best chance to heal.
- People's lives often continue to get better many years after TBI. Not drinking can increase the chance of improvement.

Alcohol, brain injury, and seizures

- People with TBI are at risk for seizures.
- Drinking may increase the risk of having seizures and can trigger seizures.
- Not drinking may reduce the risk of seizures.

Alcohol and the risk of having another TBI

- People who have had a TBI are at high risk of having another one.
- People who have an alcohol-related TBI are more than four times as likely to have another TBI. This may be because both TBI and alcohol can cause problems with vision, coordination, and balance.
- Not drinking can reduce the risk of having another TBI.

The Traumatic Brain Injury Model System (TBIMS) Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See http://www.msktc.org/tbi/model-system-centers for more information.)

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Alcohol and cognitive function

- Alcohol and TBI both affect cognitive skills like memory and flexible thinking (this is thinking about things in a different way).
- Alcohol may make some of the cognitive problems caused by TBI worse.
- Alcohol may affect people with TBI more than it did before their TBI.
- The negative cognitive effects of alcohol can last from days to weeks after drinking stops.
- Not drinking can keep your cognitive abilities at their best and help you 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.
- Using alcohol can cause depression or make it worse.
- Alcohol can make anti-depressant medicines less effective. People who take these medicines should not drink.
- One way to improve feelings of sadness or depression after TBI is to stop or cut down on drinking.

Alcohol and sexuality

- A low sex drive is the most common effect of TBI on sexuality.
- Alcohol causes low levels of testosterone in men.
- Alcohol may cause problems with erections and orgasms 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 drink may not be safe. This is especially true when you need to do things that require balance, coordination, and quick reactions, such as walking on uneven surfaces, riding a bike, or driving a car. Thus, no amount of alcohol is totally safe after TBI.

Alcohol and medicines

Drinking after TBI may be dangerous if you take prescription medicines. Alcohol can make some medicines less effective. It can also increase the effects of some medicines; this may lead to overdose or death. Drinking alcohol with medicines for anxiety or pain is risky because of the potential for multiplying the effects of both.

What about using other drugs?

Other drugs are also likely to harm the brain and how it functions. Drugs like cocaine, methamphetamine, or heroin are both addictive and illegal—they can harm your brain and your recovery. Misusing prescription opioids like Percocet, Oxycodone, or Oxycontin can be deadly. Misusing other prescribed medications like Ativan, Valium, or Xanax can also harm you.

Cannabis (marijuana or pot) use deserves special attention because it's legal in many states to use pot for medical and nonmedical reasons. People with TBI may use cannabis to ease stress and anxiety or to help them sleep. But cannabis has some downsides. Using cannabis on occasion may cause cognitive issues that last at least 1 day. Routine use may cause major problems with attention, learning, memory, thinking, or problem-solving. These issues can last up to 1 month after you stop using. People who use cannabis are at greater risk of paranoia, hallucinations, and delusions. They are also at risk for depression and losing their motivation to do things. Some people say cannabis helps their PTSD symptoms; others say it makes them worse. Little research exists on cannabis use after TBI or on the effects of THC versus CBD. Right now, the risks of cannabis use seem worse than the benefits for people with TBI who are in recovery.

If you use multiple drugs like alcohol and pot, or alcohol and pain pills, you have a high risk of addiction and overdose. Many people have died from using alcohol and pain pills together, or alcohol and anxiety medicines. Talk to your doctor if you drink and take prescription medicines.

What should you do?

Using alcohol or other drugs after a TBI is risky. Some people keep drinking or using drugs after a TBI and don't want to stop. Others know they should stop or reduce their alcohol or drug use, but they don't know how; they may have tried in the past and failed.

If you want to stop using alcohol or other drugs, you have many options. Some people benefit from self-help groups such as Alcoholics Anonymous (AA). Others get help from doctors, psychologists, or counselors with experience treating addiction. Most people who stop using alcohol or drugs do so on their own. Don't doubt your ability to change.

Ways to change, cut down, or stop drinking

Some key steps to change, cut down, or stop drinking are as follows:

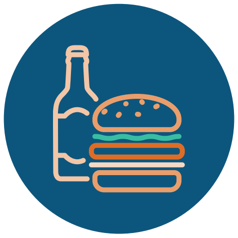
- Find people who support you in changing your drinking.
- Set a specific goal.
- Spell out how you will meet your goal.
- Figure out what people, places, things or feelings trigger drinking. Then figure out ways to cope with those triggers ahead of time.
- Reward yourself for sticking to your plan and meeting your goals.
- Have a back-up plan if your first plan doesn't work.

If you have questions or concerns about your drinking, information and help are available:

- Take a confidential, online drinking screening: http://www.alcoholscreening.org/.
- Talk to your doctor about your alcohol use. They can give you referrals for treatment. They can also prescribe medicines to help you prevent relapse or reduce alcohol cravings. One such medicine is naltrexone (Revia).
- Psychologists or counselors in your TBI rehabilitation program can help you find treatment that is right for you.

- AA has helped millions of people. You can find 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.
- The Substance Abuse and Mental Health Services Administration (SAMHSA) has a confidential treatment services locator website to help you find a reputable treatment facility near you (http://findtreatment.samhsa.gov/; 800-662-4357).

Reduce the harm from drinking



If you don't want to stop drinking, you can still reduce the harms of drinking:

- Eat food and drink water before you drink alcohol. This will help slow the effects of the alcohol. If you have a sharp rise in your blood alcohol level, it can lead to nausea, vomiting, falls, blackouts, and alcohol poisoning.
- Have a plan so you don't drink and drive. Have someone who isn't drinking take you home. Plan to spend the night where you are drinking or drink only at home.
- To avoid dangerous spikes in blood alcohol level, drink beer rather than hard liquor. You can also mix hard liquor with water instead of sweet, bubbly drinks.
- Sip your drinks slowly (no more than one per hour). Drinking too fast can make the pleasant feelings from alcohol go away.
- Drinking in bars makes some people drink more slowly because of the cost. If you go to a bar, don't drink and drive.
- Take vitamins, like B1 (thiamine), B12, and folate, to reduce the chance of brain damage from drinking.
- Have no more than two drinks per day. Cut back on certain days of the week, such as weeknights.
- Take a drinking "holiday" (days or weeks when you don't drink at all). This may remind you of some of the benefits of being sober.

How family members can help

You can't force another person to stop drinking or using drugs. But you can support them. Going to Al-Anon meetings is a good way to support a friend or a family member of someone who has problems with alcohol or drugs; it can also promote change. You can also join with other family or friends to tell your loved one about your concerns. The book *Get Your Loved One Sober* (see the Resources section) has an effective approach. Family members can learn how to talk to and respond to their loved one in ways that reward being sober but don't enable drinking-related behavior. These methods have been shown to increase the chance that people with alcohol problems will reduce their drinking and get treatment even more than Al-Anon or interventions.

Resources

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Authorship

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

Factsheet Update

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. This publication was produced by the TBI Model Systems in collaboration with the University of Washington Model Systems Knowledge Translation Center with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education, grant no. H133A060070. It was updated under the American Institutes for Research Model Systems Knowledge Translation Center, with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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Balance After Traumatic Brain Injury

January 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet looks at common balance problems after TBI and describes treatment options.

People with traumatic brain injury (TBI) often have problems with balance. About half of people with TBI have dizziness and loss of balance at some point in their recovery. When you are dizzy, you may have vertigo (the feeling that you or your surroundings are moving) and feel unsteady. You may also feel faint or lightheaded.

Many factors determine how bad your balance problem is, including:

- How severe your brain injury is.
- What part of the brain was injured.
- If you have other injuries along with your TBI. For example, in a car crash, you could have a TBI, neck injury, and broken ribs and legs. All of these injuries will affect your ability to keep your balance.
- Some medications can have an effect on your balance.

What is balance?

Balance is the ability to keep your body centered over your base of support. When standing, your base of support is your feet. When sitting, your base of support is your butt, thighs, and feet. Many factors affect your ability to keep your balance. These factors include your physical strength and coordination, your senses, and your ability to think.

Most people can control the movement of their body for a time before they lose their balance and need to change their posture or take a step to keep from falling. Changing your posture or taking a step to keep your balance before, during, or after movement is a complex process; TBI may affect this process.

Why is balance important?

Falls are one of the main causes of TBI. Falls affect children (younger than 17) and older adults (older than 65) the most. Improving balance can help prevent TBIs.

If you have poor balance after a TBI, you have a high risk of falling. Falls can cause another TBI or a broken bone. Keeping your balance while sitting and standing is important for doing daily activities. These activities include walking and self-care tasks like bathing, using the toilet, and dressing. Poor balance can keep you from being able to play sports, drive, or work.

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Diagnosing balance problems

Several of your body's systems are involved in keeping your balance. Many health care providers diagnose and treat balance problems. These may include doctors who focus on physical medicine or rehabilitation (physiatrists) or doctors who focus on the nervous system and brain (neurologists). Other providers may include doctors who focus on the ears, nose, and throat (otolaryngologists) and physical therapists (PTs). Your doctor may start by looking at the medicines you take. Medicines are a common cause of balance problems.

PTs and occupational therapists (OTs) use balance tests to identify specific problems and assess your risk for a fall. These tests also measure and track your progress with balance.

What are some common causes of balance problems after TBI?

Medicines. Many medicines can make you feel dizzy, lightheaded, and off-balance. These include antibiotics, tranquilizers, and blood pressure, heart, and seizure medicines. Ask your doctor if any of the medicines you take may be causing dizziness or balance problems. A change in medicine or dosage may fix the problem.

Postural hypotension. If your blood pressure drops when you stand or sit up quickly, you may feel lightheaded and dizzy. This can happen when you stand up quickly from sitting on the toilet or a chair or when you get out of bed. Taking your blood pressure while lying, sitting, and standing may help diagnose balance problems caused by your blood pressure.

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

Inner ear problems. Your inner ear has tiny organs that help you keep your balance. This is called the vestibular system. Your inner ear has three loop-shaped structures called semicircular canals. These canals contain fluid and have fine, hair-like sensors that monitor the rotation of your head. Your ear also has other structures called otolith organs that monitor the linear movements of your head. The otolith organs contain crystals that make you sensitive to movement and gravity. If your TBI damages your vestibular system, you may have balance problems, dizziness, or a sudden feeling that you're spinning or that your head is spinning.

Problems with your ability to feel things. Nerves in your feet send messages to your brain that help you keep your balance. If your TBI damages these nerves, your brain may not get the messages it needs. In this case, your brain may need to rely more on your eyesight and inner ear to keep your balance.

Brain stem injury. A traumatic injury to the brain stem and cerebellum (the parts of the brain that control movement) can make it hard for you to walk and keep your balance.

Mental health issues. Some people with TBIs have anxiety, depression, or a fear of falling. These issues can cause or increase balance problems. Practitioners all this psychogenic dizziness.

Treatment options

Balance problems have many different causes. Each cause requires a different treatment. Your doctor, PT and OT, and other health care providers will work with you to find out and treat the different causes. Treatment needs to be tailored to your needs. It should also challenge you without compromising your safety.

How can you improve your balance?

- Be cautious when working on your balance. Make sure you work at the right level to avoid falling when no one is around. A PT or OT can help design a program that is safe for you to practice at home.
- Increase your strength and flexibility. You can do stretches for your ankle and hip muscles. Other exercises will help strengthen your legs. These include mini squats, toe raises, or standing leg lifts. Go to www.nia.nih.gov/Go4Life for more information about these exercises. You can also talk to your doctor or PT about what you can do.
- Find your limits in balance. You can do this by moving your body over your feet as far as you can without lifting your feet. This will help you develop strategies to keep from losing your balance. You can also practice movements that allow you to move from one position to another. These movements include going from sitting to standing, reaching above your head to get something off a shelf, or picking up something on the ground.
- Practice standing or walking in different conditions. Practice standing with your eyes closed. This will decrease your dependence on using your vision for balance. Stand on a pillow; this will improve your ability to use your vision for balance. Change how far apart your feet are; bring them closer together or in front of one another. You can also stand on one leg.
- Practice activities that will improve your balance while walking. These include walking longer distances; walking and keeping up with someone else while talking; walking over different surfaces, such as on grass and sidewalks; and walking in crowded places such as the grocery store.
- Try a balance program that is based on evidence and designed for groups. Examples include A Matter of Balance, or the Otago Exercise Program. These programs may be available in your community.

How quickly can your balance improve?

The extent of your injury and your health status before your injury determine how quickly your balance problems will get better. Some balance problems can be treated effectively in one or two treatment sessions; others can take weeks, months, or years.

Research shows that:

- Most people with a TBI can walk on their own within 3 months of their injury. While most people walk again, many have problems moving quickly. They do not have the balance they need to return to 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 more common in people with TBI than in people without TBI.

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Authorship

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Changes in Emotion After Traumatic Brain Injury

May 2022 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains changes in emotion that people may experience after TBI. It also discusses ways that people with TBI and their loved ones can manage these emotional concerns.

The way people experience or express emotions may change after a traumatic brain injury (TBI). While this can be distressing for family members and friends, many strategies can help manage these emotional concerns after TBI.

Anxiety

Anxiety is common in the general population and in people with moderate to severe TBI. Anxiety may look different from person to person, but most people with anxiety have intense fear and worry. Some people also have physical signs of anxiety. For example, they may have a racing heart, rapid breathing, sweating, shaking, or the sensation of butterflies in their stomach. They may feel anxious, stressed, or overwhelmed without knowing why. This stress can make recovery after a TBI even more difficult. People with TBI may have anxiety in situations that did not bother them in the past. They may feel anxious being in a crowd, when they are being rushed, or when adjusting to sudden changes in plans. They may feel overwhelmed in situations that require a lot of attention, fast thinking, or processing a lot of information at the same time.

Depression

People with depression may feel sad, irritable, or worthless. They may feel tired much of the time and may experience changes in sleep or appetite or difficulty concentrating. Sometimes, people may even have thoughts of death, hurting themselves, or taking their own life. People with these feelings often withdraw from others and lose interest in or feel less pleasure from activities they used to enjoy. Many signs of depression, such as fatigue and frustration, are also signs of TBI. However, someone with a TBI may experience these symptoms but not be depressed. Sadness, and grief are common after brain injury. Some people feel depressed right after TBI, but these feelings may also appear during the later stages of recovery. Symptoms of anxiety may appear before depression. If these feelings become overwhelming or interfere with recovery, the person with TBI may be experiencing depression.

Anger and irritability

People with moderate to severe TBI may feel more anger, irritability, and frustration after their TBI. Family members often describe them as having a "short fuse" or "flying off the handle" easily. This anger may be a result of not understanding the changes they are experiencing caused by the TBI. After brain injury, people can have difficulty recognizing the problems they are having. They may not realize that they seem angrier to others. It can be confusing to them when others tell them about these changes. Even when people with TBI are aware they have more anger, they often don't understand why they feel this way or how it is affecting others. Anger can have a big impact on the support that people get from family and friends after TBI. It can affect closeness in relationships and lead to further isolation.

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What causes emotional changes after TBI?

- Emotional changes can occur if the TBI affects areas of the brain that control emotions. Changes to these brain regions and to the chemicals that help the brain work can affect how the person with TBI experiences or expresses emotion.
- People with TBI may have a hard time coping with their injury. They may need to adjust to a loss of independence, or to changes to their role in their family and in society. These changes can lead to frustration and dissatisfaction with their life.
- People with TBI may also have changes in their thinking abilities, such as memory, attention, speed of thinking, and reasoning. These changes can cause them to feel overwhelmed if they can't remember things or keep up with what others are doing or saying. They may respond emotionally, with sadness, worry, or anger.
- Use of alcohol or other drugs can lead to emotional changes, and emotional distress may also lead to alcohol and drug use.
- People who had problems with depression or anxiety before the TBI may find that these problems are worse after the TBI. They may feel isolated, depressed, or misunderstood which can also affect emotions.

How to address emotional concerns after TBI

- Remember that emotional distress is not a sign of weakness and it is no one's fault. A person can't get over their distress by wishing it away or "toughening up."
- Medicine and counseling or psychotherapy can help with emotional distress after TBI. Sometimes, a combination of both works best.
  - If you choose to take medicine, you should work closely with the doctor or provider who prescribed the medication. Be sure to attend all follow-up visits about your medicine.
  - If you choose counseling or psychotherapy, let your therapist know about your TBI. Ask them to help you write important concepts down so that you can review them at home. Tell your therapist if you need to have something repeated in order to understand it better.
- Stress and stressful situations can trigger emotional distress. People with TBI can take steps to reduce stress. For example, they can use relaxation techniques such as deep breathing or muscle relaxation, schedule breaks, and practice mindfulness activities.
- A daily schedule of structured activities and exercise can help reduce distress. Activities may include exercise, puzzles, or games.
- It is best to get treatment early to avoid needless suffering. Do not wait.
- If you (or your family member) have thoughts of suicide, get help. You can call a local crisis line, 911, or the National Suicide Prevention Lifeline at 1-800-273-TALK (8255), or go to your local emergency room.

Family members can help by changing the way they react to emotional distress after TBI:

- Remember that anxiety, depression, irritability, and other changes in emotion after TBI may be due to brain injury. Try not to take it personally. Also remember that changes in emotion are no one's fault and try not to blame the person with TBI.
- Stay calm and try not to react in an emotional way yourself or to argue with the person with TBI. If you are angry or hurt, take a break before you talk to them.
- When they are acting out in anger, do not give in to their demands to try to calm them down. This can actually have the opposite effect of rewarding them for expressing their emotions in a non-helpful way. Resist the urge to give in to unreasonable demands. Instead, explain that you will talk to them when they are calm. Walk away and take a break until they are calmer.

- Provide feedback in a gentle and supportive way after the person is calm.
- Give the person with TBI opportunities to take a break to process their emotions. Encourage them to use deep breathing or listen to music to relax. Offer a quiet area, away from the stressor, to calm down and regain control. Then, redirect their attention to a different topic or activity.
- Give the person with TBI time to have structured independence and more control over his or her life.
- Tell them you recognize their emotions and want to understand their feelings and give the person with TBI a chance to talk about their feelings. People with TBI often have a hard time naming their emotions and might find it hard to recognize emotions in others. This means that they may not realize that they seem angry or that they are making others uncomfortable. You can help them identify their emotions and tell them how you feel.
- Seek out support. The family may benefit from social and professional support. Counseling can help relieve the family's worry and help them to cope better each day.

Peer support and other resources:

Remember, not all help comes from professionals! You and your family may benefit from the following:

- **Support groups**: Some support groups are for the person with TBI, while others are for family members, and some are open to everyone affected by TBI. Information about support groups may be found through TBI organizations, rehabilitation facilities, and social media, among other places.
- **Peer mentoring**: A peer is a person who is currently living with a TBI. A peer can offer support and advice to others who are new to TBI and dealing with similar problems.
- **Brain Injury Association** (http://www.biausa.org): Reach out to your local chapter for resources, including training and resources for caregivers and family members.
- Find someone to talk to. Reach out to a friend, family member, member of the clergy, or someone else who is a good listener.

Recommended reading

- Senelick, R. C. (2013). *Living with brain injury: A guide for patients and families* (3rd ed.). Healthsouth Press.
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Authorship

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Cognitive Problems after Traumatic Brain Injury

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This factsheet explains common cognitive changes after TBI and how to manage them.

What is Cognition?

Cognition is the act of knowing or thinking. Some thinking abilities that can be affected by TBI include:

- Attention and concentration
- Processing and understanding information
- Memory
- Planning, organizing, and assembling
- Reasoning, problem-solving, decision-making, and judgment
- Monitoring and watching behavior to ensure that it is socially acceptable
- Communicating thoughts or ideas in ways that others can understand

Cognition after TBI

This factsheet discusses common difficulties with cognition (or thinking) that some individuals have after a TBI and presents some tips that may help reduce these challenges.

Attention

People who have experienced TBI might have trouble paying attention or staying focused. The ability to pay attention is an important thinking skill. Trouble paying attention can often lead to other problems and challenges, such as:

- Getting distracted more easily
- Having trouble finishing things
- Difficulty switching attention from one task to another
- Learning and remembering new information
- Difficulty holding long conversations or focusing on one conversation when many people are talking

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What can be done to improve attention?

- Decrease distractions. Distractions can come from the environment or from within oneself, such as headaches or worries. Find the right place and the right time for activities that require more attention (e.g., reading). For example, work in a quiet room.
- Focus on one task at a time.
- Break large or complex tasks into smaller tasks.
- Practice attention skills on simple but practical activities (such as reading a paragraph or adding numbers) in a quiet room. Gradually make tasks harder. For example, read a short story, balance a checkbook, or work in a slightly noisier environment.
- Take breaks when doing tasks that require a lot of mental energy. Return to the task when you're more refreshed.
- Talk with a doctor if you think your mood (e.g., sadness or worrying) is making it harder to concentrate.
- Get plenty of rest. Talk to your doctor about any problems you have sleeping.

Processing and Understanding Information

After a TBI, a person's ability to process and understand information often slows down and can become more challenging. This can result in some of the following problems:

- Having trouble understanding what others are saying or needing more time to understand what others are saying.
- Taking more time to understand and follow directions.
- Having trouble following storylines in television shows and movies.
- Taking longer to read and understand written information, including books, newspapers, or magazines.
- Reacting slowly to changes or warning signs in the surroundings. Slow reactions make certain activities, such as driving, unsafe. For example, not reacting quickly enough to stop signs, traffic lights, and other warning signs.
- Taking longer to carry out physical tasks, including routine activities, such as getting dressed or cooking.

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

- Decrease distractions. For example, turn the television off and silence your phone so that you can focus fully on what you're trying to understand.
- Allow more time to think about the information before moving on.
- Re-read information as needed. Try using a highlighter to identify the most important parts of what you are reading.
- Take notes and summarize information in your own words.
- If needed, ask people to repeat themselves, to say something in a different way, or to speak slowly. Repeat what you just heard to make sure you understood it.

Cognitive Communication

Thinking difficulties can make it harder to express your thoughts and understand what others are trying to say. Examples of cognitive communication problems include:

- Difficulty thinking of the right word
- Trouble starting or following conversations or understanding what others say
- Rambling or getting off topic easily
- Difficulty expressing thoughts in an organized manner
- Trouble expressing your thoughts and feelings through facial expressions, tone of voice, and body language (nonverbal communication)
- Having problems reading others' nonverbal communication and social cues that indicate others' feelings, thoughts, expectations, or intentions
- Misunderstanding jokes or sarcasm
- Aphasia is a disorder that can affect your speech or your ability to understand language properly. A speech therapist can test you for aphasia. Some of the suggestions below may be helpful to individuals with aphasia. However, speech therapy with a trained therapist who can teach strategies specific to aphasia may be needed.

What can people with TBI do to improve communication?

- Practice communicating one on one or in small groups and in environments with few distractions.
- If someone is speaking too fast, ask them to speak slowly so you can better understand them.
- If people are trying to tell you too much at once, ask them to tell you one thing at a time or ask one question at a time.
- If people ask too many questions at once, ask for one question at a time.
- If you didn't understand something someone said to you, ask him or her to repeat it or say it in a different way.
- To make sure you understand what someone says, offer to summarize what you heard.
- Before you start a conversation, think about the main point that you want to communicate. Plan what you need to say and consider what, if any, background information the person may need to better understand your message.
- When you write emails and post to social media, make sure to proofread, and read the text aloud before sending or posting it.

How can others help with communication?

People with TBI may not be able to interpret or understand words, messages, thoughts, and feelings that are part of a conversation. In such instances, others can help people with TBI by:

- Using kind words and a gentle tone of voice.
- Limiting conversations to one person at a time.
- Clearly communicate to your loved one what you are thinking or feeling or want.
- Helping them practice communication tips outlined above. Practice should be one on one or small group settings in environments with few distractions.
- Helping to redirect the conversation if the person gets off topic, by saying, "We were talking about..."
- If you are working with a speech therapist, it can be helpful to have a loved one join those sessions. Including family members in sessions can help you to carry over new skills to everyday life.

Learning and Remembering New Information

People with TBI may have trouble learning and remembering new information and events. People with TBI may also have problems remembering entire events or conversations. When this happens, the mind will sometimes try to fill in the gaps of missing information with things that did not really happen. These false memories are not lies. False memories are the brain's attempt to use the best information it has to make up for what is missing.

What can be done to improve memory problems?

- Structure your day with routine daily tasks and activities.
- Be organized: always put commonly used items back in the same place.
- Learn to use memory aids, such as:
  - memory notebooks to keep track of important information.
  - calendar reminders on smartphones, tablets, and computers to remember appointments and scheduled activities.
- Minimize distractions when learning new information and tasks (e.g. sit in a quiet area).
- Devote time and attention to reviewing and practicing new information you want to memorize.
- Link the information you want to remember with an image. Rehearse this connection either out loud or writing it down.
- Try to connect new information with something you already know. Building on existing knowledge can improve memory.
- Write down step-by-step instructions that you can reference when learning something new, such as directions to a new location, a new recipe, or learning a new computer task.
- Get plenty of rest. This will improve your focus during learning and result in better memory.
- Use relaxation techniques, such as deep breaths or meditation. This could help you focus better and reduce memory problems associated with stress and anxiety.
- Pay attention to possible side-effects of your medications, which may affect your thinking. If you notice changes in memory and are taking prescription medications, speak with your doctor about how your prescription medications may affect your memory.

Planning and Organization

People with TBI may have trouble planning the steps needed to accomplish a goal or organizing their ideas or belongings in a systematic way. Examples include:

- Difficulty planning their day and scheduling appointments
- Trouble organizing and keeping track of things like important papers, mail, and other items
- Trouble with tasks that require multiple steps to be completed in a particular order, such as laundry or cooking

What can be done to improve planning and organization?

- Use a calendar to schedule appointments and tasks. Look out for scheduling conflicts.
- List goals or things that need to be done and when. List them in order of what should be done first.
- Many mobile phones have apps with calendars and checklists that can be helpful.

- 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.
- Organize items based on similarity and use. For example, store all medical bills in one place and separate them by the type of medical service.
- Look for free smartphone apps designed to plan, organize, and remind you of appointments and events. Some apps may allow you to set alarms for reminders throughout the day.

Judgment, Reasoning, Problem-Solving, and Self-Awareness

Judgment, reasoning, problem-solving and self-monitoring are complex cognitive skills that are often affected after a TBI. Problems in these areas also impact decision-making and behaviors. People with TBI who have difficulty in these areas may have the following problems:

- Analyzing information or changing the way they think (being flexible)
- Deciding the best solution to a problem
- Getting stuck on one solution and not considering other options
- Acting quickly without thinking about the possible consequences
- Knowing what information is needed and how to evaluate the information needed to make decisions
- Judging what is safe versus unsafe behavior
- Being unaware of cognitive problems, even if the problems are clear to others
- Lacking awareness of social boundaries and others' feelings, such as being too personal with people they don't know well or not realizing what they have done or said to make someone feel uncomfortable

What can people with TBI do to improve judgment, reasoning, problem-solving, and awareness?

- Engage a trusted family member or friend when solving problems; they don't need to be solved alone.
- Use the steps below to work through a step-by-step problem-solving strategy. Depending on your needs, this could be done with the help of a family member or friend, or on your own.
  - Goal: Define the problem and the ultimate goal.
  - Plan: Brainstorm possible solutions, list the pros and cons of each solution, and pick a solution.
  - Do: Try the solution.
  - Check: Evaluate the success of the solution, and try another solution if the first one doesn't work.
- Before acting on a decision, wait a few hours or sleep on it overnight. Seek advice about your decision from a trusted friend or family member before acting on it.
- Work with friends and family to come up with cues to alert you to stop and monitor what you are doing.
- Think about your actions ahead of time and consider how they might appear to others and the consequences that your actions may have on yourself and others. Practice this with a family member or friend and make it a habit to do on your own.

How can family members help?

- Attend therapy sessions with your loved one in order to know what they are working on and help reinforce skills which are being taught.
- Give the person extra time to think things through and arrive at a solution.
- Offer to work with your loved one to problem-solve together, instead of solving problems for them.
- Give realistic, supportive feedback referring to a situation that happened and the unwanted consequence. Work together to come up with a different approach.
- Help your loved one to generate different options and alternative solutions to problems.

Cognitive Evaluation, Recovery, and Rehabilitation

- A neuropsychologist usually evaluates changes in thinking abilities after TBI. The results of this testing can be used to design a treatment plan.
- Many factors affect how someone's cognition will improve over time, which makes it very difficult to predict how much someone's cognition will recover.
- In many cases, cognition can improve with cognitive rehabilitation. Cognitive rehabilitation is a therapy known to help improve many of the cognitive skills described above.
- Some cognitive therapy approaches focus on improving skills that have been lost or impaired. Other approaches help the person to learn different ways to achieve a goal.
- Individuals with changes in thinking skills after TBI should consider getting help from a therapist who specializes in cognitive rehabilitation.
- Clinicians—such as occupational therapists, speech therapists, and neuropsychologists—often deliver cognitive therapy. A clinical psychologist or psychotherapist may not directly deal with cognitive difficulties but can be helpful in cases where depression, anxiety, or frustration are interfering with clear thinking.

Discuss Your Concerns With Your Physician or Treatment Provider

You should discuss any questions or concerns you have with a physiatrist (rehabilitation specialist) or the rehabilitation team. Do not ignore new problems. Mention new problems as they develop to your health care team. New problems could be the result of medication or require further evaluation. Bring a journal to your doctor appointments. Because you have a limited amount of time with the doctor, it is helpful to have a list of things you want to discuss prepared ahead of time so that you do not miss the opportunity to discuss important issues or ask questions. A journal can also be used during your appointment to take notes with regard to what the doctor tells you so that you can remember it later.

Recommended Reading

Check out these other MSKTC factsheets and infocomics on the impact of TBI on cognition:

- *Memory and Traumatic Brain Injury* https://msktc.org/tbi/factsheets/memory-and-traumatic-brain-injury
- *Emotional Problems after Traumatic Brain Injury* https://msktc.org/tbi/factsheets/emotional-problems-after-traumatic-brain-injury
- *Emotional Changes after Traumatic Brain Injury* https://msktc.org/tbi/infocomics/emotional-changes-after-tbi-infocomic
- *Fatigue and Traumatic Brain Injury* https://msktc.org/tbi/factsheets/fatigue-and-traumatic-brain-injury
- *Sleep and Traumatic Brain Injury* https://msktc.org/tbi/factsheets/sleep-and-traumatic-brain-injury
- *Traumatic Brain Injury and Sleep* https://msktc.org/tbi/infocomics/tbi-and-sleep-infocomic
- *Social Skills after Traumatic Brain Injury* https://msktc.org/tbi/factsheets/social-skills-after-traumatic-brain-injury

Authorship

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Concussion Recovery

July 2020 www.msktc.org/tbi/factsheets TBI Factsheet

This fact sheet is about concussions. It reviews symptoms, recovery, and long-term outcomes. It also talks about where to get support after a concussion.

What is a concussion?

A concussion is a mild traumatic brain injury (TBI) caused by a blow to the head which causes the head and brain to move rapidly back and forth. This can happen due to a car or bike crash, a fall, an assault, or a sports injury. In most cases, there are no lasting symptoms or ill effects from a concussion. During recovery, brain function and blood flow may be slightly changed and therefore it is best not to take part in rigorous activities (e.g., contact sports) that might lead to a second concussion for a few days to a week.

Recovering from concussion

Most concussion symptoms resolve within hours to days or a few months. Recovery is usually faster when a person gets some rest for a short period of time (e.g., a couple of days) and gradually returns to their activities and responsibilities over a week or so. Complete rest is not recommended, and instead, light exercise and mental activity may actually improve recovery. A small number of people may take longer to recover and need specific treatments. They could include specific support at work or school for a short period of time such as days or a few weeks while they recover.

Common symptoms of concussion

People with concussions may have temporary symptoms for a brief period of time that include a combination of headaches, poor concentration, fatigue, memory problems, dizziness, and nausea. People may feel irritable and have changes in mood or sleep. They may also have trouble thinking clearly, short-term disorientation, blurry or double vision, and be sensitive to bright light or noise.

Course of recovery

The common symptoms of concussion listed above are part of the recovery process; they are not signs of permanent damage or complications. These symptoms are normal, like the itch of stitches that are healing. Most people with a concussion who have symptoms recover in hours or a week to a few months. If you are older than 40, it may take a bit longer to get back to normal. Symptoms usually go away without treatment.

The Traumatic Brain Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See http://www.msktc.org/tbi/model-system-centers for more information).

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What can I do about my symptoms?

Some people who have had a concussion find it hard to do daily activities or their job during recovery. They may also find it hard to get along with everyone at home, or to relax. Pace yourself and be sure to get the rest you need. If your symptoms get worse, or if you have new symptoms, it may be a sign that you are pushing yourself too hard. Slow down and take care of yourself. For most people, after the injury, it is best to relax for a few hours or days and then slowly increase activity over the course of a week. Remember that symptoms are a normal part of recovery; they will usually go away on their own.

Many of the symptoms of concussion may also be due to stress, anxiety or pain. Many people have some of these symptoms once in a while even without having a concussion. Some of your symptoms may be similar to the symptoms of everyday stress that all people experience. A pulled muscle or a bruised leg needs time to heal; your brain does as well. You may have some trouble with work or school at first. This may be stressful, but it is normal. Trying to do your regular work right after a concussion is like trying to play baseball or swim with a pulled muscle. If you have concerns about your recovery, talk to your doctor. Most children and athletes with sports-related concussions need a doctor's release in order to return to play.

Concussion and outcomes

As noted above, there should be no long-term difficulties after a concussion and healing occurs relatively quickly. You may have heard of a disease called chronic traumatic encephalopathy, or CTE. A disease thought to be caused by repeated brain injury, CTE is poorly understood at this time. Most studies of CTE have used elite athletes with a long history of physical trauma. Based on existing evidence, experts think that one or two concussions do not lead to long-term conditions such as CTE, dementia, or Parkinson's disease.

Where can I go for support?

Most people find it helpful to get support from their friends and family after a concussion. They also look to health care providers like doctors, nurses, and psychologists who specialize in brain injury when possible for advice and support during recovery. But this is not always enough. Since you or your family member had a concussion, you may want to talk to other people who have been through similar experiences. Many support groups exist for people who have had a TBI and their loved ones. You can get more information from the sources below.

A free concussion recovery guide can be found at https://www.rimrehab.org/docs/librariesproviderdmcrim/default-document-library/tbi-recovery-guide-full-document-ada.pdf?sfvrsn=ad02e63e_0.

The Brain Injury Association of America can be contacted at 1-800-444-6443 or www.biausa.org. The Brain Injury Alliance can also be contacted at https://usbia.org/.

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Authorship

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Facts About the Vegetative and Minimally Conscious States After Severe Brain Injury

December 2020 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains changes in consciousness after severe brain injury.

Consciousness is an awareness of one's self and surroundings. Brain injury can cause disorders of consciousness (DOC). Some injuries are mild; they may cause minor changes in consciousness such as brief confusion. Severe injuries can cause permanent unconsciousness.

Of people with severe injuries, 60% to 80% survive. Many of those who survive are completely unconscious for some period. During this time, they aren't aware of themselves or the world around them. A state of complete unconsciousness with no eye opening is called coma. A state of complete unconsciousness with some eye opening and periods of wakefulness and sleep is called the vegetative state (VS). This refers to the "vegetative functions" of the brain (regulating body temperature, breathing, etc.) which often return before return of consciousness. (The VS is also called unresponsive wakefulness syndrome.) As people recover from severe brain injury, they usually go through several phases of recovery. Recovery through these phases can slow or stop.

As people recover from severe brain injury, they usually go through several phases of recovery.

- Coma
- Vegetative State
- Minimally Conscious State
- Confusional State
- Full Consciousness (often with specific impairments)

Features of coma

- No eye opening or sleep-wake cycles.
- Can't follow instructions.
- No speech or other forms of communication.
- No purposeful movement.

Features of VS

- Return of sleep-wake cycles with eye opening and closing.
- May moan or make other sounds, especially when tight muscles are stretched.
- May cry or smile or make other facial expressions without a clear cause.
- May briefly move eyes toward people or things but these looks are not sustained.
- May react to a loud sound with a startle or eye movement toward its location.
- Can't follow instructions.
- No speech or other forms of communication.
- No purposeful movement.

The Traumatic Brain Injury Model Systems program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See http://www.msktc.org/tbi/model-system-centers for more information).

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Care during coma or VS

People in a coma or a VS need a lot of care. This care may include:

- Feeding with a feeding tube.
- Turning the person while he or she is in bed to prevent pressure injuries (“pressure sores”).
- Helping with bowel and bladder relief. This may include using a catheter or diapers.
- Managing breathing. This may include removing mucus from the airway. It may also include cleaning a tracheostomy tube.
- Managing muscle tone. This includes helping to relieve extremely tight muscles with positioning and range of motion exercises.
- Using special equipment. This may include a wheelchair. It could also include special bedding to help with proper posture, decrease muscle tightness, and prevent pressure sores.
- Treating infections such as pneumonia or urinary tract infections.
- Managing other health problems such as fevers or seizures.

What happens after coma and the VS?

The first sign of consciousness is usually visual tracking. This occurs when the patient’s eyes follow people or an object. Other signs include:

- Following simple instructions such as, “Squeeze my hand,” or “Say your name.”
- Communicating by saying words or indicating yes or no with head nods or gestures.
- Engaging in “automatic” behaviors like scratching the skin or crossing/uncrossing the legs.

People with brain injury will recover consciousness at a slow or fast rate, based on how severe their injury is. For people with very severe injuries, return of consciousness is a slow process. People with less severe injuries may move through the phases listed above quickly. Some of the stages described here may not be recognized or may not occur at all. For people with very severe injuries, recovery may stop at one of these stages.

Coma rarely lasts more than 4 weeks. Some patients move from coma to the VS. Others may move from coma to partial consciousness. It is rare for a person with severe brain injury to move directly from coma, or the VS, to full consciousness. People who are unconscious for a short time generally have had a less severe brain injury. As a result, they are likely to have a better recovery than people who are unconscious for a long time.

Of people who are in the VS 1 month after traumatic brain injury (TBI – when brain damage is caused by a physical impact such as a car crash or fall), 60% to 90% will regain consciousness by 1 year after injury. They will likely have a slow recovery. They usually have ongoing cognitive and physical difficulties. People who are in the VS due to stroke, loss of oxygen to the brain (anoxia), or some types of severe illness may not recover as well as those with TBI. People who remain in a prolonged VS may live for a long time. But they often have complications such as pneumonia, respiratory failure, or infections, which may shorten their life expectancy.

Another stage of recovery is called the minimally conscious state, or MCS. People in the MCS can’t respond or communicate consistently.

Features of MCS

- May follow simple instructions.
- May indicate *yes* or *no* by talking or gesturing.
- May speak some words or phrases that others can understand.
- May make automatic movements. These may include scratching their head, crossing their legs, or moving their hair out of their eyes.
- May respond to people, things, or events by
  - Crying, smiling, or laughing.
  - Making sounds or gesturing.
  - Reaching for objects.
  - Trying to hold or use an object.
  - Keeping their eyes focused on people or things for a sustained time whether they are moving or staying still.

People in the MCS can do one or more of these things, but not consistently. For example, a person may follow a simple instruction one time; another time, they may not follow any instructions at all. This may make it hard to know if a person is in the VS or the MCS. People in the MCS need a lot of care just like people in the VS.

Recovering from the MCS

When a person can correctly answer simple “yes” and “no” questions or use at least two objects such as a comb or pencil consistently, they are no longer in the MCS. Some people stay in the MCS indefinitely, but many improve and regain independence. The longer a person remains in the MCS, the more permanent impairments he or she is likely to have. Both the VS and the MCS are caused by severe damage to areas of the brain that are important for consciousness. After improving from the MCS, people are usually confused. Some people move directly from coma to this confused state.

Features of the confusional state

- Acting lost or confused. This may include not being able to keep track of the correct place and time.
- Severe problems with attention, memory, and other mental abilities.
- Changes in level of responsiveness.
- Restlessness.
- Disrupted nighttime sleep.
- Feeling very tired and sleeping during the day.
- Believing things that aren’t true.
- Seeing things that aren’t there.

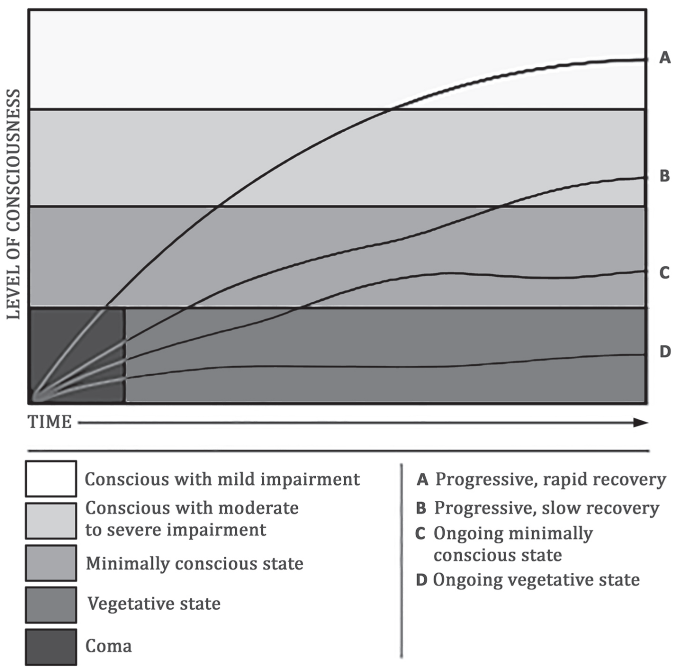
Comparison of Coma, Vegetative State, and Minimally Conscious State

	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

As with the VS and MCS, how fast people recover and how much they recover from the confusional state may vary. Most people who reach the confusional state make further progress. The severity of their brain injury and related health problems determine the degree of recovery. The less time the person is in the confusional state, the better their recovery will be. Mild problems such as poor sleep or urinary tract infections may lengthen the confusional state, but they may not affect the outcome.

> Most people who reach the confusional state make further progress.

Patterns of Recovery After Very Severe Brain Injury



Once the confusional state ends, people can usually pay attention, keep track of place and time, and hold onto memories of daily experiences again. They will likely still have serious cognitive problems such as impaired attention or memory or slowed thinking. These problems are likely to get better over time. While some people make limited progress, others make a good deal of progress.

This image shows patterns of recovery that may follow coma. Some people wake up quickly from coma; they may briefly stay in the MCS before further recovery. They may also have mild impairments. Others may be in the MCS for a long time after emerging from the VS. They usually have more long-term impairment. Slow recovery may continue for several years, especially for those with traumatic injuries. Sometimes, people stay in the VS or MCS for a long time. In some cases, these conditions may be permanent.

What treatments are used with people in the VS or MCS?

Only one treatment has been shown to help patients with TBI regain consciousness faster. Amantadine is a drug previously used in Parkinson's disease. When started between 4 and 16 weeks after TBI, it increases the speed of recovery. But it's not known whether it changes the long-term outcome or only reduces the time to reach that outcome. Its effect on patients with nontraumatic injuries (damage to the brain from medical causes) is not known.

How often health care facilities and doctors use treatments such as medicines or sensory stimulation (stimulating the person with sights, sounds, touches, etc.) to help patients regain consciousness varies. Because the degree of recovery from DOC varies, it's hard to judge the value of these and other treatments outside of research studies. You can talk to your loved one's doctor about using these treatments. Many patients may have good recoveries with good medical and rehabilitative care. Unproven treatments may slow recovery or have other bad effects or no effect; they may also improve recovery.

Transitions to different levels of care

During recovery, people in the VS or the MCS may get care in many settings. A person with a DOC will likely start treatment in an acute care hospital; the focus is on saving the patient's life and stabilizing the patient. Once those needs are met, the focus moves to restoring as much function as possible. Sometimes this takes place in an acute rehabilitation hospital. These hospitals provide high-intensity, team-oriented services. Services include physical therapy, occupational therapy, speech-language therapy, recreational therapy, neuropsychological services, and medical and nursing care.

Some patients don't go from the acute care hospital to an acute rehab program. These patients may go directly to a long-term acute care hospital (LTACH or "L-tack"), a skilled nursing facility (SNF or "sniff"), a subacute (less intensive) rehab program, or a nursing home. They may also go home with family or have home health care or outpatient treatment. People who get care in an acute rehab program first are usually discharged to one of these places as well.

The quantity and quality of medical management, nursing care, and rehab services offered in SNFs, subacute rehab programs, and nursing homes varies. Experts recommend that patients with DOC be discharged from acute care to an acute inpatient rehab program. These programs are more likely to provide the medical and rehab expertise needed. Also, they offer the team-oriented treatment planning that such patients need soon after injury. But many insurers still encourage patients to get treatment in less intensive settings that don't specialize in severe brain injury. Your loved one's doctor may be able to speak with your insurance company about the importance of receiving care in inpatient rehabilitation. Most insurance companies also have an appeal process that may include additional review of the admission request.

When patients are medically unstable or don't show signs of recovery for a long time, doctors may consider palliative care. In this type of care, the focus of treatment shifts from recovery to comfort.

Many factors affect where a person with severe DOC or other severe impairments goes after leaving an acute care hospital or rehab program. These factors include:

- The person’s medical condition.
- Health insurance coverage and other benefits.
- The person’s ability to benefit from rehab therapies such as physical, occupational, and speech-language therapy.
- The doctor’s recommendation 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.
- Practical matters such as the distance the family has to travel to visit the person at the facility.

The names used to describe levels of care and the settings in which care is given vary across the country. It’s helpful to work with a social worker or case manager in the facility where your loved one is getting care to plan any needed moves. Don’t be afraid to ask questions to make sure that you get the information you need to help make the best decision.

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

Here are some things to look for when choosing a place for care:

- Your family member’s current treatment team has received good feedback about the program’s quality of care when they have referred others there.
- The staff make you feel comfortable. They are available to talk about your concerns, and they answer your questions.
- The program has a multidisciplinary treatment team that, at a minimum, includes a rehabilitation physician, nurse, speech pathologist, physical therapist, occupational therapist, psychologist, and social worker.
- The treatment team meets together to identify treatment goals and review progress.
- The program and treatment staff have worked with the same kinds of problems that your family member has.
- The facility knows about the specific care your loved one needs and can meet those needs. You can help to make sure that a detailed nursing care plan is created.
- The program includes case management to help plan for the next level of care, whether it’s moving to a rehabilitation program, an LTACH, a SNF, or home.
- The program provides education and training for future caregivers.
- The program has a systematic approach to measure progress in all patients.
- The program is guided by recommendations for rehab programs from the American Congress of Rehabilitation Medicine and the NIDILRR’s Traumatic Brain Injury Model System.[1]
- The program receives good grades in state and/or federal quality ratings.

If support services can be arranged, some persons in the VS or the MCS can be cared for at home.

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Thoughts from families who have been there

Family members who have had a loved one in the VS or the MCS have identified a few important issues to keep in mind.

1. Communicating with health care providers

Be sure to ask questions, share your thoughts, and give your opinions.

2. Managing medical equipment and supplies

It's important to know about your loved one's equipment and supplies. You should also know how to communicate with the companies who provide these items.

3. Providing care

Family members often provide some care for their loved ones. In some cases, they may get paid for doing so. The amount of care you provide will depend on

- Your role. This can range from providing most of the care yourself to directing the care provided by others.
- The people who help you provide care. These may include sitters, attendants, nurses, and family members.
- The setting. This could be your home or a skilled nursing facility.
- The guidance you get from health care providers. It's best to get as much training as possible on the types of care you choose to provide and can manage. Such care may include bathing and grooming, bowel and bladder management, mobility and range of motion exercises, and management of other health problems that your loved one may have.

4. Learning about financial resources

You may feel overwhelmed as you learn about the financial resources that may or may not be available to your loved one. But with patience, persistence, and help from others, you will figure out which programs apply and find your way through the application processes.

Some programs that you will want to learn about include:

- Health care programs such as Medicare and Medicaid.
- Income replacement or financial assistance programs such as Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). You may also want to find out if your loved one had disability insurance through work.
- Services to help with community living such as state and community agencies that assist people in these areas. For instance, some states have Medicaid waiver programs that provide funding for in-home care to allow people to stay at home.

You may not find someone who knows all there is to know about how to access these services and programs. The key is to ask questions and follow up to make sure that you and your loved one get all the benefits available. Social workers, therapists, case managers, and your local social security office may be helpful. Others who may be able to help include your state brain injury association chapter, family members or friends who are disabled or who have family who are disabled, or the human resources department at your loved one's work.

5. Guardianship and Health Care Proxy

If your loved one named a health care proxy before the injury, that person will be able to make health care decisions on your loved one's behalf. Because your loved one may not be able to make decisions for himself or herself for a while, it may be helpful for you, or someone else, to be named as guardian. A guardian has the legal authority to make medical and/or financial decisions for someone who lacks the ability to do so. This may make it easier to handle medical decisions or manage your loved one's financial matters. If you think that your loved one may need a guardian, you will need to contact an attorney for help. Guardianship can be reversed when it is no longer needed.

How to interact with a loved one who is unconscious 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. Telling him or her about recent events in your life, what's going on in your family or neighborhood, or the latest news may make you feel connected. Talking with your loved one about what you are doing as you provide care can increase your comfort with caregiving. 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 these range of motion exercises if you have been instructed to do so by a doctor, nurse, or therapist.

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

Touch is another way to feel connected. Some family members have said that giving a massage or putting lotion on the hands or face of their loved one helps them to feel close to them. It's also important to give your loved one time for quiet and rest, such as by turning the TV off. You should also avoid overstimulation as this may cause rapid breathing, muscle tightening, teeth grinding, restlessness, and fatigue.

Taking care of yourself and other family members

Family members of a person in the VS or the MCS often feel a sense of loss or grief for the relationship they had before the injury. You can cope with these feelings in a few ways. A person in the VS or the MCS may make slow progress or go for long periods with no progress. Keeping a journal of the changes you have seen may be comforting. This may let you see how your loved one is more able to respond than he or she was at an earlier point in time.

Having a loved one who is in the VS or the MCS can be physically and emotionally draining. Dealing with this alone can be too much for one person. It's important to rely on support from others. You can look to existing supports, such as family, friends, and religious groups. You can also find new supports.

Other resources to consider include support groups and agencies, and the internet. You can contact the Brain Injury Association of America's (BIAA) National Brain Injury Information Center (www.biausa.org, 1-800-444-6443). The BIAA can give you contact information for the closest chapter of your state brain injury association. Health care providers such as doctors, therapists, and social workers may also be good sources of information about supports available to you.

Even the most committed caregivers need time for themselves.

Even the most committed caregivers need time for themselves. If your loved one is still in the hospital or living in a nursing care facility, you could create a rotating visitation schedule. This will give you a break while giving other friends and family a chance to spend time with your loved one. If your loved one is at home, you could ask a friend or family member to give you a 2-hour break to go do something for yourself. You could also hire full-time caregivers for a week or have your loved one spend time in a nursing care facility or hospital.

When your loved one was first injured, you were likely in crisis mode, focusing on problems and putting the rest of life on hold. As time goes by, you will need to shift from crisis mode to dealing with everyday matters such as paying bills, maintaining relationships with other family members, and taking care of your own physical and mental health. Although it's normal to want to focus on your injured loved one, other family members have needs. For some people, getting counseling from a therapist or clergy member can help them to adjust to the life changes that have occurred due to their loved one's injury.

Caring for a person in the VS or the MCS is a big challenge. But using appropriate resources, as described in this factsheet, can be a big help. Each person will respond differently to this challenge. But almost everyone can cope and move forward. Many family members feel a deep sense of personal satisfaction in making life comfortable and pleasant for a loved one with a severe injury.

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Authorship

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Factsheet Update

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. This publication was produced with funding from the National Institute on Disability, and Rehabilitation Research in the U.S. Department of Education, grant no. H133A031713. It was updated by the TBI Model Systems in collaboration with the American Institutes for Research Model Systems Knowledge Translation Center, with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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Headaches after Traumatic Brain Injury

December 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet provides information on the causes, types, and treatment options for headaches after traumatic brain injury (TBI).

Headache is one of the most common symptoms after traumatic brain injury (often called "post-traumatic headache"). Over 30% of people with moderate to severe TBI report having headaches which continue long after injury. An even larger percentage people with mild TBI complain of headache.

Why are headaches a problem after brain injury?

Headaches after TBI can be long-lasting, coming and going even beyond 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, a skull fracture or because they have small collections of blood or fluid inside their skulls.

Headaches can also occur soon after mild to moderate injury or, most commonly 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 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). Migraine 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.
- A "warning" signal that a migraine is coming on, such as seeing spots or bright lights. This is called an "aura."

The Traumatic Brain Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See http://www.msktc.org/tbi/model-system-centers for more information).

Tension-type headaches

These headaches are associated with muscle tension or 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 or medication overuse headaches

Sometimes the very medicines used to treat headaches can actually cause headaches. If some over the counter pain medications for headaches or certain prescribed medications are taken every day, they can actually lead to worsening headaches overall. Speak with your provider about which medications can cause overuse headaches.

Rebound headaches can occur if a person suddenly decreases the amount of caffeine they use. For example, if a person normally drinks a lot of coffee, tea or energy drinks and then doesn't get their usual amount, they may get a headache. In addition, missing one or two doses of certain medications can result in 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 more than one type of headache or for pre-existing headaches to get worse after brain injury. For certain headaches like migraine, a family history is common. It is possible for certain problems associated with brain injury to trigger or worsen headaches (like vision problems or sleep apnea).

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:

- Headaches get worse
- There is nausea and/or vomiting with a headache
- Arm or leg weakness or problems speaking develop along with a headache
- Increasing sleepiness occurs 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 the brain to make sure there is no bleeding in the 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 history and symptoms to sort out what kind of headache a person is having and how to treat it.

What can be used to treat a post-traumatic headache?

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 medications or other therapies. 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 prevent headaches by improving sleep and decreasing triggers such as poor posture. 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.
- Stretching and self-massage.
    - — Therapeutic massage.
    - — Heat or ice packs.

Treatments for recurrent headaches that happen more than twice a week

Headaches that occur frequently may require treatment such as therapy, a procedure, or a prescription from your health care provider. The following may help:

- Acupuncture.
- Therapeutic massage.
- Physical therapy for the neck and upper back.
- Local injections (numbing medication or steroids) to muscles, nerves, or joints of the cervical spine.
- Nerve stimulators such as a transcutaneous electrical nerve stimulation device (known as Cefaly device)
- Cognitive Behavioral Therapy.

These medications may be used to help prevent or decrease headaches following TBI:

- Tricyclic antidepressants (like amitriptyline, also called Elavil®).
- Antiseizure medicines (like topiramate, also called Topamax® or Trokendi®).
- Certain blood pressure medication called beta-blockers (like propranolol).
- Botulinum toxin (Botox®) injections.
- CGRP inhibitors (calcitonin gene-related peptide blockers) such as erenumab (Aimovig®) or galcanezumab (Embality®).

While headaches after TBI can make it hard to manage activities, fortunately there are many treatment options that exist to prevent headaches from becoming chronic. Speak with your health care provider about an effective treatment strategy.

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Authorship

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Loss of Smell or Taste After Traumatic Brain Injury

January 2020 www.msktc.org/tbi/factsheets TBI Factsheet

This fact sheet explains the loss of the sense of smell or taste after TBI.

What you need to know

- Your senses of smell and taste are important for many aspects of your life.
- Traumatic brain injury (TBI) can cause problems with smell and taste.
- Loss of smell is often the cause of loss of taste after TBI.
- Talk to your doctor about changes in your smell and/or taste.

Why are smell and taste important?

- Smell and taste add to our enjoyment and experience of food and nice smells, like perfume or flowers.
- Both smell and taste are important for safety as they serve as warning signs. Our sense of smell can alert us to harmful things around us, like a gas leak or a fire. Things that taste bad or smell a certain way may not be safe to eat or drink.
- Smell and taste prepare the body to digest food.
- Sense of smell and taste helps us form new memories and recall old memories; it can also cause a strong emotional response. For instance, the smell of apple pie can bring on a memory of your grandma and how much you love her.

Why does someone lose their sense of smell after trauma to the head or brain?

As air enters the nose, it triggers certain nerves. These nerves bring information to a part of the brain called the olfactory bulb. That information then goes to the part of the brain that creates our sense of smell. Loss of smell may result from damage to the lining of the nose or nasal passages (diagram A). Other causes may be injury to the nerve that carries smell sensation from the nose to the brain (olfactory nerve, diagram B) or harm to parts of the brain that process smell (diagram C). Other possible causes are infections, toxins, and medicines.

The Traumatic Brain Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See http://www.msktc.org/tbi/model-system-centers for more information).

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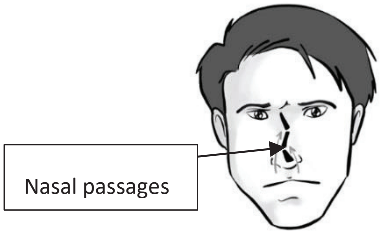

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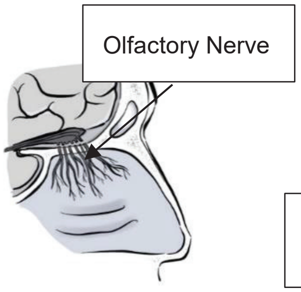

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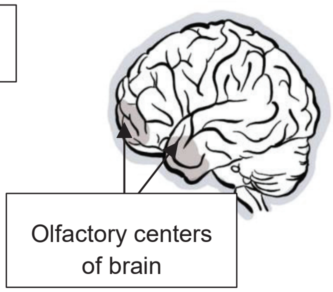

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Smell and taste are part of an overlapping sensory system. "Flavor" comes almost entirely from the nose. Smell and taste are directly related because they both trigger the same nerves. Taste receptors on the tongue and nerves in the nose work together to tell us about the air we breathe and the food we eat.

How are smell and taste problems found after TBI?

You may not notice smell and taste problems right after TBI. Over time, as you go back to your usual foods and start to recover from the TBI, you may notice problems with smell and taste. If you are concerned about your smell or taste talk to your doctor about it. Different kinds of doctors can check your sense of smell. Such doctors may include physiatrists, who focus on physical medicine or rehabilitation; neurologists, who treat conditions of the nervous system; and ear, nose, and throat (ENT) doctors (also called otolaryngologists). These doctors will decide what tests you may need to see why you have loss of smell or taste and make recommendations for how to manage the problem.

How does loss of smell and taste affect your appetite?

- The smell of food triggers the appetite; loss of smell can lead to reduced appetite and lack of interest in food.
- Loss of smell can reduce saliva production. This makes dry foods, like biscuits and crackers, harder to eat.
- Many foods that are needed for a balanced diet may no longer be appealing; this can lead to a diet that doesn't have a balanced variety of nutrients.
- Changes in taste may make some foods, such as meat, taste bad and make you avoid those foods.
- Any of these problems may affect what food you choose and lead to a poor diet.

Smell and taste problems can impact day-to-day life and lead to safety risks:

- Loss of appetite or loss of enjoyment or interest in food can make you eat too little, which may result in not getting important vitamins and nutrients that the body needs, and/ or lead to unsafe weight loss.
- Not feeling satisfied by food can cause you to eat too much because you are constantly searching for something to satisfy the lack of taste; this can lead to unsafe weight gain and/or other health problems.
- Some may use too much salt in attempt to add flavor, which can contribute to health problems, such as high blood pressure.
- Eating old or rotten food or eating something toxic may lead to food poisoning.
- Inability to smell gas leaks, toxic fumes or chemicals, which can be harmful if undetected.
- Inability to know which liquids are harmful or poisonous, and which liquids are safe.
- Loss of smell may lead to not knowing when you need to bathe, put on deodorant, or wash your clothes. This will result in poor hygiene.

Are there other challenges associated with loss of smell and taste?

The parts of the brain involved in smell and taste are close to parts of the brain that deal with other functions. If the areas of the brain that deal with taste and smell are injured, other nearby parts of the brain may also be injured. As a result, some people with taste and smell problems may also have the following issues:

- Emotional problems (depression, irritability)
- Behavioral problems, such as being impulsive or aggressive
- Trouble seeing and responding to others' feelings
- Reduced concern for others' feelings and needs

Will your sense of smell and taste get better?

- Recovery can happen. Research shows that 30% of affected people get better naturally over time.
- The sooner your symptoms improve, the better. Most people who improve do so 6 to 12 months after TBI.
- The chance of getting better over time is more likely if you have mild loss of sense of smell.
- Some people recover the ability to identify strong odors, but not more subtle scents.

How can you help yourself if you have loss of smell or taste?

- Cook with lots of spices (but be careful not to add too much salt!).
- Try foods that are hot and spicy.
- Choose foods that are salty, sweet, bitter, or sour.
- Find foods that have texture or crunch, such as pretzels.
- Set reminders to eat.
- Consider using a smart phone app that tracks the nutrients and calories you are getting each day.

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- Ask your doctor about vitamin supplements.
- Put dates on food and open cartons; check expiration dates before eating.
- Install smoke alarms on every floor. Keep fire extinguishers handy.
- Choose an electric oven or stovetop instead of gas.
- Buy a high-quality natural gas detector that gives a warning signal if there is a leak. Some gas detectors can be linked to the gas supply to automatically shut it off. This is especially helpful if a leak occurs while you're out, so you don't walk into a house full of gas. You can also get detectors for propane, butane, and liquefied petroleum gas (LPG) if you use gas cylinders, for instance, on a boat.
- When using household cleaners, make sure the area is well ventilated or use a mask.

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Authorship

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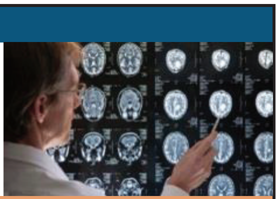
Memory and Moderate to Severe Traumatic Brain Injury



June 2016

TBI Fact Sheet

This fact sheet explains memory problems that may affect people with moderate to severe traumatic brain injury (TBI). By understanding the new limits on their memory and ways to help overcome those limits, people with TBI can still get things done every day.

The Traumatic Brain Injury Model System is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See http://www.msktc.org/tbi/model-system-centers for more information).

Memory and Traumatic Brain Injury

- Memory problems are very common in people with moderate to severe TBI.
- TBI can damage parts of the brain that handle learning and remembering.
- TBI affects short-term memory more than long-term memory.
- People with TBI may have a tough time "remembering to remember." This means remembering to do things in the future, such as keeping appointments or calling someone back when you've promised to do so.
- People with moderate to severe TBI may not remember the incident surrounding the injury.
- With the help of certain strategies, people with TBI can learn to work around memory problems and get things done every day.

What kind of memory is affected by TBI?

"Memory" isn't just one kind of ability. There are several kinds of memory, and TBI affects some more than others.

Long- and short-term memory

TBI-related memory problems don't work the way you might see "amnesia" portrayed on TV. You don't forget everything from your past and remember what happens going forward. In fact, you're more likely to remember things from the past, including much of what you learned in school. This is known as *long-term memory*. However, after a TBI, you may have trouble learning and remembering new information, recent events, or what's happening from day to day. This is known as *short-term memory*. Here are some short-term memory problems that are common in people with TBI:

- Forgetting important details of a conversation, such as remembering to pass along a phone message
- Forgetting where you left things, like keys, a cell phone, or a planner
- Feeling unsure of what you did or said this morning, yesterday, or last week; this can lead you to say things or ask the same questions many times
- Losing track of time or feeling unsure of what day it is

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- Being unable to retrace a route you took earlier in the day or week
- Forgetting all or part of what you read in a book or what you saw in a movie

Prospective memory

TBI may also affect *prospective memory*, or “remembering to remember.” This means remembering plans and intentions long enough to act on them. Here are some prospective memory problems that are common in people with moderate to severe TBI:

- Forgetting to keep appointments or showing up at the wrong times
- Telling someone you will call or visit at a certain time, then forgetting to do so
- Forgetting what you were supposed to do or intended to do at home, work, or school or in the community
- Forgetting important occasions, such as birthdays, holidays, and family events
- Forgetting to take medicines at the right time
- Forgetting to pick up children at a certain time

Although TBI affects new memories more than old ones, people with TBI may have trouble retrieving the correct information when needed. For example, you may recognize your aunt and know who she is, but have trouble remembering her name. Or you may be able to define all the words on a vocabulary test, but have trouble remembering the exact word when you’re talking.

Memory of the injury

People with TBI may not remember the injury itself. In this case, the brain has not stored the injury as a memory or series of memories.

People may remain confused and unable to store memories for some time after the injury. The loss of memory from the moment of TBI onward is called post-traumatic amnesia. It can last from a few minutes to several weeks or months, depending on the severity of brain injury.

If you can’t remember the events of your TBI, you likely never will. That’s because your brain did not store those memories. The best way to learn about the injury is to ask family members, friends, or medical personnel who may have objective information.

What Can You Do to Help Your Memory?

After a moderate to severe TBI, you may have more trouble remembering things from day to day. Research has found very few ways to *restore* the brain’s natural ability to learn and remember. One or two medicines may be worth trying (ask your doctor). But “brain training” programs and memory drills don’t really help.

Using *compensatory strategies* is the best way to tackle memory problems and still get things done. This approach uses memory devices that we all use to make up for limited memory storage in the brain (e.g., a grocery list, address book, notepad, or alarm on a cell phone).

Some people think that these methods weaken memories. But that's not true. When you write down information or enter it into a phone or computer, you may actually strengthen the memory trace in your brain, and the information will always be available for you if you need it.

Here are some compensatory strategies to help work around memory difficulties:

- Get rid of distractions before starting on something that you want to remember.
- Ask people to talk slower or repeat what they said to make sure you understand it.
- Give yourself extra time to practice, repeat, or rehearse information you need to remember.
- Use organizers, notebooks, or a cell phone calendar or "apps" to keep track of important information, such as appointments, to-do lists, and telephone numbers.
- Keep all items that you need to take with you (e.g., wallet, keys, and phone) in a "memory station" at home—like a table by the door or a special section of the counter.
- Use a pill box to keep track of and take your medicines accurately.
- Use checklists to keep track of what you've done or different steps in an activity. For example, make a checklist of bills that you need to pay each month and the dates on which they are due.

Having memory problems after TBI may make it harder for you to remember to use some of these strategies. At first, ask a family member or friend to remind you of these strategies. Over time, the strategies will become a habit, and you can use them on your own.

Other Supports

Memory problems can make it especially difficult for people with moderate to severe TBI to succeed in school, or to perform well in jobs that demand a lot of learning and memory. College students can contact the Disability Supports Services office at their school to receive assistance with note-taking and other services to support learning. The Vocational Rehabilitation services available in every state may be able to supply job coaching or counseling to assist workers who need memory supports, and may provide additional help to college students.

Authorship

Memory and Traumatic Brain Injury was developed by Tessa Hart, Ph.D., and Angelle Sander, Ph.D., in collaboration with the Model Systems Knowledge Translation Center. Portions of the material were adapted from educational materials developed by Angelle Sander, Laura Van Veldhoven, and Tessa Hart for the Rehabilitation Research and Training Center on Developing Strategies to Foster Community Integration and Participation for Individuals With TBI (National Institute on Disability, Independent Living, and Rehabilitation Research [NIDILRR] grant no. 90DP0028).

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Being a Parent With a Traumatic Brain Injury

November 2022 https://msktc.org/tbi/factsheets TBI Factsheet

Parenting can be a very rewarding experience, but is often challenging. This factsheet includes tools for how to overcome parenting challenges that might be encountered after a TBI.

Introduction

Being a parent can be one of the most rewarding experiences in a person's life. It can also be one of the most challenging experiences. Parenting requires many skills, such as good communication, patience, attention to detail, and a good memory. Parents also need to be flexible and able to handle complex emotions. Juggling the responsibilities of being a parent with other life demands can be hard for anyone. But having a traumatic brain injury (TBI) can make it especially difficult. This factsheet includes information about how being a parent with a TBI can be difficult and offers suggestions for overcoming parenting challenges.

Keeping Everyone Safe and Healthy

Keeping your family safe and healthy is one of your top priorities as a parent. A parent's biggest fear is that they are not keeping their kids safe. Sometimes after a TBI, a parent may *lose confidence* in their ability to keep their kids safe. But in most cases, they are still very capable. Many books and websites provide tips on how to make a home safe, how to protect your child from danger, and what children need to be healthy. The following tips can help you care for your child, in spite of coping with TBI-related changes:

- **Do things a little different**. Know yourself and what you can and cannot do. If your body moves differently than it did before the TBI, you may need to change how you carry your infant or hold your child's hand when you cross the street. If your vision has changed, you will need to do some childcare tasks differently. Talk to an occupational or physical therapist about alternate ways to do some tasks and devices that can help you. For example, you may use a stroller in your home or have your child hold onto a rope or strap that is attached to your belt when you cross the street.
- **Get input from others**. It is a good idea to talk to another adult you trust about how to childproof your home and come up with rules for safety. This can help you think of ideas; it can also boost your confidence.
- **Set up a healthy routine**. Children of all ages need a good sleep schedule, healthy food, and regular checkups with their doctors. To help you keep track of these, use daily or weekly schedules and checklists.

The Traumatic Brain Injury Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See https://msktc.org/tbi/model-system-centers for more information).

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- **Set rules** in your home that encourage good habits. For example, you might not allow cell phones in the bedroom at bedtime. Use your pediatrician as a resource and support in how to care for your child.
- If you have complications from the TBI, such as seizures, **create a plan for what to do if a crisis occurs.** For example, you may need a medical alert button. You may also need to teach your child to dial 911 in case of crisis.
- **Learn to recognize when you need help.** Sometimes being a good parent means knowing when you can't keep your child safe on your own. When this happens, ask another trusted adult to help look after your child.

Supporting Your Child's Education

During childhood and adolescence, school is a central focus of life for children and their parents. School educates children for the future and teaches them social skills. As a parent, you want to support them as they learn to be independent and help them succeed. It can be hard to *keep track of the schoolwork, due dates, and meetings*. You are expected to *communicate* with teachers and other parents. Sometimes you have to manage conflicts between your child and other children or teachers. Your child will have times when they feel proud and times when they feel frustrated.

Here are some tips to help you interact with the school and support your child:

- **You may wonder if you should disclose your TBI.** You don't need to share this information with everyone. But it is important to let the teacher or other main contact at school know if you need them to communicate differently with you. For example, tell them if you need them to highlight the most important information, or if you need to get requests through email and not in your child's backpack.
- There are many forms to complete. If this is hard for you, **set up a way to complete forms** with your family and friends or with the school. (Maybe they can be done verbally or carried over from year to year.)
- **Checklists can be helpful** for you and your child. Teachers often provide these for students when they start school. As children get older, they encourage kids to make their own checklists. Help your child make a checklist of assignments and tests, with dates. Post this where you can both see it and review it with your child each day. You can also list any materials that your child needs for projects. As they get older, put your child in charge of making the checklists.
- Children will reach a point where they are studying things that their parents don't understand. Don't worry if you don't fully understand what they are studying. You can still **help them study**. First, be supportive and encourage them to meet the deadlines on their assignment checklist. Second, make sure they have the tools they need. This may include books, teacher resources, and a quiet place to study and do homework. This may include monitoring time spent on the Internet that is not related to schoolwork.
- **Is your child struggling academically?** Are they frustrated or are their grades poor? Sometimes they just need you to listen to their frustrations. However, if your child can't manage an assignment, guide them to ask their teachers for help. As they get older, their schools may also have resource centers and tutors. Remember that you have a community of support for your child, including your social supports and the school.

- For young children, **reading together is important**. If your TBI makes it hard for you to read, ask your child to read to you. You can also share books with pictures, while encouraging your child to create their own story from the pictures.

Managing Your Child's Activities

As a parent, you must coordinate many activities for your child. These include doctors' appointments, social activities with family and friends, and leisure activities, such as team sports, piano lessons, and scouts. TBI can make it hard for you to manage your child's activities. For example, fatigue may make it hard to start or continue a leisure activity. You may also have a hard time planning, organizing, and remembering activities. This can make it hard to keep track of activities, set up transportation, and help with events. Here are some tips:

- **Use a calendar or agenda** to track appointments. Include when sign-ups are due, when and where practices and events are, and when you need to call for appointments. Take advantage of reminder calls offered by doctors' offices.
- You will likely feel tired before your child does. Know your limits. **Pace yourself.** You will need to decide what you can help with and when to say *no*. Your child can do some activities without you.
- **Use checklists** with your child to make sure you bring everything they need to the appointment/event.
- **Work with other parents**. Working together can help you overcome expected and unexpected challenges. If there are things that you can't do, see if you can coordinate with other parents so that they do those tasks, and you do others. For example, if the other parent can drive, you can offer to bring sliced oranges to sports practice. For some, hiring help is an option.
- **Take note of changes in your child's interests** after your injury or a change in your health. They may need encouragement or support to stay with activities that they enjoy.

Emotional Support for Your Child

You may think that forming an emotional bond with your child occurs naturally, but it takes work. As children go through different developmental stages, their interests change, along with how they interact with others. Over time, they grow into independent people with their own needs and likes. In addition to keeping up with their emotional changes, children need discipline and rules to keep them safe. Changes in thinking and emotions caused by TBI can make it hard to give them the structure and support they need. For some, TBI can make it hard to recognize their child's emotions, especially when they rely on facial expressions and body language. TBI can also affect your ability to recognize your own emotions and to monitor how you express them. Forming an emotional bond with others also requires your attention and mental energy. TBI can cause rapid mental fatigue and make it difficult to pay attention. So, after a long day, your ability to respond to your child's emotional needs may not be the same as before your TBI.

Here are some tips to help provide emotional support to your child:

- **Take time to listen**. Set aside a regular time for check-ins. Check in with your children about how they are feeling. Ask "How has your day been?" If they respond with one-word answers, such as "good," gently probe for more detail with something like, "Can you tell me something that made you happy?"

- If you have a young child who is learning new tasks, watch them and say aloud what they are doing. For example, if your child is playing with Legos, say, “You are putting the blue Legos together to make a train,” or “You decided to build a tree.” This lets your child know that you **notice what they do and supports them**.
- **Make a few simple rules**. Writing them down can make them clearer to you and to your child. Written rules can help you communicate the rules consistently when you are under stress. Teach these rules by example. Children are more likely to follow what you do than what you tell them. Show them what you want them to do.

- If you have trouble recognizing good behavior, work with another adult **to identify what “good” looks like.** Look for that behavior in your child and praise them for it.
- If you find yourself losing your temper with your child, **give yourself a time-out**. If you make a mistake or hurt someone, apologize. Explain to them what you are doing. This is good way to be a role model for your child. **Make notes about things that your child seems to take an interest in**. When you are feeling alert, ask them to share a favorite song with you or ask them about their favorite sports team. Schedule an activity around their interests (e.g., a concert, shopping, or watching an online video). Let them know you care about what is important to them.
- **Talk to them about the consequences** of their actions. Use language they can understand. For example, point out to a toddler that their friend is sad. Ask a teenager how an action affects a friendship and whether they want to keep the friendship.
- When children are upset, it helps them *and* you to **name the emotion**. You can give them choices so they can pick the emotions that fit. For example, ask, “Are you feeling sad or are you feeling jealous?” Also share your emotions honestly when you can.

- If you feel that your child is more distant since your TBI, talk to them about this. **Let them know that you understand that your injury may be scary to them**, and that it may have changed some things about you. Invite your child to share their feelings about this. Share your feelings about the TBI, too. You may also involve other family members to this discussion.
- If your child is acting out, **work with another adult who cares** about your child to set rules. Also work with them to problem-solve difficult behavior issues.
- **If you think your child is struggling emotionally, get help**. Are they withdrawn? Are they acting out a lot? Do their mood swings seem severe? Did their grades drop suddenly? Your pediatrician or your school can help direct you to get help from therapists, counselors, psychologists, etc.

Co-Parenting When Your Partner Has TBI

Co-parents may be together, separated, or no longer in a relationship. No matter what their status is, they may share responsibility for raising a child. Co-parents may have a mutual commitment to promote and support their child’s healthy development from infancy through adulthood. Like parenting, co-parenting is hard work and can be stressful. It requires a lot of time, communication, and problem-solving, which is challenging for all parents and becomes even more so for a co-parent with a TBI.

There are many ways that you can help your co-parent with a TBI. Here are some tips:

- Learn about TBI and its effects so that you can understand the mental, physical, and social challenges your co-parent faces. Understand that the journey after TBI has many **ups and downs, which affect the whole family**. TBI is an invisible disability and can be easy to forget in the moment, yet remembering and using these strategies and resources can lead to greater success for all.
- The parenting responsibilities that your partner had before the TBI may be too much now. Talk to your partner about a **weekly schedule or calendar that spells out the responsibilities** that you both feel are realistic and that each of you will take on. Post the schedule and review it each week.
- Your partner may not be aware of the impact of their actions—or their lack of action—in any given situation. **Understand** that what they do or don't do may not be on purpose.
- To **nurture your relationship**, schedule time for just the two of you to be together. This should be separate from your time with your children.
- Learning how to deal with the effects of your partner's TBI can be hard for you on many levels. *Get the* **outside support that you need** so that you remain supportive of your partner and your children.
- Realize that every happy family looks a little different—there is no one way to be a happy family. Love, attention, good communication and understanding how your TBI is part of the family are keys to success.

Resources for Parenting With a TBI

Living with Traumatic Brain Injury (TBI): https://msktc.org/tbi

Parenting After Brain Injury:
https://www.headway.org.uk/media/3998/parenting-after-brain-injury-e-booklet.pdf

Positive Parenting Tips: https://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/index.html

Ultimate List of Resources for Co-Parents: https://talkingparents.com/blog/ultimate-list-of-resources-for-co-parents

Traumatic Brain Injury Factsheets: https://msktc.org/tbi/factsheets

Authorship

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Seizures After Traumatic Brain Injury

June 2020 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet provides information about seizures after TBI. It also discusses treatment for seizures.

Seizures are one health problem that can occur after a traumatic brain injury (TBI). Although most people with a TBI will never have a seizure, 1 out of 10 people who were hospitalized after a TBI will have seizures. It's good to know what a seizure is and what to do if you have one. Most seizures happen in the first few days or weeks after a TBI. But some may occur months or even years after the injury. About 70% to 80% of people who have had a TBI and who then have seizures are helped by medicine and can return to most activities. In rare cases, seizures can make it harder for a person with a TBI to function because of new difficulties with thinking or moving.

What are seizures?

A seizure is sudden and abnormal electrical activity in the brain. During a seizure, one or more of the following symptoms may occur:

- Unusual movement of the head, body, arms, legs, or eyes. This may include stiffening, jerking, or shaking.
- Unresponsiveness and staring.
- Chewing, lip smacking, or fumbling movements.
- Changes in sense of smell, hearing, or taste.
- Changes in vision, such as an aura or seeing things that aren't there.
- Sudden tiredness or dizziness.
- Not being able to speak or understand others.
- New outbursts of anger or tearfulness.

These symptoms of a seizure happen suddenly, and you can't control them. Seizures usually last a few seconds or minutes but can last for 5 to 10 minutes. During a seizure, you may have a bladder or bowel accident; you may bite your tongue or the inside of your mouth. After a seizure, you may feel drowsy, weak, or confused or have a hard time talking to or understanding others. After a severe seizure, which lasts longer than 2 minutes, it may be hard for you to stand, walk, or take care of yourself for a few days or even longer.

Some conditions that may 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.

The Traumatic Brain Injury Model Systems program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See http://www.msktc.org/tbi/model-system-centers for more information).

What do we call seizures after TBI

- A seizure that occurs within 1 week of a TBI is called an early posttraumatic seizure. About 25% of people who have an early posttraumatic seizure will have another seizure months or years later. This is called epilepsy.
- A seizure that occurs more than 1 week after a TBI is called a late posttraumatic seizure. About 80% of people who have this kind of seizure will have another seizure (epilepsy).
- Half of all people who develop epilepsy will continue to have seizures throughout their lives, but they can usually be managed with medications.

Medicine to treat seizures

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

Some common side effects of AEDs are:

- Sleepiness or fatigue.
- Worsening balance.
- Lightheadedness or dizziness.
- Trembling.
- Double vision.
- Confusion.

You may need to have blood tests to make sure you are getting enough medicine and to make sure the AED isn't causing other problems. Although AEDs rarely cause birth defects in newborns, you should tell your doctor if you are pregnant or may become pregnant. Sometimes your doctor will prescribe two or more AEDs to stop your seizures. Some common AEDs are listed below.

- Carbamazepine (also known as Tegretol).
- Lamotrigine (also known as Lamictal).
- Levetiracetam (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 medicine doesn't work?

Anti-seizure medicines usually work. But sometimes they can't stop your seizures. If you still have seizures after trying medicine, your doctor may send you to a comprehensive epilepsy center. At the center, you will see special seizure doctors called epileptologists or neurologists who specialize in epilepsy. These doctors may do brain wave tests and take a video of you during one of your seizures to help figure out what's causing them. This information may help your doctor decide what medicine will work best. It may also help the doctor figure out if other types of treatment will help with the seizures you are having.

To find a center near you, you can visit the websites of the Epilepsy Foundation (www.efa.org) and the American Epilepsy Society (www.aesnet.org).

Safety issues

In most states, if you have had a seizure, you can't drive, and you must notify the department of motor vehicles. Usually you won't be able to drive for a certain period of time, or until your seizures have stopped. The laws vary from state to state.

If you are still having seizures, you should take certain steps to stay safe.

- Talk to your doctor about your seizure risk based on your type of injury, your medical status and how long it has been since your injury.
- People with seizures should not drink alcohol or use marijuana because this will increase your risk for another seizure.
- After a seizure you should not operate heavy equipment until you meet with your doctor.
- Always have someone with you when you are in water. This includes pools, lakes, oceans, and bathtubs.
- Don't climb on ladders, trees, roofs, or other tall objects.
- When eating, tell the people with you what to do if you have a seizure and start choking.

What your caregiver should do if you are having a seizure

Family members and caregivers should watch closely during a seizure so they can describe what happened to your doctor and other health care providers. They should make a diary with the date, time of day, length of time, and a description of each seizure. Your doctor will need this information, along with the medicines you are taking to control your seizures. Most seizures are short and don't cause serious injuries. But it's important for your caregivers to know what to do to keep you from hurting yourself during a seizure.

When someone is having a seizure, do the following:

- Loosen tight clothing, especially around the neck.
- Make sure the person doesn't 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, doesn't block the throat.
- Don't put anything in the person's mouth as you may get bitten.
- If you know cardiopulmonary resuscitation (CPR), check the heartbeat in the neck. Start CPR if there is no pulse. Call 911.
- Listen for breathing at the mouth. Extend the person's neck if breathing is difficult. If the person isn't breathing, start CPR. Seal your lips over the person's mouth and breathe two quick breaths. Continue breathing every 5 seconds unless the person starts breathing on his or her own. Call 911.
- If this is the first seizure after a TBI, call the person's doctor for advice.
- If the seizure doesn't stop after 3 minutes, call 911.
- If the seizure stops within 3 minutes, call the person's doctor.
- If the person doesn't return to normal within 20 minutes after the seizure, call 911.

For More Information

The Epilepsy Foundation
Phone: 1-800-332-1000
Website: www.efa.org

American Epilepsy Society
Phone 1-312-883-3800
Website: www.aesnet.org

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

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Severe Traumatic Brain Injury: What to Expect in the Trauma Center, Hospital, and Beyond

July 2017

TBI Fact Sheet

This fact sheet explains how a severe TBI affects the injured person, what to expect from a team of doctors and other health care professionals providing care, and how you can support this team and your loved one on his or her road to recovery.

A severe traumatic brain injury (TBI) affects more than just the injured person. It also affects family members and friends who love and are close to the person who is injured. As one of these people, you play a very important role in caring for a loved one with a severe TBI. For many, this role is new and comes with a lot of questions.

What is severe TBI?

TBI occurs when an outside force disrupts the brain's normal function. Falls, car crashes, assaults, and a blow or strike to the head are the most common causes of TBI. Severe TBI always includes a period of unconsciousness (uhn-KON-shuh s-nis). During this time, the person will not be able to stay awake. He or she will not be able to interact with surroundings in a purposeful way, such as reaching for an object. Here are the levels of impaired consciousness often seen in people with a severe TBI are the following:

- A **coma** is a state of complete unconsciousness. People in this state can't be awakened. They can't see because their eyes are closed, and they may not respond to sound, touch, or pain. They can't communicate, follow commands, show emotions, or engage in purposeful behaviors.
- People in a **vegetative state** are still unconscious but may be awake at times. They may start to open their eyes. This is also known as "Unresponsive Wakefulness Syndrome." They may react briefly to sounds, sights, or touch and may even cry, smile, or make facial expressions. But these responses are reflexes and are not under the person's control. As with a coma, people in a vegetative state can't show emotions or engage in purposeful behaviors. People in a vegetative state aren't aware of themselves or their surroundings. They can't communicate or follow commands. The word *vegetative* doesn't mean the person is a "vegetable." It refers to the "vegetative" or automatic functions still being controlled by the brain, such as breathing, heart function, and digestion.
- People in a **minimally conscious state** begin to regain consciousness. They may have some awareness of themselves or their surroundings but not all the time. People in a minimally conscious state may engage in purposeful behaviors from time to time. For example, they may follow a simple command, look at people or objects around them, or keep their eyes focused on people or objects that are moving. They may reach for or try to use a common object, like a hairbrush. They may show appropriate emotional responses or try to communicate through gestures or talking.
- **Emerged from the minimally conscious state** refers to people who can communicate consistently or use at least two objects in a purposeful way**.** During this stage, they may be able to answer simple questions correctly by saying or gesturing responses like "yes" and "no." They may also be able to follow instructions and perform simple tasks.
- When people regain consciousness, they may enter a **post-traumatic confusional state.** This state of recovery may include a condition known as **post-traumatic amnesia** (am-NEE-zhuh). People in this state are confused and have problems forming new memories. They may not be able to walk or talk, recall memories, or recognize people they know. Typically, people can't remember where they are or what happened. They can't remember day-to-day details or events. They can't perform lengthy tasks. They may sleep a lot during the day but find it hard to sleep at night. They may be restless and/or agitated. People in this state may also do unsafe things, like pull on feeding and breathing tubes or try to get up without help.

The Traumatic Brain Injury Model System program is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See http://www.msktc.org/tbi/model-system-centers for more information.)

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What happens during the acute hospital stay?

Each TBI is unique. Most people with a TBI need a combination of intensive medical treatments. These may include neurological, surgical, and rehabilitative treatment. In the acute care setting, doctors and other health care professionals first address life-threatening injuries. Next, they address and treat other injuries and medical problems that arise. Finally, doctors make sure the injured person is medically stable. Many other health care providers and specialists may be involved too. This can be overwhelming. The following is an overview of the health care team members who will likely be involved. Aside from providing care, the members of this team are an important source of information and support to family members and friends during this difficult time:

- **General medical team:** This team of doctors, nurses, and nursing assistants provide care daily to people with TBI. This team treats medical conditions and manages medicines.
- **Intensive care specialists:** One or more medical professionals who specialize in trauma care and recovery may be a part of the health care team:
    - **Surgeons –** Depending on the injuries, surgeons may be a part of the team. Examples include trauma surgeons, neurosurgeons, orthopedic surgeons, and plastic surgeons.
    - **Critical care doctors –** These medical doctors treat people who require intensive care. They monitor a person's medical condition closely. They also help diagnose and treat medical problems.
    - **Critical care nurses –** These nurse specialists do frequent (in some cases hourly) rounds. They perform informal bedside neurological exams. They may also help doctors perform procedures. Because they interact frequently with the patient and family, they are often the "first line" of communication, education, and support for families.
    - **Neurologists –** These medical doctors evaluate and treat disorders of the brain. They may perform tests to help determine the extent of a brain injury. They may also perform bedside evaluations to guide diagnosis and monitor neurological recovery.
    - **Pulmonologists or respiratory (RES-per-uh-tohr-ee) therapists) –** These specialists diagnose and treat breathing problems. They determine whether a person needs a breathing tube or machine to help them breathe.
    - **Dieticians or nutritional specialists –** These professionals monitor a person's nutritional status and manage their dietary needs. They may also help determine whether a feeding tube is needed to provide nutrition.
- **Pharmacists:** In a hospital setting, these specialists work closely with the doctors to monitor a person's medications. They help with medication dosing and prepare medications. They may also provide education to the medical team and sometimes directly to families. They can explain the purpose of the medications being given and provide information on medication side effects.
- **Physiatrists (fiz-ee-A-trists OR fi-ZAHY-uh-trists):** These doctors help diagnose and treat medical conditions—including pain, muscle, joint, and nerve problems—during the rehabilitation (rehab) process. They also direct and oversee a team of brain injury rehab specialists, including physical therapists, occupational therapists, and/or speech therapists.
- **Rehab therapists:** These specialists provide various types of therapies, for example, physical, occupational, or speech-language. People with TBI may receive these rehab services while they are in the intensive- or acute care unit. These services help prevent muscle loss and keep the range of motion in arms and legs. They can also help with swallowing, feeding, and communication difficulties.
- **Neuropsychologists:** These psychologists evaluate and diagnose changes in behavior, thinking, and emotion caused by TBI. They may perform bedside assessments to help diagnose levels of consciousness. They may educate and support family members of people with TBI.
- **Case managers and social workers:** These providers coordinate the health care plan by handling insurance benefits and other financial matters as well as overseeing discharge planning. They are a valuable resource for families and can provide both emotional support and information about TBI. These providers can also plan for future phases of care.
- **Other professionals:** A psychologist, chaplain, and/or patient representative may be available to provide spiritual and emotional support to people with TBI and their family members.

Throughout the recovery process, people with TBI undergo tests and procedures to assess the location and level of brain damage. This will help with diagnosis, prognosis, and treatment decisions. Such tests and procedures may include the following:

- **Neuroimaging studies:** These tests use computed tomography (tuh-MOG-ruh-fee) (CT scans) or magnetic resonance imaging (MRI). They help identify bleeding and injured parts of the brain. Doctors can also use the results of these tests to help determine if surgery is needed.
- **Electroencephalograms (ih-lek-troh-en-SEF-uh-loh-gram) (EEGs):** These tests measure electrical activity in the brain. Results of EEGs can be used to diagnose seizures. They can also show the location and extent of a brain injury.

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- **Neurological monitoring/neuromonitoring:** Devices such as intracranial pressure monitors track the amount of pressure in the brain and help manage brain swelling. These devices require placing a tube in the brain that is attached to wires and a monitoring screen. If needed, the tube device can be used to drain excess fluid and relieve excess pressure in the brain. Neuromonitoring also helps diagnose and treat hydrocephalus (an excess of fluid buildup in the brain) and can help determine if surgical placement of a more permanent pressure valve, called a shunt, is needed.
- **Informal bedside neurological exams and formal behavior assessment scales:** Doctors may use these tests to diagnose a disorder of consciousness caused by a TBI. They can help determine a person's level of impaired consciousness. A typical exam tests basic reflexes; doctors look at how the eyes react to light and they assess a person's response to sound, voice, touch, and pain. Doctors also look for signs of purposeful behaviors, like following a moving object with the eyes. This is called *visual tracking*. Other signs doctors look for are following commands and communicating.

What is known about recovery of consciousness and outcomes after a severe TBI?

Some doctors consider certain severe TBIs to be beyond hope. However, this can't be determined in the first few days after an injury. It may take weeks—or even months—for a doctor to determine how or if a person will recover over time. Many people (but not all with a disorder of consciousness related to a TBI) will eventually regain consciousness. The following are some important facts to keep in mind about recovery from a disorder of consciousness caused by a severe TBI.

- Recovery usually follows a step-by-step path. Most people progress through the stages of coma, vegetative state, minimally conscious state, emerged from minimally conscious state, and post-traumatic confusional state. Then, people often continue to improve slowly over time.
- There is a lot of variation in how people move through these stages and how long each stage lasts. Not everyone goes through every stage. Some people move through the stages quickly or skip stages. Others may get stuck in a stage.
- Recovering from a severe TBI can take a long time. Some people regain consciousness within a few days or weeks and recover quickly. Others progress more slowly and may remain in a state of impaired consciousness for months or years. Every injury is different and follows its own timeline.
- As a general rule, the longer a person remains in a coma or in a state of impaired consciousness, the more likely it is that they will be severely disabled.
- Visual tracking is a sign of improvement. It is often one of the first meaningful behaviors seen when a person moves from a coma or vegetative state to a minimally conscious state.
- The earlier a person improves from a coma or vegetative state to the minimally conscious state, the better the long-term outcome. For example, if a person can follow simple, one-step commands by 2–3 months after the injury, the better the outcome is likely to be. This is true even if the responses are delayed or inconsistent.
- People with disorders of consciousness that last for several months after a severe TBI can still improve. They may benefit from specialized TBI rehab.
- Age also plays a role in recovery outcomes. Among those with a prolonged time of impaired consciousness, younger people are more likely to return to living more independent, productive lives.
- An accurate diagnosis about level of consciousness is essential. It helps predict short- and long-term outcomes. It can help when deciding if specialized rehabilitation is needed. An accurate diagnosis is also helpful for family members and decision makers as they sort through difficult decisions like whether to stop care.

What can I do to help?

You may feel powerless, helpless, and afraid. But you play an essential role in the care of your loved one. You can do many things to move treatment along and support ongoing recovery:

- Be ready to answer questions from the health care team. These could be about your loved one's medicines, allergies, or other medical conditions. The more information you can provide, the better prepared the medical team will be in preventing new problems.
- Your loved one won't be able to make decisions about medical procedures. If you are not the legal decision maker your loved one, then find out who is. Other family members and loved ones can support the legal decision maker during this tough and emotional time. If your loved one has an advance directive, discuss with the medical team his or her wishes about resuscitation.

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- It might be helpful for you or someone else to become the legal guardian for your loved one. A guardian is someone the court assigns to manage personal, legal, and financial matters for a person who can't make their own decisions. Having a guardian appointed may help when making decisions about your loved one's medical care. Elder law attorneys are lawyers who can assist with this process. These lawyers can also help with financial planning and other legal matters for people with long-term care needs.
- Learn about changes that may occur in people after a severe TBI. These include cognitive, physical, behavioral, and psychological changes. This will help you know what to expect as your loved one recovers.
- Learn about the skills needed to take care of your loved one. This will help you feel more ready during the treatment and recovery phases.
- Don't forget to take care of yourself. When in crisis mode, family members often put their own needs last. But it is important to take breaks, eat regularly, and get a good night's sleep. Trust the care team to be there while you rest. By taking care of yourself, you can be a better support for your loved one.
- Family and friends are often the first ones to notice changes in their loved one's status. Noticing these changes is very helpful to the medical team. It's important to ask questions, raise concerns, and share your observations.
- Understanding how to interact with your loved one may help his or her recovery. It can also help you to quickly recognize signs that may indicate a change in his or her status.

Here are some suggestions on how to interact with a loved one with a severe TBI:

- Balance periods of rest and stimulation. Don't provide too much stimulation at once. For example, limit the number of visitors to only a few at a time. When people are visiting, turn off the TV and make sure the room is calm and quiet. Always follow the care team's recommendations about how much and what type of stimulation is appropriate for your loved one.
- Even if your loved one can't respond, physical contact is important. Hold his or her hand. If the bedside nursing staff allow it, gently massage your loved one's hands, arms, legs, or feet.
- Stimulate your loved one's senses. Offer different smells, sounds, things to look at, and things to touch. Show pictures of friends and family. Play his or her favorite music. Bring in a favorite blanket, stuffed toy, or piece of clothing.
- Talk to your loved one as if he or she can hear and understand you. Read him or her a book or a newspaper. Recall important, special, or funny life events; or put on his or her favorite TV show.
- Occasionally "test" your loved one's ability to make eye contact or watch people move around the room. Ask him or her to follow simple commands like "squeeze my hand," "raise your arm," or "open your mouth." Ask him or her to answer simple "yes" or "no" questions. It may take several seconds for him or her to respond each time. Let your loved one rest briefly between questions.
- Don't pressure your loved one when he or she doesn't show you the behaviors you're hoping for, or if he or she only shows them some of the time. Your loved one can't control changes in consciousness. As recovery continues, you may see these behaviors more often.
- When your loved one regains consciousness, he or she may be confused, and behavior problems may develop. Tell your loved one often that he or she is in a safe place and that people are there to help. Remind him or her of what happened; where he or she is; and the current day, date, and time. Keep a clock and easy-to-read calendar in clear view.
- Help identify things that trigger any behavior problem in your loved one. Write down what was going on just before the problem occurred.

What should I ask the doctors and other health professionals who are treating my loved one?

- *What is my loved one's level of consciousness, and what information and tests were used to determine the diagnosis and prognosis?*

  You or other decision makers may have to make decisions about treatment in the first hours and days after the injury. These decisions may need to be made based on unclear information. This can be scary and overwhelming. You may feel more confident when a disorder-of-consciousness diagnosis is based on both bedside exams and objective tests (e.g., results of an EEG). Doctors may deliver a poor prognosis "with certainty." Ask questions about what this means. Often, more specialized bedside exams, tests, and time are needed. This is especially important when deciding whether to remove your loved one from life support. If a definite poor prognosis is given, ask the health care team to give you the full range of possible outcomes, and ask what data they are basing the prognosis on. You may also want to consult a disability specialist with expertise and experience in TBI rehab. Consider what they say along with information from the health care team. These specialists can offer an expert opinion about your loved one's diagnosis and prognosis. They can also help match your loved one with the right rehab services.

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- *Are there any other medical conditions that can be treated to help promote my loved one's recovery?*

  Factors other than the main injury may make it tough for your loved one to interact with his or her surroundings. For example, medicines may make him or her sleepy. He or she may be having seizures. There could also be an infection or a build-up of fluid on the brain. Ask the doctors to look for these and other factors that can affect recovery.
- *What are the care options for people with severe TBI?*

  When your loved one is medically stable, treatment will focus on preparing him or her for the next level of care. At this point in the recovery process, many people still need specialized, inpatient services including rehab. Specialized rehab services are offered in many settings. These include acute care or inpatient rehab hospitals or subacute rehab facilities. However, many health insurance plans won't pay for these services if your loved one can't actively engage with surroundings. Your loved one could also receive care at a skilled nursing facility, but specialized TBI services are often limited in that type of setting. To decide on the next level of care, doctors will look at your loved one's medical status and diagnosis and at brain injury programs in your area. The search for the right placement and services can be difficult. Social workers and/or case managers can help you explore the available options. Additional information and resources to help find the right placement for your loved one may also be available through your local, state, and national brain injury associations. Whatever the next level of care is, you should look for a program with experience in caring for people with severe TBI. If your loved one is in a vegetative or minimally conscious state, look for facilities with experience in caring for patients with disorders of consciousness. Here, your loved one will get care and be observed for a longer period of time. This can help reach an accurate prognosis and guide long-term care planning. Such settings are also best prepared to monitor progress, prevent complications from developing, and help with a discharge home when appropriate. If your loved one doesn't get placed in a facility with specialized TBI services, you may want to stay in touch with a neurologist, rehab medicine physician, and/or a rehab case manager so someone with TBI expertise remains involved in the care of your loved one.
- *How is my loved one progressing, and what is the care team doing today to manage his or her condition?*

  Especially in the early phases of recovery, your loved one's condition may change quickly and often. You may feel as if you are in a constant state of worry about his or her medical stability. This can be extremely stressful for families. It may help to stay informed about your loved one's daily status and the progress that the care team is observing. Ask questions to help you better understand his or her care needs, what is being done to manage his or her condition, and what the next days and weeks might look like based on the care team's observations. Information, education, and regular communication with the care team may reduce your stress level and help you feel actively involved in your loved one's care.

Summary of key points about severe TBI

- Severe TBIs always involve a period of unconsciousness. When this period lasts for an extended amount of time, the term *disorder of consciousness* is used. Disorders of consciousness include coma, vegetative state, and minimally conscious state. Each disorder of consciousness is marked by different levels of awareness and ability to interact with surroundings in a purposeful way.
- Many people with a severe TBI regain consciousness; however, recovery is a long process and it involves several stages.
- People with disorders of consciousness that last several months after a severe TBI can still have meaningful recoveries. They often benefit from rehab in programs that specialize in treating people with severe TBI.
- An accurate diagnosis of level of consciousness is essential. It can help predict short- and long-term outcomes. It can also help in treatment planning and informing important decisions early in recovery.
- Early predictions of long-term recovery are often inaccurate. It may take time to make an accurate prognosis. Such a prognosis is based on your loved one's changing condition, especially as the medical condition improves and care is simplified.
- The health care team should have expertise in managing severe TBI. These professionals are best prepared to handle the many complex issues that may come up during your loved one's recovery.

Where can I learn more about severe TBI and DOCs?

- "Facts about the Vegetative and Minimally Conscious States after Severe Brain Injury": http://www.msktc.org/tbi/factsheets/Vegetative-And-Minimally-Conscious-States-After-Severe-Brain-Injury
- "Traumatic Brain Injury and Acute Inpatient Rehabilitation": http://www.msktc.org/tbi/factsheets/Traumatic-Brain-Injury-And-Acute-Inpatient-Rehabilitation
- Brain Injury Association of America: 1-800-444-6443, http://www.biausa.org
- Brainline.org: http://www.brainline.org

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Authorship

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Social Skills After Traumatic Brain Injury

January 2020 www.msktc.org/tbi/factsheets TBI Factsheet

This fact sheet explains what social skills are, how a TBI may affect them, and some tips to improve them after a TBI.

What Are Social Skills?

Social skills are the skills people use to communicate and interact with others. Social skills include what you say, as well as your body language, eye contact, facial expressions, tone of voice, and other actions. Cognitive skills (for example: staying focused, memory) and emotions (for example: anxiety, anger, sadness) also play a part in social skills. Examples of social skills include:

- Listening to and understanding what people say
- Communicating thoughts, needs, and feelings through words and actions
- Managing your emotions in social interactions
- Respecting social boundaries and social rules (for example: not standing too close to someone, not asking overly personal questions)
- Adjusting what you say and how you say it, as well as what you do, based on the situation

Why Are Social Skills Important?

Good social skills can help you:

- Have enjoyable interactions
- Get along with others
- Keep old friendships and make new ones
- Feel confident socially
- Succeed at school, at a job, or in a volunteer position

How Can a Brain Injury Affect Social Skills?

After a traumatic brain injury (TBI), people may have problems with social skills. These problems can differ from person to person and can be harder to manage when feeling strong emotions, such as anger or excitement. Common examples are:

- Feeling out of place and uncomfortable around other people
- Interrupting conversations
- Losing focus during a conversation
- Forgetting what someone has said
- Misunderstanding the words, facial expressions, tone of voice, or actions of others
- Difficulty getting along with others
- Talking too little or too much
- Having trouble expressing thoughts and feelings
- Not showing interest in what others have to say
- Not knowing how to start or maintain a conversation

The Traumatic Brain Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See http://www.msktc.org/tbi/model-system-centers for more information).

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Can Social Skills Get Better After a Brain Injury?

Research shows that social skills can improve after a TBI, even many years later. Working on your social skills with a therapist can help you to improve these skills. Therapists who help with social skills after TBI include speech-language pathologists, neuropsychologists or clinical psychologists, clinical social workers, and other health care professionals. You can also practice social skills with a family member or close friend.

How Can Social Skills Get Better After a Brain Injury?

Below are some tips that may help you improve your social skills. It may be helpful to ask a family member or friend to help you with this:

1. **Evaluate.** The first step in improving your social skills is thinking about your social skills: What you do well? What is challenging for you? It may help to think about someone who communicates well, or observe someone who is a good communicator. What skills or behaviors make that person a good communicator? This may help you gain a better understanding of the social skills you would like to improve.

Below is a list of some common social skills. Again, ask a supportive friend or family member for feedback on how you are doing on each of these skills:

- Taking turns in conversation
- Staying focused on the topic
- Listening to others
- Showing interest in the other person
- Asking questions of the other person
- Getting to the point
- Coming across as friendly and relaxed
- Being supportive of the other person
- Keeping emotions in check, and using a calm tone of voice
- Taking the time to speak as clearly as possible

2. **Set Social Skills Goals.**
   - Decide on one or two areas you would like to improve and write them down.

   For example, you could set a goal to ask more questions during conversations to keep the conversation going.
   - Post your goals in a place where you'll see them every day (for example, on your refrigerator or on your phone).
   - Share your goals with a supportive family member or friend, who can help "coach" and practice with you.

3. **Practice Social Skills and Get Feedback.** Practice at home, at work, or in other social situations. Here are some specific ways to practice:
   - Visit places in the community where you have a chance to interact with other people (for example, take a walk with a friend or neighbor, visit the library or recreation center, or have coffee with a friend).
   - Think about what you're going to say before you speak, and about how others might feel about that.
   - Show interest in the person you are talking with (smile, have eye contact, ask friendly questions).
   - Pay attention to feedback you get from the other person (did he/she smile, ask questions, keep eye contact, etc.).

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- At least once a week, ask your family member or friend to give you feedback about how you're doing on your goals.
- Practice social skills in front of a mirror, or have someone videotape you practicing. Watching yourself can help you notice areas to work on. It may also help you realize that you are doing better than you thought!
- Write a short script that you can practice to say when a specific situation comes up (for example: when a conflict comes up, when you are talking to someone new).

Tips for Working on Your Social Skills in Specific Situations

1. To start a conversation, especially with someone new:
    - Talk about some of the things that are around you (such as a slogan on a hat, the weather, the person's dog, etc.).
    - When you're first getting to know someone, stick with neutral topics. Avoid talking about politics, religion, money, or personal information.
    - Ask open-ended questions, for example, "What did you do over the weekend?", "What do you think about the movie?", "What kind of hobbies do you have?", "What did you do over the holidays?", or "What are your plans for the weekend?"

2. To keep a conversation going:
    - Focus on topics that you think might be interesting to the other person, and ask open-ended questions related to the conversation.
    - Be aware of your body language. For example, make comfortable eye contact (looking at the person but not staring), nod your head, and smile.
    - Take turns talking and listening.
    - Watch for cues that the other person might want to end the conversation (such as looking at the clock, looking away, making comments about being in a hurry).
    - Be respectful of other people's personal space by not standing too close.

3. When you feel like there could be a conflict:
    - Let the other person finish talking and listen to what they have to say. Try to see the other person's point of view. What is it that the person wants you to know? If you don't know, it's okay to ask. For example, "It sounds like you're upset that I didn't clean the kitchen, is that right?" If you can't agree on something, try to meet them half way.
    - Use friendly body language and tone of voice. For example, avoid pointing your finger, yelling, or rolling your eyes. Try to stay calm and have your body and face as relaxed as possible. Remember to breathe.
    - Pay attention to your emotions. Let the person know what you are feeling and start with the word "I": "I feel frustrated right now," or "I'm feeling upset about that." If you think you need time to calm your emotions, let the person know that you need to take a break.
    - Show respect to the other person by talking to them in a way that you would want someone to talk to you.

Improving your social skills takes time and effort. Social skills usually improve one step at a time. Give yourself a pat on the back when you realize that you've taken even a small step toward your social skills goals.

For Families and Friends

Interacting with someone who has had a brain injury may require you to adjust your own social skills or the environment. For example, give the person more time to process what is being said and give them time to respond. Limit the amount of information you communicate at a time. Pay attention to the topic being discussed and the person’s reactions: Do they affect the person’s emotions and/or cognitive function? If the person seems fatigued or overwhelmed, wrap up the conversation.

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Authorship

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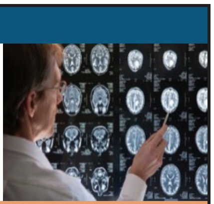
Spasticity and Traumatic Brain Injury



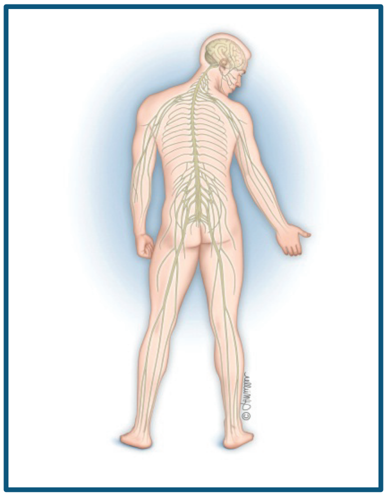
February 2015
TBI Fact Sheet

This fact sheet tells you about how to manage spasticity (muscle tightening) after your brain injury.

What is spasticity?

Spasticity is the uncontrolled tightening (increased muscle tone) caused by disrupted signals from the brain. It is common in persons with severe brain injuries (TBI). People with spasticity may feel as if their muscles have contracted and will not relax or stretch. They may also feel muscle weakness, loss of fine motor control (for example, being unable to pick up small objects), and overactive reflexes.

What you need to know



- Many people with TBI either do not have spasticity or have easily controlled spasticity.
- Your brain injury may cause the muscles in your body to become stiff, overactive, and difficult to stretch. The muscle may "spasm" or tighten suddenly. Doctors call this effect spasticity (pronounced spas-TIS-it-ee).
- Spasticity may not be bothersome and does not always need treatment.
- Spasticity may come and go. It may be worse during certain activities or it may become worse at night. It can interfere with sleep or limit the ability to function. When problems such as these arise, there is more need to consider treating it.
- Severe spasticity may cause almost continuous spasms and can cause permanent shortening of muscles, making even simple movements difficult.
- There are ways to treat spasticity or relax muscles, ranging from controlling triggers to taking medicines.
- When only a few muscles are affected, focal treatments such as nerve blocks and botulinum toxin injections (described below) may be considered. There may also be surgery options.

The Traumatic Brain Injury Model Systems Program is sponsored by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education. (See http://www.msktc.org/tbi/model-system-centers for more information)

Understanding Your Body: How Muscles Work

Your brain communicates though your spinal cord and nerves to your muscles and causes them to contract and relax. After brain injury, the messages between brain and muscles may become unregulated leading to unwanted muscle contractions.

What are the symptoms of spasticity?

The symptoms and degree of spasticity are different in each person and can include:

- Sudden, involuntary tightening or relaxing of a limb, or jerking of muscles in the trunk (chest, back, and abdomen).
- Hyperactive (overactive) reflexes, such as a muscle spasm when the arm or leg is lightly touched.
- Stiff or tight muscles at rest, so that it is difficult to relax or stretch. This is more pronounced than normal muscle tightness when a person sits for a long period of time. In spasticity, the tightness is so high that it is difficult to stand or walk.
- Muscle tightness during activity, making it difficult to control movement.

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When am I most likely to experience symptoms?

Spasticity can happen at any time, but is most likely to occur when you:

- Stretch or move an arm or a leg.
- Have a urinary tract infection or a full bladder.
- Have constipation or large hemorrhoids.
- Have an injury to the muscles, tendons, or bones (including bone fractures).
- Wear tight clothing or wraps.
- Feel emotional stress.
- Have any kind of skin irritation*

(Skin irritation includes rubbing, chafing, a rash, in-grown toenails, or a skin sensation that is too hot, too cold, or causes pain. This also includes pressure sores or ulcers caused by staying in one position for too long.

Does spasticity need to be treated?

Spasticity is not always harmful or bothersome and does not always need to be treated. Sometimes, however, there are problems caused by spasticity that can be bothersome or harmful.

Problems caused by spasticity include:

1. Pain when muscles tighten.
2. Limited motion, especially in joints that can limit walking or moving in and out of beds or chairs.
3. Difficulty taking deep breaths.
4. Falls
5. Poor positioning in a chair, wheelchair, or bed.
6. Poor sleep and tiredness during the day.
7. Skin pressure ulcers.
8. Difficulty maintaining proper hygiene.
9. Limits on normal activities such as feeding or grooming.
10. Limited use of your hands.

What can I do to manage my muscle spasticity?

Urinary tract infections and skin breakdown can be avoided by keeping skin clean, wearing loose clothing, and changing positions regularly. Taking extra care when moving from a chair or bed can also help keep triggers from occurring. Other triggers such as constipation or large hemorrhoids can be avoided by eating a high fiber diet and drinking plenty of water. Even though stretching can sometimes be a trigger of spasticity, daily stretching can actually help you maintain flexibility. Sometimes, wearing splints can keep spasticity from becoming worse.

Coping with Spasticity through Physical Treatments

The following treatments will help to maintain flexibility and therefore reduce spasticity and the risk for permanent joint contracture:

1. Regular stretching (range-of-motion) exercises will help maintain flexibility and temporarily reduce muscle tightness in mild to moderate spasticity.
2. Standing with support, often with the help of braces, will help stretch muscles.
3. Splints, braces, or progressive casting into the desired position provides continuous muscle stretching that helps to maintain flexibility; ideally it is a position that does not trigger your spasticity.
4. Careful use of cold packs or stretching and exercise in a pool may help.

It is important to get the advice of a physician or therapist on what physical treatments are correct and safe.

Oral Medication

Medication may help control spasticity but may have side effects, and is probably most useful when you have spasticity in several parts of your body. Common side effects, such as sleepiness, might be more intense after a brain injury. You should discuss the benefits and side effects of various medications with a physician. Appropriate medications may include:

- Baclofen (Lioresal®)
- Dantrolene (Dantrium®)
- Tizanidine (Zanaflex®)
- Benzodiazepines such as diazepam (Valium®) or clonazepam (Klonopin®)

Focal Interventions

Sometimes a person may have side effects to oral medication or may only have spasticity in a single location. For those types of spasticity, anesthetic medications, alcohol, phenol (pronounced FEE-noll), or neurotoxins (such as botulinum toxin, Botox®, Dysport®, Xeomin®, Myobloc®) can be injected into the muscles and nerves (usually in the arms and legs) to reduce unwanted muscle hyperactivity to control spasticity in local areas. These injections rarely cause widespread side effects and do not affect the brain or spinal cord. The benefits of the injections are temporary, so they must be repeated several times a year. These injections require regular stretching to be most effective. Injections can be used safely in combination with other spasticity management.

Intrathecal Baclofen (ITB) Pump

Intrathecal baclofen pumps are small hockey-puck sized devices that release tiny amounts of baclofen into the space around the spinal column. Baclofen is the most commonly used medication for spasticity. Intrathecal baclofen (pronounced in-TRAH-theh-cal BAK-loh-fen) pumps can be especially helpful after a traumatic brain injury. A surgery is performed to implant a small battery-powered computer and pump, usually in the patient's abdomen. Intrathecal baclofen can be used along with other spasticity treatments. Like other treatments, this pump can reduce the frequency and intensity of spasms. It has the advantage of maximizing the beneficial effects of baclofen with fewer side effects than taking baclofen by mouth.

Although rare, there are serious risks associated with intrathecal baclofen and it is important to discuss the risks with your physician and comply with careful monitoring.

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Spasticity. Knowledge NOW. American Academy of Physical Medicine and Rehabilitation. http://now.aapmr.org/cns/complications/Pages/Spasticity.aspx

Authorship

Spasticity after Traumatic Brain Injury was developed by Kathleen Bell, M.D. and Craig DiTommaso, M.D., in collaboration with the Model Systems Knowledge Translation Center.

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

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Staying Healthy After TBI

June 2022 https://msktc.org/tbi/factsheets TBI Factsheet

This factsheet includes information about how to monitor and maintain your physical and mental health after TBI. It also includes resources to help you stay healthy after TBI.

Staying healthy after having a traumatic brain injury (TBI) can be hard. TBI can cause negative changes in your physical and mental health and change how you think and feel. These changes can make it hard to take care of yourself and to prevent or manage other health problems. This factsheet aims to help you understand how TBI can affect your health and offers tips for staying healthy throughout your life.

Monitoring Your Health

To stay healthy, we all need to know the signs that tell us that something may be wrong. But TBI can make it hard to do this. For example, you may have a hard time noticing your body's signals or remembering what health problems to tell your doctor about during an appointment. You may also have a hard time recognizing the emotions that may signal a mental health problem. Here are some tips to help you monitor your health after a TBI:

- **Get some tools to help monitor your health at home.** Body weight, temperature, blood pressure, and waist size are important health measurements. Important tools to monitor these include a scale, a thermometer, a blood pressure cuff, and a soft tape measure. If you have problems with low or high blood sugar, you may need a glucose or blood sugar monitor. Remember that your health measurements can change for many reasons. Work with your health care provider to decide the best times to take your health measurements and how often to take them.
- **Use technology to help monitor your health.** Other tools to help you monitor your health might include smart watches or fitness trackers, phone apps, digital blood pressure cuffs, and smart scales. These tools can make it easier to track your health over time. Many of these tools have alarms or reminders, which are helpful when you have trouble remembering. Some apps and devices can help you monitor all aspects of your health, such as mental and cognitive health, physical health and fitness, social health, and sleep. For example, some apps ask you to set health goals, such as a certain amount of exercise or an annual wellness check. They can track progress toward goals and send you reminders and motivational messages. You can also find apps to assist you to manage specific health conditions, such as diabetes or cardiac disease. These can help you monitor and care for symptoms related to these specific conditions. Some apps can even monitor your spiritual health goals (e.g., meditation, prayer, reading religious texts). You can find health and fitness apps by searching the Apple or Google Play App Store based on whether your cell phone is an iPhone or Android. You can try different apps to find the ones that work best for your unique needs. It is important to be aware of safety issues when entering any personal information in an app.

The Model System Knowledge Translation Center works with Traumatic Brain Injury Model System centers to provide free research-based rehabilitation resources for people living with traumatic brain injury (see https://msktc.org/tbi for more information).

Take care to only use apps that you have researched for how they protect your privacy. Ask someone that you trust to help you determine how apps handle your personal information. Remember to delete apps that you are no longer using.

- **Keep a health journal or diary.** Keeping a journal or diary may help you notice changes in your body or behaviors that you may need to pay attention to. It is also a great way to help you keep track of problems that you want to talk to your doctor about. You may want to start with basic health information, such as your age, height, weight, allergies, and surgeries. Decide what about your health you want to monitor and how often. Some good things to keep track of are how much you sleep; the amount and type of food you eat; how much water you drink; when you take medicines or vitamins; when you have pain; when you exercise or are active; when you feel sick; and when you have a doctor's appointment.
- **Schedule a yearly check-up with your regular doctor or primary care provider.** These check-ups are important for monitoring your health and finding potential problems early. During these visits, your doctor or other health care provider will check aspects of your health that you can't monitor at home. This may include blood work or breast or prostate screenings. Yearly exams give you a chance to talk to your health care provider about any concerns you may have. Your health care providers can also help you identify resources to help you better manage your health and remind you of important vaccinations, like flu or shingles. If you have a doctor that has seen you specifically for your brain injury (such as a physiatrist or a neurologist), then you can ask for an appointment if you are having a problem that your regular provider does not address.

Preventing and Taking Care of Other Health Conditions

People with TBI may have other health issues, such as high blood pressure or heart disease. Problems caused by the TBI, like issues with memory or planning, can make it hard to care for other health problems. Here are some tips to help you prevent or take care of other health conditions after TBI.

- Ask your providers about other health records and how to link your records from their treatment to your other medical records.
- Keep a list of your medicines, their dosages, and why you are taking each one. Take this list with you when you go to doctors' appointments.
- Use a pill box to organize your medications so that it is easy for you to take the right amount at the right time.
- Keep a list of your doctors, what they do, and how to reach them.
- Use a calendar to keep track of your doctor's appointments. Smart phone calendars can be useful for this, and often allow you to set alarms to remind you of appointments.
- Before you go to the doctor, write down the questions that you want to ask. During the visit with your doctor or healthcare provider, write down their answers or put them in the notes section of your smartphone. If it is OK with the doctor, you can also audio record your conversation. Consider bringing a family member or friend to your appointment. They can help you remember what to ask and remember what doctors or health care providers tell you. At the end of the appointment, repeat what the provider has told you. This will help make sure that you understand things and clarify any confusion.
- Talk to each of your doctors about your TBI and about how your medicines may affect your recovery. Some medications may not be recommended for people with TBI in certain cases, and not all physicians may be aware of this. If you are seeing a doctor who has not treated you for TBI, let them know about your TBI and

ask if any medicines they prescribe could worsen your TBI symptoms, or interact with current medications. You might also consider calling your brain injury doctor and asking if any new medications are OK for you.

- Avoid medicines that can make TBI-related thinking problems worse. Some medicines that are prescribed for pain and for breathing problems may worsen problems related to TBI. When you are prescribed a new medicine, talk to your doctors about how it may affect your recovery.

Maintaining Your Physical Health

There are a lot of things that you can do each day to support your physical health. These include exercising, eating well, avoiding alcohol and drugs (including tobacco), and sleeping well. Getting support from your family, friends, and health care providers can help you stay healthy. Here are some tips to help you support your physical health after a TBI.

Exercising

Your goal should be to do 150 minutes of safe, moderate exercise each week and to do strength training 2 days a week. You can work up to 150 minutes by starting small- even 10 minutes of exercise a few times a day will soon add up. You can reach this goal by walking, jogging, swimming, or biking. But other activities, such as gardening, cleaning your house, climbing stairs, and doing laundry also count as exercise. The key is to move as much as you can. Find an activity that you enjoy, do it safely, and try not to sit for long periods of time. Exercising with friends and family are also great ways to add social support to your exercise routine. You will know you are doing moderate exercise when you find it physically hard to talk to someone when exercising. Talk to a health care provider before starting a new exercise program. Talk to a physical therapist or physical medicine and rehabilitation doctor if you have mobility impairment that may require modified exercises.

Eating Well

At every meal, try to fill half of your plate with fruits and vegetables, a quarter with protein (fish, chicken), and the last quarter with grains (rice, oatmeal). Tofu and seitan are high-protein options for vegans or vegetarians. Filling your plate with lots of color and different types of fruits and vegetables is good for your health. It’s also a good idea to keep healthy snacks on hand so you are not tempted to choose an unhealthy snack. For example, have bowls of fruit or nuts on your kitchen counter or healthy granola bars in your car. Memory aids can also be helpful when you are trying to eat healthy. Examples include setting a timer on your phone to remind you when to eat, organizing your refrigerator or pantry so that healthy food is at eye level (middle shelf) and unhealthy food is lower or higher, and keeping a diary of foods that you ate throughout the day. You may also set a timer to remind you to take short breaks when eating, to ensure that you have time to recognize when you are full. If you are trying to gain or lose weight, you should talk to a health care provider to find out how many calories you should take in each day to stay healthy.

Avoiding Alcohol and Drugs

We know that alcohol and other recreational drugs can have a toxic effect on the brains of people who have not had a TBI. This impact may be more pronounced in people with TBI because injury to the brain makes the brain more vulnerable to other types of damage. Alcohol and drugs can have a negative effect on the injured brain and can limit the brain’s ability to recover and get better. Drugs and alcohol impair judgment and can also effect coordination and balance, making people more likely to injure themselves or others. For these reasons, it is advised that people with TBI avoid consuming alcohol and drugs.

Sleeping Well

To be healthy and function well, our bodies need sleep. Not getting enough sleep may affect our memory, thinking, energy level, and mood. Repeated lack of sleep over many years may contribute to long-term problems with memory and thinking. Aim to get at least 7–8 hours of sleep each night. If you are having trouble sleeping, talk to your doctor.

Here are some more tips that may help you to sleep better:

- Avoid large meals at night.
- Choose a caffeine cutoff time.
- Keep a consistent schedule, including on the weekend. Go to bed at the same time each night and use an alarm to wake up at the same time each day.
- Avoid napping during the daytime. If you do take a nap, keep it to no more than 20 minutes.
- Limit television and the use of electronics for at least one hour before bedtime.
- Use your bedroom only for sleep and intimacy; find another space for work and recreation. Give yourself 20 minutes to fall asleep. If you are not sleepy, get out of bed. Go back to bed when you feel sleepy.

Preventing Another TBI

TBIs have a “cumulative effect” on how well the brain functions. This means that a second injury, even if it were the same as the first, would have a bigger effect on your brain. That is why it is important to do everything you can to prevent another TBI. This may be hard because your past TBI may have affected your vision, your coordination, or your ability to pay attention. It is also important to take precautions to keep yourself safe, such as making sure your home is safe from falls and wearing a seatbelt. You should also use a helmet when recommended. You should avoid sports or activities that have a high chance of causing a blow to the head.

Maintaining Positive Mental Health

While mental health is just as important as physical health, we often don’t take care of our mental health. TBI can cause negative changes in your emotions. It can also make it hard for you to handle other types of stress, such as financial stress or conflict with your family members or friends. Paying attention to your mental health each day can help you handle unexpected stress when it happens. Here are some ways to maintain your mental health:

- **Keep a journal or diary to write down what you think and feel each day.** You can do this once a day, or at different times each day, such as in the morning and evening. You may notice that you think and feel differently at different times of the day. Being in touch with what you think and feel can help you spot patterns, like when you obsess over one idea that makes you feel sad or irritable. Just being aware of your thoughts and feelings can have positive effects on your mental health.
- **Take frequent breaks with time set aside to be with yourself**. Having quiet time for yourself each day is important for your mental health. It does not have to be a lot of time. If all that you have is 5 minutes, start there. You can sit quietly, meditate, drink a cup of your favorite non-alcoholic beverage, listen to music, or

pray. Try not to use this time to plan your next day's activities or do some other mental chore. Reserve the time to just sit with yourself and your thoughts and feelings.

- **Try mindfulness exercises**. Mindfulness means being aware of whatever you are thinking and feeling, without judgment. It means just noticing whatever you are thinking and feeling, without attaching any special meaning to it or labeling it as good or bad. Scientific evidence shows that being mindful in our daily lives has positive health benefits.
- **Reach out to others.** Being with other people can have a positive impact on your mental health, while loneliness can have a negative impact. TBI can make it hard to socialize. You may not feel like being with people, or you may not have the same social network that you did before. The following suggestions may help.
  - Try taking part in a support group. The Brain Injury Association or Brain Injury Alliance in your state can help you find TBI support groups near you.
  - Join a social media support groups for people with TBI. You could also join social media groups that are not related to TBI- such as interest in art or music.
  - Look for leisure learning courses in your community. You can take courses that interest you, such as photography or art appreciation. This can help you meet other people with similar interests.
  - Volunteering is another way to meet others who are passionate about the same things. Volunteer opportunities may include working on political campaigns, helping at a homeless shelter, or helping at a local pet rescue and adoption site. Look at your local city's website for other volunteer activities.
- **Focus on what you are grateful for.** Being grateful has positive health effects. Take a moment each day to think of something that you are grateful for. You may also find something around you, such as a beautiful flower or a pretty bird, and spend a few minutes watching it and appreciating it. Consider writing these positive thoughts in a journal.
- **Get help for your mental health when you need it.** It is normal to feel sad or worried sometimes, especially if it feels like your life has changed a lot since the TBI. If you find that you are so sad or worried that you don't enjoy activities or being with people, or you feel hopeless, don't be afraid to reach out for help. Talk to a family member or a friend or a doctor or other health care provider. There are ways to feel better. You may try medicine or talk therapy. It is not weak to ask for help; it makes you stronger.
- **Getting Social Support.** Staying healthy can be hard. You may have more success if you ask others to help you stay healthy. This can include family members, friends, or people that you meet when exercising at the gym or park. You can encourage each other, push each other to reach new goals, and just support each other. You may also join a nutrition or exercise group. Many workplaces have these, or you can connect with neighbors on community social media platforms or during community meetings.

Resources to Help You Stay Healthy

Cognitive Health and Older Adults:
https://www.nia.nih.gov/health/cognitive-health-and-older-adults

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Physical Activity Recommendations for Adults with Chronic Health Conditions and Disabilities: https://www.cdc.gov/physicalactivity/basics/pdfs/PA-adults-with-chronic-health-conditions-508.pdf

Protecting Against Cognitive Decline: https://www.health.harvard.edu/mind-and-mood/protecting-against-cognitive-decline

What's Your Move? Move Your Way: https://health.gov/sites/default/files/2019-11/PAG_MYW_Adult_FS.pdf

What's on Your Plate? https://www.myplate.gov/

Body Weight Planner: The Body Weight Planner allows users aged 18 and older to make personalized calorie and physical activity plans to reach a goal weight within a specific time period and to maintain it afterwards. https://www.niddk.nih.gov/bwp

Authorship

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider about specific medical concerns or treatment. The contents of this factsheet were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90DP0082, 90DPKT0009, 90DPTB0016, 90DPTB0002, 90DPTB0013, and 90DPTB0001). NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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Stress Management for Caregivers of Individuals with Traumatic Brain Injury

September 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This fact sheet explains strategies caregivers can use to manage stress.

Introduction

A traumatic brain injury (TBI) can change a person in many ways. As a caregiver of a person with a TBI, you may feel stressed or overwhelmed in this role. You are not alone; these feelings are normal. Using strategies to manage stress may help you take care of yourself.

Symptoms of Stress

Caregiver stress can take many forms. Some common symptoms of stress are shown below.

Physical Health	Cognitive Health	Emotional Health
• Neck and shoulder tightness • Muscle tension • Stomach upset; nausea • Constant aches or pains, headaches, and cramps • Weight changes (overeating, undereating) • Sleep issues/fatigue	• Forgetfulness • Difficulty with concentration • Confusion • Trouble making decisions	• Feelings of hopelessness • Feelings of isolation • Feelings of guilt, worthlessness • Constant sadness, feeling blue • Fear, worry, anxiety • Crying spells • Viewing problems as overwhelming • Loss of interest in activities, hobbies, sex

Coping Strategies

A little stress is part of life. But having a lot of stress that lasts for a long time can have a negative effect on the mind and body.[1] Below are strategies to help you cope with stress. There are many holistic strategies to help cope with stress. Some include yoga, meditation, and deep breathing exercises. You may want to try the deep breathing exercise in this box.

For instant relief from stress, do deep breathing.

Take a breath, hold it for a few seconds, and let it out. Keep breathing until you feel yourself calm down.

These strategies can help you in the moment to instantly feel less stress. They can also help you manage stress over time. Resources are available to track your mood, help you relax, and practice these strategies. Check out some of these on the following website. https://www.medicalnewstoday.com/articles/mood-tracker-app#mood-tracker-apps Don't give up if something does not work right away. It may take time and practice to learn which stress management strategies work for you.

The Traumatic Brain Injury Model Systems program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See http://www.msktc.org/tbi/model-system-centers for more information).

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Mindfulness

Mindfulness is a mental state in which you focus your awareness on the present moment. This includes what you are thinking or feeling and what's happening around you. It helps you live in the present and not get caught up in worries about the past or future. You can practice mindfulness in your daily life. Try the 1-minute mindfulness exercise below.

STOP: 1-minute Mindfulness[2]

Stand up and breathe. Feel your connection to the earth.

Tune in to your body. Lower your gaze. Scan your body and notice physical sensations or emotions. Discharge any unpleasant sensations, emotions or feelings on the out breath. Notice any pleasant ones and let them fill you up on the in breath.

Observe. Lift your eyes and take in your surroundings. Observe something in your environment that is pleasant and be grateful for it and its beauty.

Possibility. Ask yourself what is possible or what is new or what is a forward step.

Reprinted with permission from Leoni Stewart-Weeks. (2020). 1-minute mindfulness exercises. PsychCentral®. Retrieved from https://psychcentral.com/blog/1-minute-mindfulness-exercises/

Accepting Thoughts and Feelings

Sometimes stress comes from us believing that we should think or feel differently than we do. There is no right way to think or feel. Whatever you are thinking or feeling is OK. If you learn to be OK with your thoughts and feelings, instead of struggling with them or trying to change them, you may find that you feel less stressed. Try to notice what you are thinking or feeling at different times each day. Don't judge your thoughts or feelings as good or bad. All your thoughts and feelings are legitimate. If you are having thoughts or feelings that could possibly lead to dangerous or harmful behaviors to yourself or others, reach out for help immediately.

Maintain Personal Activities and Reward Yourself

You're no good to anyone else if you're not good to yourself. This means that it's important to do things that you valued and enjoyed before your loved one's TBI.

Based on your answers to these questions, make a plan. Schedule time for the activities that you identified *IN PEN!* Especially at first, don't set the bar too high. For example, to start, set aside 15 minutes a day to read a book, listen to music, or write in a journal in a quiet spot where you won't be distracted or interrupted. Over time, you could increase those 15 minutes to 30. If 15 minutes is all that's possible, that's fine, too, but *PROTECT THAT TIME*!

To identify your interests, ask yourself:

1. What activities did I like doing before TBI became a part of my life?
2. Which one(s) do I miss doing the most?
3. How can I make it possible for me to do these again?
4. How will doing these things help me and my loved one?

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Reward yourself after getting through stressful activities and interactions.

Rewards may cost money (e.g., a massage) or they may be free (e.g., a walk). Depending on how much time you have, they can last for 5 minutes (e.g., step outside for a breath of fresh air) or longer (e.g., watch a 30-minute comedy).

To identify rewards, ask yourself:

1. What is rewarding to me?
2. What rewards can I realistically give myself?
3. When and why should I let myself have rewards?
4. How does letting myself have rewards help me and my loved one?

Creative Thinking and Problem-Solving

When you feel overwhelmed, even small problems can feel hard to solve. Here are some tips that may help.

- **Don't try to solve problems when you are feeling high stress.** Wait until you feel calmer and can think more clearly. Try a mindfulness exercise or a relaxation exercise to calm yourself.
- **Define your goal.** Where do you want to be? What do you want to happen? Work backward from that goal to figure out what steps you need to take to reach it.
- **Brainstorm ideas.** Do not worry about how possible each one is. The best ideas often seem crazy at first! Write down all ideas; then list pros and cons for each one. Pick the one with the most pros and the least cons and try it.
- **Start small.** Break bigger problems into smaller ones. Then brainstorm solutions to each one. Solving small problems can give you confidence to solve bigger problems.
- **Don't give up!** No one makes perfect decisions every time. If your first solution doesn't work, try to figure out why and try another solution.

Seek Support

***Support from Family and Friends*—**As hard as it may be, share how and what you are feeling with your family or a close friend. If you feel overwhelmed, ask not only for a listening ear or a shoulder to cry on, but for help. Family and friends often truly *want* to help, but won't always know *how* to help, or may be uncomfortable offering. Try to think of and express specific ways they might be able to help you.

Example of Specific Request for Help:

If you could use some help during a doctor's appointment, ask a family member or friend to come with you.

***Support from Other Caregivers*—**Consider forming your own informal support group in person or on social media. Reach out to other caregivers you see in the waiting room or family room at a care facility or rehabilitation (rehab) center or online.

Introduce yourself!

- Ask how they are doing.
- Ask if they would like to get a cup of coffee.
- Share something about how your day is going

Support through Professional Counseling—Seeking needed professional counseling is a positive thing to do for yourself! Ask your care providers about the various types of counseling available for caregiver and family needs. The rehab facility counselor may offer counseling services or recommend counselors in your area who understand TBI and are a good match for you and your needs.

Family sessions focus on helping with communication, defining roles, or coordinating care.

Individual sessions allow you to freely say what you feel without the worry that may be felt when talking with other family members present.

Group Counseling or Organized Support Groups provide an opportunity to meet with a trained counselor in a group setting with other caregivers. A counselor's guidance and insight are combined with information sharing and support among families going through similar experiences. Topics covered may include stress management, coping skills, available resources, coordination of health care services and navigating insurance benefits. Program coordinators keep caregivers informed and emphasize the importance of "taking care of the caregiver."

Conclusion

Many strategies are available to help you manage stress when caring for someone with a TBI. It is important to be open to new ways to coping with stress. Consider these strategies and find out what works best for you, instantly and over time. Whether the person you are caring for makes a full recovery or not, these coping strategies can help you improve your stress levels and overall health. If you can help the person with injury compensate for cognitive difficulties in a way that helps them be more independent, that can also reduce your stress. At https://msktc.org/tbi there are some related factsheets you may want to review, such as: Changes in Memory; Cognitive Problems; Emotional Problems; Irritability, Anger, and Aggression; and Relationships after Traumatic Brain Injury.

For Caregivers of Service Members and Veterans

The Fisher House is a home for family members of injured and hospitalized service members and veterans. Many of our TBI Model Systems families have stayed here. Some caregivers who meet at the Fisher House form a strong connection and keep in touch after returning to their caregiver roles at home. Learn more about Fisher House at: Home - Fisher House Foundation

Impact of Military Culture: Research on caregivers of veterans and service members with TBI shows that these caregivers may have special difficulties because they may not feel comfortable showing sadness, worry, or stress. They may be used to putting on a brave face for others and may feel that they have to do this after TBI as well. But hiding feelings can lead to emotional issues. As a caregiver of a spouse with TBI, it's OK to feel stressed and to admit you need help. You are not alone. Finding safe ways to express what you're thinking and feeling is important.

Posttraumatic stress disorder (PTSD) is a health problem that some veterans and service members with TBI experience. It may increase your stress. To lower your stress, find a support group for caregivers of persons with PTSD or talk to a specialist to learn how to manage PTSD symptoms.

Recommended Readings and Resources

[1] Sander, A.M. (2011). *Picking up the pieces: A guide for family members.*

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Authorship

Stress Management Strategies for Caregivers was developed by Bridget A. Cotner, PhD; Angelle M. Sander, PhD; Margaret Wells, BS; Therese M. O'Neil-Pirozzi, ScD, CCC-SLP; Jill Coulter, BS; and Bridget Miller, BA, in collaboration with the Model Systems Knowledge Translation Center.

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this factsheet were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082; 90DPTB0016, 90DPTB0011). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The development of this factsheet was also supported by the Veterans Health Administration Central Office VA TBI Model Systems Program of Research and subcontract from General Dynamics Information Technology (W91YTZ-13-C-0015, HT0014-19-C-0004)from the Defense and Veterans Brain Injury Center (DVBIC); the United States Department of Veterans Affairs (VA; grant number W81XWH-13-2-0095); and the United States Department of Defense (DOD) Congressionally Directed Medical Research Programs. The contents of this factsheet do not necessarily represent the view or policy of NIDILRR, ACL, HHS, DVBIC, VA, or DOD, and you should not assume endorsement by the U.S. government.

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Traumatic Brain Injury and Acute Inpatient Rehabilitation

January 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet describes acute inpatient rehabilitation after a TBI. It explains what problems are addressed, who is involved, and how to pick a facility. It also talks about what happens after a patient goes home.

What is acute inpatient rehabilitation?

Acute inpatient rehabilitation (rehab) is an intensive form of medical rehabilitation in which patients receive three or more hours per day of core therapies (physical therapy, occupational therapy and speech therapy) overseen by a physician specialized in rehabilitation with around the clock nursing care. This team of physicians, nurses and therapists work together to restore function after traumatic brain injury. Research has shown that participating in inpatient rehabilitation after injury increases the likelihood of discharge to home and decreases risk of mortality among trauma patients, most of whom sustained TBI.

How do I choose an acute inpatient rehabilitation facility?

Here are some factors to consider when choosing an acute rehabilitation facility:

- Is this program covered by the patient's insurance?
- What kind of experience does the staff have?
- What kind of accreditation does the facility have? (This is a process rehab facilities undergo to confirm they meet high standards for care.)
- Can the facility meet the patient's medical needs?

The "References" section of this factsheet lists two resources to help you find an acute rehab unit.

What are some common challenges addressed by acute inpatient rehabilitation?

- **Thinking challenges.** These include problems with memory, language, concentration, judgment, and problem-solving.
- **Physical changes.** These include loss of strength and problems with balance, coordination, movement, and swallowing.
- **Sensory changes.** These include changes in the patient's sense of smell, sight, hearing, and touch.
- **Emotional changes.** These include changes in mood or feeling impulsive or irritable.
- The patient has a new TBI that keeps them from going home to family care.

The Traumatic Brain Injury Model Systems program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See http://www.msktc.org/tbi/model-system-centers for more information).

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Who is eligible to receive inpatient rehab?

A patient can receive inpatient rehab if:

- The patient's medical condition is stable enough to allow them to take part in therapy.
- Some insurers, including Medicare, have a specific definition of "participation in therapy" to approve inpatient rehab.
- The patient can make progress in therapy.
- The patient has insurance or other ways to pay for treatment.

How does acute inpatient rehab work?

Therapies are designed to meet the specific needs of the patient. The patient will receive at least 3 hours of different types of therapy throughout the day with breaks in between. The patient will have therapy 5–7 days a week.

The patient will be under the care of a doctor who will see them at least three times a week.

Most people with TBI who are in an acute inpatient unit take part in:

- Physical therapy,
- Occupational therapy, and
- Speech therapy.

Each type of therapy may be given in an individual or group format.

Who is part of the rehab team?

Rehab usually involves a team of highly trained health care providers. Members of the team are from different areas in health care. The team works together every day and shares information about your treatment and progress. At least once a week, the team meets to talk about the patient's progress and discharge plan. This plan describes the patient's care after they leave rehab.

The patient's team may include the following members:

Doctors. This may be a physiatrist (a doctor whose focus is rehab medicine), a neurologist (a doctor whose focus is the nervous system), or another doctor familiar with rehab for TBI. This doctor is in charge of the patient's overall treatment and directs the patient's rehab program. The doctor will:

- Assess the patient's physical abilities.
- Assess the patient's thinking and behavior.
- Prescribe medicine to manage the patient's mood, sleep, pain, and diet.
- Prescribe tailored physical, occupational, and speech therapy.
- Order tests or treatments to help maintain and improve the patient's health.

Rehab nurses. These nurses work closely with the patient's doctor to manage medical problems and prevent medical complications. The nurse will:

- Assess the patient's self-care, bowel and bladder function, sexual function, diet, and ability to move.
- Assist with the treatments of other team members.
- Educate the patient and their family about their TBI and any medicines they take.

Psychologists or neuropsychologists. These doctors will assess and treat any problems the patient has with thinking, memory, mood, and behavior. He or she may counsel the patient's family members or educate them on how to help the patient. The goal is to ensure that the patient's family understands the treatment plan and possible outcomes.

Physical therapists (PT). The PTs will help the patient improve their physical function and ability to move. The PT's role is to teach the patient how to be as independent and safe as possible in their environment. The PT will give the patient exercises and re-train their muscles and nerves. The aim is to restore normal function. The PT will also help the patient strengthen their muscles and improve endurance, walking, and balance.

Occupational therapists (OT). The OT's will work on the patient's activities of daily living to help the patient become more independent. These activities include eating, bathing, grooming, and dressing. They also include moving to and from your bed, wheelchair, toilet, tub, and shower. The OT will work with the patient on strength, balance, and trunk control. Depending on the facility, the OT may:

- Assess the patient's thinking skills. These skills include orientation, memory, attention, concentration, calculation, problem-solving, reasoning, and judgment.
- Assess the patient's vision for any problems.
- Help the patient manage more complex tasks. These include meal prep and cooking, managing money, and getting involved in community activities.
- Recommend and order any equipment the patient may need before going home.

Speech-language pathologist (SLP). The SLPs will treat problems with speech, swallowing, and communication. The SLP will:

- Help the patient understand what others say and speak clearly.
- Teach the patient exercises and techniques to improve their ability to speak and express themselves. This may include exercises to strengthen the muscles used in speech or swallowing. The patient may also learn speech drills to help them speak more clearly.
- Assess the patient's language skills. These skills include orientation, memory, attention, concentration, calculation, problem-solving, reasoning, and judgment.
- Assess the patient's ability to swallow if they have problems swallowing (dysphagia).
- If needed, recommend foods and drinks that the patient can eat or drink safely.

Recreation therapists. These therapists will help the patient find activities to help improve their health and well-being and get the patient back into the community. Getting back into recreation or finding new activities is an important part of recovery. This may include going on outings or taking part in social and group activities in the hospital.

Social workers. The social workers will give the patient and their family information about community resources. He or she will also help with the patient's discharge plan and their return to the community. He or she will:

- Help figure out what benefits the patient is eligible for. This may include Medicaid or Social Security.
- Help the patient and their family find community resources.
- Give the patient ongoing, supportive counseling to help the patient get used to their new situation.

Nutritionist or dietitian. The dietitians will assess the patient's nutritional status. He or she will also make recommendations about good nutrition and the patient's diet. Patients are often underfed and underweight after a hospital stay. Focusing on the patient's diet and how many calories the patient eats each day will help with recovery. The dietitian will also talk to the patient and their family about choosing a menu, the right food consistencies, and diet changes that fit their needs.

What role does the family play during acute inpatient rehab?

The family can:

- Get to know the team members caring for the patient.
- Ask when and how they can take part in therapy sessions.
- Ask about improvements that they can expect to see during rehab.
- Ask questions about the different therapies used.
- Ask about and talk about the discharge process early in a patient's stay; the time in inpatient rehab can be short.
- Go to family training as the patient's discharge gets closer.
- Find out what additional help and supervision the patient may require on discharge from rehabilitation.

What happens after inpatient rehab?

Leaving inpatient rehab is a change that may cause anxiety. Many questions may come up at the time of discharge. These may include:

- How will the patient be able to continue to get better after they leave the hospital?
- Who will take care of the patient when they go home?
- What if the patient needs more help than their family can give them?

To help you through this change, the patient's social worker will make sure that they have what they need to continue to recover after they leave the hospital. As the date of the patient's discharge gets closer, depending on their specific setting, a social worker, care manager, and/or discharge planner will meet with them and their family to form a discharge plan. This team will also:

- Give the patient emotional support.
- Help you get the care the patient needs. This includes figuring out where the patient will get the services they need and who will provide them. They will also help the patient get the most out of their insurance benefits.
- Help the patient find resources that will help them function well in their community. This may include help with finances, home care, and transportation, as well as community therapy services. This may also include government services such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, Medicare, and other disability benefits.

Discharge Plans

Every discharge plan is different. This plan reflects a patient's unique personal and social situation. Recovery from a TBI may take months or even years. Most people will need ongoing therapy after they go home. Discharge plans fall into one of four categories:

Discharge home with referral for home-based rehab services. This plan is for people who are well enough to be at home, but who are not well enough to travel for therapy. In this case, the social worker will refer the patient to a nursing agency. Staff from the agency will come to the patient's home, assess their needs, and give them any needed care. Such care may include physical and occupational therapy. The patient may also need a home health aide. Family is almost always needed to provide some of the help that the patient will need at home.

Discharge home with referral for outpatient services. This plan is for people who are well enough to be at home and can travel to an outpatient clinic for therapy. In this case, the patient's family will provide all the help and supervision they need at home. The patient will go to an outpatient clinic that is convenient to them for all therapy.

Discharge to a residential TBI rehab program. This plan is for people who are well enough to live in the community but need a supervised and structured environment. This option is best for people who do not need inpatient care from a nurse or doctor but may need more therapy to move back into the community. The availability of these programs depends on the patient's insurance and where they live.

Discharge to a nursing facility. This plan is for people who are not ready to go home and who need more therapy in a structured environment with nursing care. In this case, the facility provides nursing care and rehab in specialized rehab wings. These wings are sometimes called subacute rehab or skilled nursing facilities, or SNFs. How long people stay depends on their medical needs, how much progress they make, and other insurance limitations. If the patient's team recommends a nursing facility that provides subacute rehab, the social worker will help them find one that meets their needs.

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Authorship

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Traumatic Brain Injury and Chronic Pain: Part 1

August 2020 www.msktc.org/tbi/factsheets TBI Factsheet

Part 1: This factsheet will help you understand the common causes and symptoms of chronic pain for people with traumatic brain injury.

What Is Chronic Pain, and How Can It Affect People?

Pain is an unpleasant sensation that can range from mild to very severe. Pain is very personal; two people can have the same type and amount of pain and have very different reactions to it. Pain can affect many other parts of our lives. It can cause changes in your sleep, emotions, behavior, and even the way your body works. And it works the other way too: All of these things can make pain worse or make you more aware of it.

Pain can be either acute or chronic. Pain from an injury that is healing is considered acute pain. This kind of pain may help protect you from getting hurt again, by reminding you to be careful with the place you feel pain. Most of the time this pain goes away as you heal.

Pain is usually considered chronic when it lasts more than three months. Many people with traumatic brain injury (TBI) have chronic pain at some time or other. There is typically no “quick fix” for chronic pain. Medicines used for acute pain often don’t work well for chronic pain and may be habit forming. Even over-the-counter pain medications like ibuprofen, aspirin, and acetaminophen might not work very well for chronic pain. If you’re using any of these for more than a week or two, you should talk with your doctor. Long-term use of any medicine may be habit-forming and could damage your kidneys or liver.

Common Types of Pain After TBI

There are many types of pain that can be chronic after a TBI. Some common ones are listed below but there are many others.

Headache

Most people with TBI have headaches at some point after injury. For many people the headaches start right after their TBI. But for others, they can start weeks, or even months, after their injury. There are several types of headaches. To learn more, refer to the factsheet *Headaches After TBI.*

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Neurological or Nerve Pain

The brain and central nervous system process pain signals. These signals are usually caused by damage or injury to tissue. When a nerve is injured, it can cause different kinds of pain than the pain you may feel after damage to other types of tissue. Nerve pain can feel “electric” or like “burning”; it could also feel like hot or cold; or even give you a sensation of numbness or “tingling” in your arms or legs. These types of pain often need to be treated with special prescription medications. Chemical changes in the brain can also cause the feelings of pain without obvious damage or injury.

Spasticity

A TBI can cause damage in the brain or to the nerves that makes muscles not respond as they should. This is called spasticity. Spasticity is not pain, but it can be painful. It may make muscles stay flexed when they should be relaxed or make them shake in a way that is hard to control. Over time, spasticity may cause muscles to lengthen or shorten, which can cause pain. Not enough sleep, stress, infection, or pain in another part of the body, may make spasticity worse. Many of the tools used to control pain can also help with spasticity.

Muscle or bone pain and co-occurring injuries

Often, other parts of the body get hurt when TBI happens (e.g., fractures, disc injuries, torn ligaments). Pain from multiple injuries can be harder to treat because the symptoms may add to each other.

Pain sensations

Not all pain feels the same, it can vary based on its cause. Two people might have the same type of pain in the same place but feel it differently. Pain could feel:

- Hot or burning
- Sharp like a needle prick or bee sting
- Tingly like a foot that has fallen asleep
- A dull ache that is worse with movement
- Throbbing pain that goes between more and less severe
- Pressure like squeezing or a vice grip
- Numb or decreased sensation

Common Effects of Pain

After a TBI, it is common to have fatigue, anxiety, depression, and sleep issues. Pain can make these problems worse, and these problems can also make pain feel worse. This reinforcing cycle can make it hard to tell if pain is the cause or an effect. No matter the source, it is important to address these symptoms along with pain to get the best results.

Sleep

Most people with a TBI who experience chronic pain report some type of sleep disturbance. Not getting enough quality sleep can increase pain and other symptoms. There are many therapies and medications that can help with sleep. If pain is disturbing sleep it will probably not get better until the pain is managed.

Talk to your doctor before you take medicine to help with sleep. Behavioral changes can be the best way to manage pain that interrupts sleep. Many drugs that help with sleep can be dangerous for people who have TBI. For more information about this, refer to the factsheet *Sleep and TBI.*

Fatigue

Not getting enough sleep or being in pain for a long time can cause fatigue. Fatigue is a heavy tired feeling that can make it very difficult to do normal things. Fatigue can also cause trouble with memory or thinking.

Cognitive effects of pain

For people in pain, it might be more difficult to think through complex ideas. Pain can also make it hard to remember things, stay focused, or be patient. Pain often makes people grumpy or short-tempered. All of these things are true even for people in pain who do not have TBI.

Anxiety

Anxiety is closely related to pain, and each can make the other worse. Anxiety can add to memory or sleep problems. Anxiety may lead a person to believe that a bad outcome is likely or certain. This type of thinking is called “catastrophizing.”

Depression

Pain itself can make people feel depressed. Many people with chronic pain begin to feel that they do not have control over their lives. If these feelings or the pain causing them are not addressed, depression can develop. Pain can also make it harder to do things in the community. This isolation can heighten existing depression. Behavioral therapy, activity, medicine, or a combination of these can help. If pain is contributing to depression, the two should be treated at the same time. Many treatments promote overall health and long-term pain relief.

PTSD

People who go through traumatic events can have post-traumatic stress disorder (PTSD). People with PTSD may feel stressed or afraid even when they are not in danger. Some people with PTSD will have flashbacks and may “re-experience” the event. PTSD can make people want to avoid things that remind them of the trauma, startle easily, or have changes in their moods. Both pain and PTSD may lead people to avoid places or activities. This can be limiting and result in isolation, which can make pain or PTSD worse.

Pain can change your thinking

Often, we have thoughts that we're not fully aware of called "automatic thoughts". They can influence our emotions and the things we do, even if we don't realize it. Pain by itself or with depression, anxiety, or PTSD can make people have more negative automatic thoughts. These thoughts can make their pain worse. A therapist who practices cognitive behavioral therapy can help change these thinking patterns.

Moving Forward

Pain can complicate a lot of other symptoms that are common after a TBI. Everyone experiences pain in their own way. Treating pain is just as personal and finding the right way to manage your pain is a process. In Part 2 of this factsheet, you will read about different ways people learn to manage their pain.

Authorship

Traumatic Brain Injury and Chronic Pain: Part 1 was developed by Silas James, MPA; Jeanne Hoffman, PhD; Sylvia Lucas, MD, PhD; Anne Moessner, APRN; Kathleen Bell, MD; William Walker, MD; CJ Plummer, MD; Max Hurwitz, DO, in collaboration with the Model Systems Knowledge Translation Center.

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Traumatic Brain Injury and Chronic Pain: Part 2

August 2020 www.msktc.org/tbi/factsheets TBI Factsheet

Part 2: This factsheet will explain some of the more common ways people with traumatic brain injury (TBI) manage chronic pain without the use of medication.

What You Can Do About Your Pain

In the same way that pain is personal, so too are strategies for managing it. Learning to manage pain is a process that takes practice. Don't get discouraged if the process is difficult at the start.

In this document, you'll find some common strategies for dealing with pain, but there are others. You may have to try a few approaches before you find the right one. Using a combination of many techniques may work best for you. Most pain medicines do not work well for chronic pain, and many are habit-forming. This factsheet explores ways to manage pain that do not involve taking medication. Most people with pain will benefit from seeing a psychologist or other health care provider for help. At the end of this factsheet is a log that you can use to record your pain and how you are working to manage it. Tracking your pain for two weeks and showing the log to your health care provider is a great way to begin.

There are many different strategies that people use to manage their pain. Some of them are:

- Exercise
- Cognitive behavioral therapy (CBT)
- Scheduled rests or pacing
- Meditation
- Biofeedback
- Breathing exercise
- Hypnosis
- Visualization
- Art therapy
- Acupuncture
- Massage
- Heat or ice
- Social activities

Exercise

Exercise is a proven way to manage pain. It prompts your brain to release serotonin and endorphins. These chemicals are strong pain killers and elevate your mood. If you have limitations, talk with your health care team about exercise. Your team can help you plan a routine that is safe for you.

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Yoga

Yoga is usually a low-impact exercise that involves timing movements with your breath. There are many different styles of yoga, and some can be adjusted for people with disabilities. Regularly doing mind-body exercise, like yoga, can help with strength, function, and mood, all of which can improve pain. The stretching and slow movements can also decrease painful muscle spasms.

Cognitive Behavioral Therapy

Cognitive Behavioral Therapy (CBT) helps you change your thoughts or actions. It helps you make the voice in your head work for you instead of against you. CBT usually means you will set goals and work with a counselor to plan for how to achieve them. CBT is often used to manage anxiety, depression, post-traumatic stress disorder, and pain. If you are interested in learning more, ask your health care team to help find a provider who practices CBT.

Coping Thoughts

Grounding yourself with coping thoughts can help you get through a stressful or painful time. It may be a good idea to make a list. Some examples are:

- “I know I can handle this.”
- “It could be worse.”
- “This is tough, but I will survive.”
- “I am strong enough to do this.”
- “I have gotten through more difficult things.”

Managing Your Activity

Pacing will help you shift from stopping an activity after you feel pain to pausing before you feel pain. Pacing helps you to do the things that are important to you while conserving your energy. Taking short breaks throughout your day, or even during an activity, will allow you to do more over time. Pay attention to how your body feels during and after activities. Learning to pace takes practice. You can use the log at the end of this factsheet to track your activity and help you start pacing.

Delegating is finding ways to have other people do some things so you can save energy, which is likely to help with your pain.

- Use a grocery service or app instead of going to the store yourself.
- Ask your partner to carry the laundry to the washing machine before you wash and fold it.

Adjusting is finding different ways to do things that might be draining or time consuming, which can also help lessen pain.

- Instead of cooking every night, you might use a slow cooker to make several meals at once.
- Lay your clothes out and iron them before you go to bed to save time in the morning.

Distraction

Pain needs an audience. If you're not paying attention to your pain, it will trouble you less. Some things you can try to take your mind off of pain include:

- Read or watch TV.
- Listen to music or a podcast.
- Do some cleaning.
- Focus on your breathing.
- Call a friend.
- Go to a park, museum, or library with someone who you enjoy spending time with.
- Play cards or a game with friends.
- Do some gardening.

Relaxation Strategies

There are many ways that you can help your body relax. Reducing tension in your body can reduce your pain. You may need to try a few things before you find the one that is right for you.

Mindfulness

Mindfulness is a type of meditation. The idea is to be present in the moment. Do not worry about what has already happened or may happen in the future. This practice centers on being aware of your breath and observing yourself. Notice your thoughts, feelings, and emotions without judging or placing value on them. This calm attention leads to awareness of things that we often ignore. Mindfulness gives many people a new understanding of their pain and more control over it. Mindfulness can also help with anxiety and improve focus, both of which can help with pain.

> *Acknowledge your pain and examine it as you would something that you've just discovered. Study how it feels, the emotions you have in response to it, and how your body reacts to those sensations and emotions. Then direct your attention to the sounds around you. After you've examined those, repeat this with your other senses (sight, smell, touch).*

Biofeedback

There are many kinds of biofeedback. The idea is to understand the signals in your body related to pain or anxiety and learn to control them. For example, fast heart rate and rapid breathing are connected to anxiety. Slowing your breath and heart rate can tell your body it's alright to relax. A trained therapist can teach you biofeedback.

Controlled breathing

Controlled breathing is one type of biofeedback. It uses the fact that your heart beats slower while you are exhaling than during the inhale. Drawing out your exhale can help you slow your heartrate. Breathing into your belly can stimulate digestion. Controlled breathing does both of these things, signaling your body to return to a calm state.

> *Sit in a comfortable place with few distractions. Place one hand over your stomach and the other on your chest. Breathe in through your nose while counting to two in your head. Feel the hand over your stomach rise as you inhale. Breathe out through your mouth with your lips pursed. As you do this, count in your head to four and feel the hand on your stomach fall.*

Autogenic relaxation

Autogenic means “self-regulated.” During autogenic relaxation, you tell yourself that you are relaxed. While you do this, picture different parts of your body relaxing. Learning how to relax takes practice; be patient and treat this like any other skill you have learned. It’s normal for this to be challenging in the beginning.

> *Sit in a comfortable place with few distractions. Close your eyes and picture your right arm. Tell yourself, “My right arm is warm and heavy”; then feel your right arm relax. Repeat this exercise with your left arm, shoulders, jaw, back, right leg, and left leg.*

Finding What Works

Remember that both pain and how to manage it are personal. Something that works for you may not work for someone else. Don’t be discouraged if you don’t find the right method to manage your pain right away. At the end of this factsheet, there is a log that you can use to record your pain. Tracking your pain for two weeks and showing the log to your health care team is a great way to begin.

Many of the techniques discussed in this factsheet can help you reach your pain-management goals and live a more functional and satisfying life. When you do find the right strategy or strategies, practice them daily even if you don’t have pain. Controlling your pain is a skill, and it takes time to develop skills. There are many apps, video tutorials, and websites that can help you build these pain management skills. You can also use the log at the end of this factsheet to track your pain-management progress.

Consider asking your health care team about a **pain rehabilitation program**. This is a more intensive program where many different specialists work with you. They will teach you ways to manage pain without medication. Treatment may last for several days or weeks.

Authorship

Traumatic Brain Injury and Chronic Pain: Part 2 was developed by Silas James, MPA; Jeanne Hoffman, PhD; Sylvia Lucas, MD, PhD; Anne Moessner, APRN; Kathleen Bell, MD; William Walker, MD; CJ Plummer, MD; Max Hurwitz, DO, in collaboration with the Model Systems Knowledge Translation Center.

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this factsheet were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90DP0031 and 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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Activity Log

You can use this log to track activities or events that may be related to pain.
This log can also be used to record your pain management practice.

Date/Time							
What was happening? (Event or activity)							
For how long/When?							
Did you have pain? (0-10) (Where?)							
Other emotions?							
What thoughts did you have?							
What did you do in response?							

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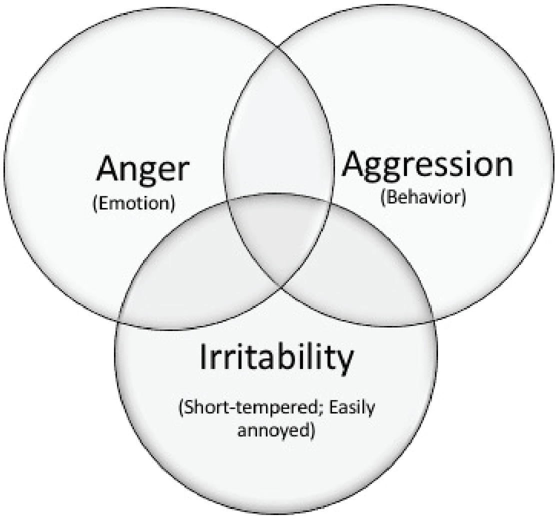
Understanding and Coping With Irritability, Anger, and Aggression After TBI

February 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains irritability, anger, and aggression after TBI.

What are irritability, anger, and aggression and how can you recognize them?

- **Irritability** is an emotional state in which a person has a short temper and is easily annoyed or angered. As a result, small things can lead to harsh reactions (for example, snapping at family or friends). This is most likely to happen if the person does not know how to manage their feelings or if the person is stressed. People may feel tense, uptight, touchy, or on edge when they are irritable.
- **Anger** is an *emotion.* It's a strong feeling of annoyance or displeasure. Sometimes angry emotions can get intense and feel out of one's control. Anger can lead to aggressive acts. When angry, people may feel tension in their forehead, jaw, shoulders, or fists. They may feel their heart beat faster and their bodies may feel hot.
- **Aggression** is a type of *behavior*. It is often an expression of anger. Actions can range from mildly aggressive to extremely aggressive. Aggression can be hurtful comments—what you say and how you say it. It may include insults, cursing, or yelling. On the more extreme and less common end, it can include acts of violence, such as throwing things or hitting someone or something. Aggression may include other threatening actions meant to cause fear or displeasure, such as following a driver on the highway to intimidate them or refusing to do something your loved one wants to do.
- As shown below, irritability, anger, and aggression are not the same, but they can overlap or occur together. However, each can also happen on their own. For instance, someone could feel angry but not act aggressively, or someone could get angry without being irritable. Tips for managing these emotions and behaviors are presented below.



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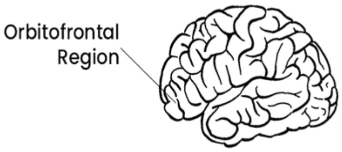
What changes can be expected after a TBI?

Feeling irritable or angry from time to time is common for most people, but a TBI may cause changes that make these feelings more of a problem.

- **Irritability and anger are more common in people with TBI than they are in people without TBI.** Some research shows that up to three-fourths of people with TBI have irritability. In addition, up to 50% of people with TBI have problems with anger. A person who was not prone to irritability or anger before their TBI may now be easily irritated or angered after their TBI.
- **Irritability and anger after TBI can be sudden and unpredictable.** After a TBI, feelings of irritability and anger can occur suddenly and ramp up quickly. These feelings may be triggered more easily than before the TBI. They may also be hard to predict.
- **Anger and aggression can lead to behaviors that are difficult to control after a TBI.** A TBI can make it hard for a person to talk in a respectful way about things that make him/her angry or frustrated. The person may also find it hard to stop an aggressive response, such as shouting, saying mean things, or cursing. Sometimes, they may express anger through physical acts, such as throwing things, punching a wall, or slamming doors. In more extreme and rare cases, anger can lead to physical fights, such as hitting others.

Why do people with TBI have problems with irritability, anger, and aggression?

- **Injury to parts of the brain that control how we feel and manage our emotions.** TBI often causes injury to one or more of the many parts of the brain that control how we feel and manage our emotions. An example is the orbitofrontal region (pictured to the right). This front part of the brain helps us to monitor and evaluate our feelings, and to think rationally about situations. This helps keep our anger in check and stops us from being impulsive and aggressive. It helps us figure out appropriate ways to deal with our anger and the situation. People who have injured this part of their brain often have trouble controlling their anger and aggression.



- **Changes in how the person thinks.** After a TBI, changes such as slowed thinking, trouble focusing, poor memory, or difficulty solving problems can occur. These issues can be frustrating and may increase irritability and anger.
- **Emotional struggles.** Irritability is often a sign that a person is dealing with other emotional struggles, such as feeling sad, depressed, and/or anxious.
- **Not fully recognizing emotions.** People with TBI may find it hard to know when they are getting upset or irritated. As a result, feelings of anger can easily grow and get out of control.
- **Adjusting to the injury.** Many people with TBI have a hard time coping with changes after their injury. Limitations in activities and responsibilities (e.g., driving, managing bills, household chores) may make them feel irritable or angry.
- **Misunderstanding others.** TBI can affect a person's ability to interpret other people's actions and emotions. They may think that other people are angry or have bad intentions when they don't. This can lead to anger.
- **Feeling unwell.** Pain, fatigue, and poor sleep are common after TBI. These can lead to irritability and aggression.
- **Sensitivities to surroundings.** People with TBI may be more sensitive to light and/or noise. This can lead to irritability.

What are the consequences of irritability, anger, and aggression after TBI?

Below are some common areas that can be impacted by these emotional and behavioral changes:

- **Negative health effects.** Anger may cause a faster heart rate and the person may be in a constant state of alert. In the long term, this can have negative physical health effects and mental health effects, such as heart disease and anxiety.
- **Intimate relationships.** It may be difficult for others to relate to a person who is easily irritated, angry, or aggressive. Unpredictable reactions may make partners feel as if they have to "walk on eggshells" around the person with TBI. This can lead to stress, conflict, and/or fear, and the quality of the relationship may suffer.
- **Friendships.** Friends of persons with TBI may have similar reactions as spouses or partners do. If not addressed, friendships are likely to dwindle and it may be harder to make new friends.
- **Return to work.** Trouble controlling emotions and behaviors can lead to friction or arguments with peers and employers. Irritability can make learning new skills and receiving critical feedback from others more difficult. Aggressive or defensive behaviors may lead to disciplinary action or job loss.
- **Legal troubles.** Due to the injury, a person with TBI may have difficulty controlling impulsive and inappropriate reactions when they are irritable or angry. Some acts may even be illegal (e.g. property damage, assault) and can result in fines, arrests, or even incarceration. Reasons for these actions after TBI can often be misunderstood. If someone with a TBI is accused of an illegal act, law enforcement and the legal system should consider recommending rehabilitation services that can treat the person's needs, as opposed to criminal punishment.

How can health care providers help reduce irritability, anger, and aggression?

Find a licensed health care provider who is trained in treating emotional problems after TBI. Examples include psychologists, rehabilitation counselors, physiatrists (physicians who specialize in rehabilitation), social workers, occupational therapists, or speech pathologists. The following methods are often used by providers with good results.

- **Psychotherapy or counseling**. Healthcare providers, such as psychologists or licensed professional counselors, can help people with TBI learn to cope with anger and related emotions (e.g., posttraumatic stress disorder, anxiety, and depression) in healthy ways. They may do this in different ways, such as helping people to notice their thoughts and feelings without judging them, helping them to evaluate how their thougts or feelings may be leading them to act in unhealthy ways, and/or assisting them to evaluate the accuracy of their thinking.
- **Problem solving.** Some health care providers can help people with TBI learn problem-solving skills, which is known to reduce anger and aggression.
- **Early detection.** Some health care providers can teach people with TBI how to spot early warning signs of irritability and anger so that they can try to lessen the chance that they will become aggressive. Meditation and mindfulness can help people notice how they feel and calm themselves.
- **Social skill training.** Some providers can help persons with TBI re-learn key social skills that are often impacted by the brain injury. This may help the person with the TBI to better understand others' thoughts, intentions, and feelings (e.g., to see things from others' perspective). This can prevent misunderstandings and reduce anger and aggression.
- **Medications.** Doctors can use medicines to treat irritability, anger, and aggression. However, no medicines have been approved by the Food and Drug Administration for behavioral problems related to TBI. After TBI, people may be more sensitive to medicines. Talk to your doctor about what changes you notice in yourself with the medicine and side effects for all the prescription medications you are taking.

What can a person with TBI do to help reduce irritability, anger, and aggression?

- **Rest.** Try to get at least 7 hours of sleep every night. If you are having trouble sleeping, consult a physician or other health care provider.
- **Move your body.** Make sure to exercise, such as walking or doing yoga, every day.
- **Relax.** Practice relaxation exercises, like mindfulness, meditation, and/or deep breathing every day.
- **Practice a healthy diet.** Drink eight glasses of water every day, eat healthy foods, and don't use recreational drugs or alcohol.
- **Remember your medications.** Make sure to take the medications your doctor has prescribed for you (see above).

How can caregivers help people with TBI reduce their irritability, anger, and aggression?

Caregivers often find their loved one's irritability, anger, and aggression to be some of the most difficult changes to deal with after the injury. Here are some helpful hints for caregivers.

- **Notice patterns.** Be aware of things that cause irritability or anger. Being tired, overstimulated, or too hot may be triggers. Some topics, like being reminded of things that he or she has difficulty with, may be very upsetting for the person with TBI. Try to be sensitive about triggers such as these. It's not your job to avoid every situation that may trigger these emotions, but noticing patterns can be helpful.
- **Empathize and try to understand the problem.** Do your best to understand where the person with TBI is coming from and what is causing your loved one to be upset. Realize that something you are doing or saying may be interpreted in a way that triggers their anger. Try to help resolve the situation that is upsetting the person.
- **Manage your own expectations and emotions.** Make sure your expectations of the person are realistic. Try to remain calm in response to anger and aggression. Suggest a break until everyone has calmed down. Go to another room or leave the house if needed. Come back later to talk calmly. Consider attending caregiver support groups for support, and/or make sure to get help and care from other family and friends.
- **Agree on ground rules for communication.** Everyone should agree to be respectful toward one another. For instance, speak calmly, without yelling or any other aggressive behavior.
- **Focus on positive behavior.** Pay attention to and reward positive behaviors, such as when the person calmly expresses his/her feelings. Try not to respond to negative behaviors, which can sometimes increase them.

- **Try not to take things personally.** Understand the injury to the brain often makes it harder for the person to manage anger and other emotions. Knowing that it is not personal or not the person's fault may help you stay calm.
- **Note any safety concerns.** Your safety and the safety of other family members is important. If you have safety concerns about yourself or your loved one, talk to your doctor or another health professional. In some cases, you may need to consider living apart from the person with TBI.

Recommended Readings

- You Did That on Purpose! Misinterpretations and Anger after Brain Injury
- Anger and Frustration After Brain Injury (Brainline.org)
- MSKTC TBI resources at https://msktc.org/tbi on:
  - Emotional Problems After TBI
  - Understanding TBI
  - Depression After TBI
  - Fatigue and TBI
  - Sleep and TBI
  - Headaches After TBI
  - Cognitive Problems After TBI

Authorship

Irritability, Anger, and Aggression After TBI was developed by Dawn Neumann, PhD, Shannon R. Miles, PhD, Angelle Sander, PhD, and Brian Greenwald, MD in collaboration with the Model Systems Knowledge Translation Center. Special thanks to Sagar Parikh, MD, for creating the picture of the brain used in this factsheet.

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Understanding Behavior Changes After Moderate to Severe Traumatic Brain Injury

August 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains behavior changes after TBI.

What are some possible behavior changes?

People who have a moderate or severe traumatic brain injury (TBI) may have changes in their behavior. People with a TBI and their families encounter some common behaviors:

- **Problems managing emotions.** People with a TBI may have a sudden change in mood; they also may have an extreme emotional response to a situation. They may raise their voice, cry, or laugh.
- **Restlessness.** People with a TBI may fidget, pace, or move in a repetitive way. For example, they may sway at an unusual pace.
- **Problems with social behavior.** People with a TBI may avoid others, interrupt others, or say things that do not fit the situation or are hurtful. They also may make sexually inappropriate comments.
- **Refusing to do things.** People with a TBI may say “no” to doing something, such as going to therapy or doing other activities.
- **Feeling unmotivated.** People with a TBI may have difficulty engaging in an activity even though they know the benefit of doing it or why it needs to be done. This is not caused by fatigue or laziness.
- **Difficulty starting tasks.** People with a TBI may have trouble starting tasks or conversations, even if these are things they want to do.

Who is at risk for behavior changes?

Behavior changes (also called personality changes) are common for people with a moderate or severe TBI. These changes often occur soon after the TBI and may change across time. The types of changes people have and how long they last depend on where their injury is, how severe it is, and other factors. People with a severe TBI are more likely to have behavior changes that last for a while. The good news is that behavior changes can get better as time passes.

This factsheet talks about why changes in behavior happen. It also includes tips for what to do when problem behaviors occur. It includes a framework that people with a TBI, their families, and others can use to help manage changes in behavior caused by TBIs.

Why do changes in behavior happen?

Changes in behavior after TBI happen for many reasons, including changes in the way the brain works. The following are some of the most common changes.

- Some people with a TBI may have **problems with focusing, thinking, or communicating.** They also may have issues with how long it takes to process information and respond to it. These issues can make it hard to **keep up** with a conversation or **understand a situation.** As a result, people with a TBI may appear to be uncooperative. They also may appear “off-task” or out of sync with what is happening in a fast-paced situation. They may avoid social situations because they feel uncomfortable or embarrassed when they are with other people.

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- People with a TBI may have **problems with thinking skills.** These problems may make it hard for them to understand *why* some things happen or *what to do* when they happen. This can make the person feel irritated, refuse to do things, or not do things that they agreed to do. They also may have a hard time making choices.
- People with a TBI may have **poor impulse control.** This can make it hard for them to filter their thoughts or actions. They may not think about or understand the effect of what they say or do before they say or do something inappropriate or unsafe.
- People with a TBI may not be fully **aware** of their current issues. This can cause them to refuse to use a walker or wheelchair. They also may refuse to take part in therapy. Some people with a TBI may not follow recommendations or restrictions that are meant to help them be independent, keep them safe, and help them recover.
- Keep in mind that people with a TBI cannot always control their behavior, which is especially true in situations that are highly stressful. The **A-B-C framework** discussed later in this factsheet includes strategies to help people with a TBI prevent problem behaviors. If the behavior does occur, the framework includes techniques to distract the person or help them relax.
- People with a TBI often have an **emotional response** to their injury. They may feel a sense of loss because of less independence, changes to their role within the family, and a lack of control over their situation. The following factsheets may help in these situations (see Depression After TBI; Relationships After TBI, Emotional Problems After TBI; Understanding and Coping With Irritability, Anger, and Aggression After TBI). The following sections address problem behaviors.

What can I do to deal with problem behaviors?

Identify problem behaviors

The goal of the A-B-C framework is to keep the problem behavior (the “B”) from occurring. Other strategies involve changing the things that happen after a behavior occurs, which can help change how intense, severe, or frequent the behavior is.

- The first step is to identify the behavior. Make a list of behaviors that you see that are a problem.
- Work with a professional to review the list to identify the behavior(s) that need to change. Keep in mind that a specific behavior may not be a problem to everyone. Ask family and friends for their input.
- Update the list as new behaviors come up and old ones are no longer a problem.

Follow the A-B-C approach to better understand problem behaviors

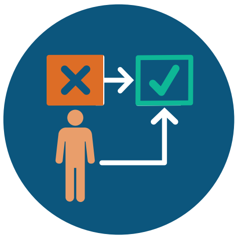
The A-B-C framework can help you understand the approach a professional may use to figure out when and why a behavior or emotional response may occur. This section discusses the framework. You may have a family member or friend assist with this exercise. If you have questions, you can contact a professional with experience in managing behavior after TBI before using.

A. **Antecedent.** An antecedent is what happens right before the problem behavior occurs. Take notes on everything you remember; it may not be clear what the “trigger” was for the behavior. Your notes can help you find patterns. From them, you will come up with ideas about triggers or causes of the problem behavior; triggers may include pain, fatigue, noise, or light sensitivity. The following are some questions to help you identify antecedents.

  - Who is or is not present before the problem behavior happens?
  - Where does the problem behavior take place?
  - What desired items (e.g., television, video game, cell phone) are present or absent just before the problem behavior takes place? What about undesired items?
  - What events took place before the problem behavior occurred?
  - What time of day does the problem behavior happen?
  - Is there a root cause for the behavior? Causes such as poor sleep, a reaction to medicine, changes in schedule, and diet changes set the stage for problem behaviors throughout the day.

B. **Behavior.** Take a close look at the problem behavior or behaviors on your list. Make notes. Describe the problem behavior in as much detail as you can. Here are some questions to understand problem behaviors.

- What does the behavior look like?
- How often does the behavior happen?
- How long does the behavior last?
- How intense is the behavior?



C. **Consequences.** This is what happens right after the problem behavior occurs. Take notes on all changes you see within a few minutes of the behavior. It is not likely that things that happen several minutes, hours, or days after are causing the problem behavior. The following questions should help.

- What happened right after the problem behavior?
- How did people react?
- Did the person get something from the behavior? For example, did they get attention (either good or bad)?
- Was something taken away or avoided because of the behavior?
- Did the environment change because of the behavior? For example, did the person leave a situation or place?

Identify and Change Antecedents (to Prevent Problem Behavior)

Spend time identifying a list of triggers and ways to prevent a problem behavior. If you cannot avoid triggers, find ways to decrease the impact of those triggers. You can organize your notes in a chart (such as the following chart) to make it easier to track your results.

A-B-C Plan: Changing the Antecedent (to "Prevent" Problem Behavior)

A Antecedent	B Behavior	C Consequence	Ideas for change	Results
Physical therapy session focused on stretching activities in a patient with limited mobility because of stiffness or physical injuries that are painful during stretching	• Screaming • Hitting therapist • Refusing physical therapy	• Session ended early • Person with TBI returns to his or her room • Family upset • Therapist relieved	• Pain during exercises may serve as a trigger. • Talk with a doctor about ways to reduce pain while stretching. • Explain the purpose of stretching. • Add activities that make the person happy but also are therapeutic.	• Decreased frequency and intensity of screaming or loud volume • Therapist less anxious working with person with TBI

Change Consequences

Consequences can be hard to pinpoint. Some may be obvious and others not so obvious. It is helpful to use a chart to list things that may make it more or less likely that the problem behavior happens again. The following example shows how to organize a chart to help identify consequences.

Consequences	
Things that may happen right after a problem behavior that might lead to it happening **more often**	Things that may happen right after a problem behavior that might lead to it happening **less often**
• Gets other people to laugh when acting out • Gets more attention • Gets out of doing an activity that he or she does not want to do, such as going to therapy	• Sees that other people are disappointed in the behavior • Thinks he or she is being nagged • Gets less time to hang out with friends or loved ones

You can use an A-B-C chart when you work with experienced professionals, caregivers, or trusted friends to come up with ideas to improve behavior. If you feel stuck or need additional ideas, check with an experienced professional. Praise and access to desired activities are positive actions. These methods have a better impact on behavior change than negative actions and reactions (such as screaming or arguing as a response to a problem behavior).

A-B-C Plan: Changing the Consequence (to encourage or discourage a problem behavior)				
A Antecedent	B Behavior	C Consequence	Ideas for change	Results/Goal
• Does not want to do therapy	• Refuses to do therapy • Is verbally abusive	• Gets out of doing therapy	• Give the person a reward that is exciting to them, such as extra game time if they go to therapy. • Let them choose from different activities that are fun and therapeutic.	• More likely to do therapy
• Forgets to take medication/forgets that medication has already been taken	• Does not take medication as prescribed	• Misses therapeutic dose of important medication/takes too much medication	• Use pill box, phone, or calendar reminders; place pill box in easily visible location.	• Improved medication compliance

You also want to think about how to handle things that are seen as punishments. You should clearly explain the reasons and time frame for any punishments. Keep any restrictions in place for a short time. Talking about these things in detail helps avoid confusion. It also helps keep the punishment from being seen as random and unfair.

What are some realistic goals for behavior change?

- Aim to reduce the number of times that problem behaviors happen and their intensity. Do not expect to prevent all problem behaviors.
- Aim to make small changes across time. Changing behavior takes time. Do not expect changes to happen quickly.
- Focus first on behaviors that are easy to recognize and occur often. As you build your confidence and make progress changing behavior, you can focus on more challenging behaviors.
- Problem behaviors can be exhausting for everyone. Take time for yourself. Get help from others.
- As you start to see success in changing behavior, slowly reduce positive reinforcements. At first, you will likely use positive reinforcements each time you see good behavior. Your goal is to reach a point when you need to use only positive reinforcements from time to time and they are not expected every time. Using the A-B-C chart to track changes across time may be helpful.

Other tips

- Come up with a plan to address problem behavior. It should include the person with a TBI and use the A-B-C approach.
- Reward positive or good behavior often (“Catch them being good”). Avoid giving attention only when the problem behaviors occur. Do not hit or push the person with a TBI. It will not change problem behavior and may cause them to hit or push back in response.
- Come up with ideas to use when behavior problems happen. Have a plan in place that is ready to use. For example, be ready to leave a situation if you need to or bring distracting items with you. Be consistent! Your response to problem behavior should be the same each time. You should respond within a few minutes of the behavior. Behavior changes are most likely to happen when everyone involved is consistent and responses are quick.
- Do not be surprised if you notice an increase in problem behaviors at first. This is normal, not a sign that you have done something wrong or that your efforts are not working. Stick with your plan!
- Make eye contact. Speak slowly and in a normal voice. Do not touch the person without first saying why you are touching them.
- Explain changes in routine.
- Clearly end conversations. You can say, “I need to go do something else in the other room now. We’ll talk some more later.”
- You may choose to bargain for positive behavior. For example, a person with a TBI wants to go outside but they do not want to do their daily exercise. One way to bargain is to let them go outside but make sure they exercise while outside and in a certain time frame. Doing some stretching while outside may help make them want to take part in physical therapy.
- Take a deep breath to help stay calm. Problem behaviors are a result of the TBI; they are not meant to target anyone. Try not to take them personally.
- Avoid arguing. Fighting can make things worse and will not help the person calm down.
- Do not call attention to problem behavior in front of others; this may make the person with TBI feel embarrassed. Instead, use a nonverbal cue such as a head shake or time out signal. You can come up with the cue ahead of time.
- Leave the situation if you need to but only if the person is safe.
- Be mindful of your own actions and reactions. You cannot control someone else’s behavior. Behavior tends to get better across time as the person recovers. Learn to understand what causes problem behavior. You also can model desired behavior. Be consistent.

Sample A-B-C Chart

A Antecedent What was happening before?	B Behavior What does the behavior look like?	C Consequence What happened afterward?	Ideas for change	Results

Authorship

Understanding Problem Behavior Changes After Moderate to Severe Traumatic Brain Injury was developed by Sean Hollis, PhD; Phillip Klebine, MA; Risa Nakase-Richardson, PhD, FACRM; Tom Novack, PhD, ABPP-CN; and Summar Reslan, PhD, ABPP-CN, in collaboration with the Model Systems Knowledge Translation Center.

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Understanding Traumatic Brain Injury

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

March 2019 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains what happens to the brain during TBI 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 injury). 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

A TBI can range from mild to severe in effect. The TBI Model System program focuses on those with moderate to severe TBI that requires participation in rehabilitation. Much of the information provided below focuses on those with moderate-severe TBI.

Causes of TBI

Statistics from the Centers for Disease Control and Prevention for 2007 to 2013 indicate that the leading cause of brain injury is falls (47%). This is followed by being hit by or against an object (15%) and car crashes (14%). Many of these injuries are mild. If you focus only on moderate to severe TBI (those injuries that may require admission to a neurointensive care unit), falls are the most common cause of TBI, followed by car crashes and assaults.

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

The Traumatic Brain Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See http://www.msktc.org/tbi/model-system-centers for more information).

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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. When brain injury occurs at high speed, the brain rotates inside the skull. This type of rotational movement damages axons (part of the nerve cells) and blood vessels by stretching and tearing them. 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 routine brain scans like computed tomography (CT 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 a coma.
- 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 theGCS 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.

The duration of a confusional state following injury, often referred to as 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 some time 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 confusion/amnesia, the more severe the brain damage.

CT or MRI Scan Results

The computed 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 (particularly CT scans) 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.

Neural 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 may go on for months and sometimes years following TBI.

More in the Understanding TBI series

- Understanding TBI, Part 2: Brain injury impact on individuals' functioning
- Understanding TBI, Part 3: The recovery process
- Understanding TBI, Part 4: The impact of a recent TBI on family members and what they can do to help with recovery

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Understanding Traumatic Brain Injury

Part 2: Brain injury impact on individuals' functioning

March 2019 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains the impact of TBI 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

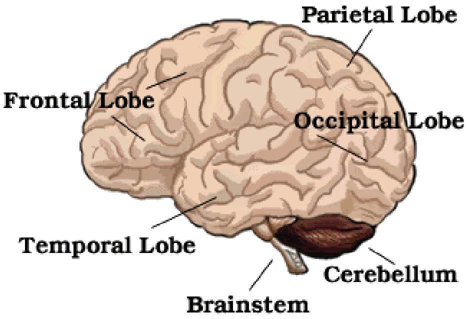
The brain is the control center for all human activity, including vital processes (breathing and moving) as well as thinking, judgment, and emotional reactions. Understanding how different parts of the brain work helps us understand how injury affects a person's abilities and behaviors.

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.



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Six parts	*Functions*
Brain Stem	▪ Breathing ▪ Heart Rate ▪ Swallowing ▪ Reflexes for seeing and hearing ▪ Controls sweating, blood pressure, digestion, temperature ▪ Affects level of alertness ▪ Ability to sleep ▪ Sense of balance
Cerebellum	▪ Coordination of voluntary movement ▪ Balance and equilibrium ▪ Some memory for reflex motor acts
Frontal Lobe	▪ How we know what we are doing within our environment ▪ How we initiate activity in response to our environment ▪ Judgments we make about what occurs in our daily activities ▪ Controls our emotional response ▪ Controls our expressive language ▪ Assigns meaning to the words we choose ▪ Involves word associations ▪ Memory for habits and motor activities ▪ Flexibility of thought, planning and organizing ▪ Understanding abstract concepts ▪ Reasoning and problem solving
Parietal Lobe	▪ Visual attention ▪ Touch perception ▪ Goal directed voluntary movements ▪ Manipulation of objects ▪ Integration of different senses
Occipital Lobe	▪ Vision
Temporal Lobe	▪ Hearing ability ▪ Memory acquisition ▪ Some visual perceptions such as face recognition and object identification ▪ Categorization of objects ▪ Understanding or processing verbal information ▪ Emotion

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 newinformation 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 un- able 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.

More in the Understanding TBI series

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- Understanding TBI, Part 3: The recovery process
- Understanding TBI, Part 4: The impact of a recentTBI on family members and what they can do to help with recovery

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Understanding Traumatic Brain Injury

Part 3: The Recovery Process

March 2019 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains the recovery process after a traumatic brain injury (TBI).

Possible stages of recovery

In the first few weeks after a moderate to severe 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 with eyes closed continuously, does not respond to visual stimulation or sounds, and is unable to communicate or show emotional responses.
- Vegetative state: Another term for this is Unresponsive Wakefulness Syndrome. Typically, the person can breathe on their own. Their eyes can be open, and they have sleep-wake cycles. Reflexes are functioning. For example, the person may startle to noises and visual stimulation, and make some movements, but the movements are not purposeful.
- Minimally Conscious State: The person is partially conscious, may know where sounds and visual stimulation are coming from and recognize objects. Sometimes they reach for objects upon request. They may respond to commands, utter words, or show emotion, but these responses are often inconsistent. Once the person is able to accurately answer basic questions (e.g., "Is your name John?," Is it daytime now?"), or show that they know how to use at least two different objects correctly (e.g., spoon, pencil), then they are considered "emerged" from the minimally conscious state.

A period of confusion and disorientation often follows a moderate-severe TBI. This may be referred to as post-traumatic amnesia; but a more correct name is confusional state. A person's ability will have difficulty paying attention and remembering things during this time. Often, they are agitated, nervous, restless, and easily frustrated. Sleeping patterns may be disrupted. The person may overreact to stimulation, such as noise. They may get upset easily. Sometimes a person may not know what's real and what isn't. They may see things that aren't there. This stage can be disturbing for family because the person behaves so uncharacteristically.

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Inconsistent behavior is also common. Some days are better than others. This stage of recovery may last days or even weeks for some people. In this stage of recovery, ups and downs are normal and are not cause for concern. Ups and downs are normal.

Later stages of recovery can bring increased mental and physical function. In most cases, the person's ability to respond gets better over time.

Length of recovery

Often, the fastest improvement happens in the first six months after injury. During this time, the person with the injury will likely move and think better. As time goes by, the speed of improvement will slow down, but the person may continue to gain more function for years after the injury. Rate of improvement varies from person to person. We do not know the reasons that the rate is different between people. For this reason, it is recommended that people with injury do what they can to support the health of their brain for the rest of their lives. Brain health is supported through healthy behaviors, such as exercise and avoiding alcohol and other drugs.

Long-term impacts

It is common and understandable for family members and other caregivers 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, when a person first starts to get better, it's hard to know the long-term effects for many reasons.

- We have just begun to understand the possible effects of TBI many years after injury. The TBI Model System program will continue to do studies focusing on outcome after TBI.
- Brain scans and other tests are not always able to show the full extent of the injury, so early in recovery it is sometimes difficult to understand how serious the injury is.
- The type of brain injury and extent of related problems, such as brain swelling, varies a great deal from person to person.
- Age and pre-injury health and 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. How long a person remains unconscious and how long they remain in the confusional state after that may help to predict how well and how quickly a person will recover.

Recovery two years after brain injury

Research from the TBI Model System program, at 2 years after injury, offers information about recovery from a moderate to severe TBI.

- About 30% of people need some amount of assistance from another person. This may be during the day, at night, or both. Over time, most people can move around again without help. They can also take care of themselves. This includes bathing and dressing.

- Trouble with thinking is common. This includes how fast a person can think. It also includes forming new memories. The severity of these problems varies.
- About 25% of people have major depression. In some cases, it's caused directly by the brain injury. In addition, people with TBI are also dealing with major changes in their lives caused by the trauma, including changes in employment, driving, and living circumstances.
- Just over 90% of people live in a private home. Of those who were living alone when they were injured, almost half go back to living alone.
- About 50% of people can drive again, but there may be changes in how often they drive or when.
- About 30% of people have a job, but it may not be the same job they had before the injury. Many people get help from vocational rehabilitation counselors who help people with TBI and other disabilities to go back to work.

Keep in mind that these percentages apply across a large group of people recovering from moderate to severe TBI and refer to a time 2 years after injury. For an individual, particularly early in recovery, it is difficult to say if that person will return to work, live independently, require supervision, and so forth. Also, recovery in these areas can still occur after 2 years. Age of the injured person, health history, environmental factors, and independence/activities before the injury are important factors in recovery as well. This information is not intended to discourage a person with TBI or family members, but to raise awareness that recovery from moderate-severe TBI is a long road for some people and there can be consequences from the TBI that may require adjustment on the part of the person with the injury and family members.

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

More TBI Factsheets from the Model Systems Knowledge Translation Center (MSKTC)

Several of the issues mentioned in this factsheet are presented in more detail in other MSKTC factsheets on TBI. Visit https://msktc.org/tbi/factsheets to read and download these factsheets, as well as the Understanding TBI factsheet series at https://msktc.org/tbi/factsheets/Understanding-TBI.

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Understanding Traumatic Brain Injury

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

March 2019 www.msktc.org/tbi/factsheets TBI Factsheet

This factsheet explains the impact of 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, notseeing 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 abilityto 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.

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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

- 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.
- 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.
- 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.
- 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.
- 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?
- 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 per- mission from a health care professional prior to using alcohol or other substances at any point after their injury. Also, NO DRIVING until ap- proved 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

Authorship

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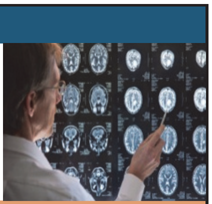
Vision Problems After Traumatic Brain Injury (TBI)



April 2014 TBI Factsheet

This factsheet tells you about problems with your vision after a TBI and how to treat them.

The Traumatic Brain Injury Model Systems Program is sponsored by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education. (See http://www.msktc.org/tbi/model-system-centers for more information)

What you need to know

- Your vision is important for many aspects of life.
- Traumatic brain injury (TBI) can cause problems with your vision.
- Treatment can either fix the problem completely, improve your vision, or help you better manage the problem.

What is vision and why is it important?

We often think about vision as being simply what we see. However, vision also includes how our brains make sense of what we see. Vision also helps other systems in the body work well. These include the systems for thinking and moving. When the visual system isn't working properly, there can be a wide-ranging impact on our daily living activities (e.g., reading, driving, employment, school, and recreational activities) and quality of life. Depending on its location and severity, a TBI can affect your vision by damaging parts of the brain involved in visual processing and/or perception (e.g., cranial nerves, optic nerve tract or other circuitry involved in vision, occipital lobe). .

How are vision problems found after TBI?

Many members of your care team can find vision problems after TBI. An eye doctor may be part of the team and can check for vision difficulties. Therapists or other rehabilitation clinicians may be the first to notice a problem. They can make a referral to an eye doctor who can examine you and offer advice for treatment. Eye doctors who diagnose and treat vision problems after TBI include optometrists (op-TOM-ah-trists) and ophthalmologists (op-thal-MOL-oh-jists). Neuro-optometrists and neuro-ophthalmologists are specialists with additional training in working with people with brain-related vision problems. Consult with your care team to identify the most appropriate resources for your evaluation and treatment.

What are common types of vision problems after TBI?

There are a variety of visual problems that can occur at different time points in your recovery. Some of the most common types of vision problems include the following:

- Blurred vision, especially with seeing up close
- Double vision
- Decreased peripheral vision

There can also be complete loss of vision in one or both eyes depending on the injury.

How can these vision problems affect my day-to-day life?

Many of the visual problems after TBI can make it more difficult for you to read or do activities up close. For example,

- Close objects may look blurry some or all of the time.
- It may take longer than is typical to focus when looking up from reading.
- Printed letters or numbers and other objects may look as if they're moving.
- It may be difficult to read a computer screen.

It may also be harder for you to be comfortable in some kinds of environments. You may feel:

- Irritable in places with a lot of patterns or motion (visual overload).
- Bothered by light or glare.

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Vision problems can also cause discomfort or pain. For example,

- Your eyes may ache or hurt.
- Your eyes may tear up more than usual.
- You may feel like your eye is “pulling.”
- You may have more headaches or motion sickness than usual.

Other visual problems can affect posture, balance, or moving through space. These types of problems may cause you to:

- Have difficulty judging where objects are in space (depth perception).
- Lean forward, backward, or to one side when sitting, standing, or walking.
- Feel as if the floor is tilted.
- Have difficulty participating in sports or other recreational activities.

Other visual problems may affect your brain’s ability to take in and understand visual information (visual cognition), including the following:

- Problems moving the eyes together or making other eye movements
- Difficulty searching and scanning for visual information (visual scanning)
- Difficulty mentally focusing on objects (visual attention)
- Problems encoding, recognizing, and/or recalling visual information (visual memory)

What are common causes of vision problems after TBI?

Sometimes, the eye itself is injured during the head injury. There can also be medical conditions that aren’t related to TBI. These include cataracts or glaucoma. Other vision problems occur due to damage to the wiring in the brain.

Vision problems after TBI are complicated. There is often more than one cause for your symptoms. Sometimes, the eyes are causing the problem. Other times, brain processing may be the problem. For example,

- There may be problems with eye movements. The eye movements we use when scanning stationary objects may not work as well. These eye movements point our eyes toward an object so we can see it clearly. People may also have difficulty following a moving target.

- The eyes may not work together properly as a team. For example, the eyes may not move inward toward the nose to see objects clearly up close (convergence insufficiency). Or, the eyes may not realign outward as needed to focus on objects at different distances (divergence insufficiency).

- The muscles that control the lens inside the eye may not be working properly. This causes difficulty with changing focus when a person switches between seeing objects up close and at a distance.

- There may be a weakness or imbalance in the muscles that move the eyes. One or both eyes may be turned in more toward the nose or out toward the side of the face than usual. This is often the result of injury to the nerves that control the eye muscles. Sometimes, a hairline fracture of the eye socket can cause a problem with the muscles that move the eye up or down.

- You may have difficulty seeing above, below, or out to the sides (decreased visual field). When you lose vision to one side (right or left) of your visual field, it is called hemianopia (hem-ee-en-OH-pee-ah). This may cause such problems as bumping into objects, being struck by approaching objects, or falling.

Vision can also be affected by some medications. For example, some medications can affect the focusing of your eyes. Others can make the eyes feel dry.

What kinds of professionals can I consult with and what kinds of treatment are available?

Professionals who provide vision treatment include eye doctors who specialize in brain-injury-related visual problems, low vision specialists, and occupational therapists. Sometimes, treatment is aimed at treating the underlying problem. This may involve surgery and/or vision rehabilitation therapy including therapeutic eye exercises.

If it is not possible to completely treat the problem, then compensatory devices or strategies may be used to help you make up for reduced or lost eyesight. A rehabilitation professional can help determine which devices and strategies will work best.

What kinds of optical devices can help me manage vision problems?

Some options include

- *Corrective eyeglasses*. If you have blurry vision, regular eyeglasses may be recommended. Glasses that magnify objects can be helpful for up-close activities such as reading, using a cell phone, and doing crafts. Sometimes, glasses to improve distance vision are helpful. If you wore glasses before your injury, even a small change in the glasses' prescription may be useful. If you need glasses to see objects that are both near and in the distance, you may find it difficult to use bifocals. It may work better to have separate pairs of glasses for reading and for distance and even a third pair for the computer.
- *Specialized glasses such as prism glasses*. These are glasses with a prism ground into or put onto the lens. The prism changes the way the light comes into the eye. These glasses may help you with double vision or visual field loss.
- *Patching*. Patching one eye or part of the visual field of one eye is sometimes used to help those with double vision. The patch is placed to eliminate the information that results in the double image from coming into the brain. Patching should be done under the supervision of a trained professional, as it can make the double vision worse if not done correctly.

What other types of devices and strategies can help me manage vision problems?

The following devices and strategies may help you, depending on your vision problem. It is always best to consult with an eye doctor trained to evaluate and treat vision problems after brain injury for specific advice for your particular situation.

- Take breaks often when doing tasks that rely on vision. This is especially important when reading, watching television, or using a computer or other electronic devices. Look up every 20 minutes and focus on something at least 20 feet away to give your eyes a break.
- Magnify objects. Magnifying glasses and other types of magnifiers make objects bigger so they are easier to see. Electronic readers can be used to increase print size and contrast.
- Increase contrast. Making an object stand out from the background can make it easier for you to see it. For example, use a dark-colored cutting board instead of a white one to cut an onion.
- Avoid bothersome light sources. Fluorescent lights can be irritating to some people. Use natural light or non-glare nonfluorescent lighting whenever possible. Wearing tinted sunglasses, indoors or out, may help. The vision specialist can help find the best color and type of tint.
- Reduce glare. Wearing tinted sunglasses can help with glare. Covering shiny surfaces that reflect light into the eyes is another possibility. For example, attach a non-glare filter to computer screens.
- Avoid visual overload. Cut down on clutter in your home and at work. Try to keep all the items needed to complete a task together in one place. Designate one storage place for a frequently used item. For example, place a bowl by the door to hold your keys. Not having to search in multiple places for what you need will reduce the amount of input to the visual system. This can help keep you from being overwhelmed by visual information.
- For those with complete vision loss, devices such as talking timers, alarm clocks, microwaves, thermometers, tactile dots, screen-reading software for computers, talking books, various mobile phone apps, and mobility canes may be helpful. Learning Braille may also be helpful.

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Authorship

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Voting Tips for People Living With Traumatic Brain Injury

August 2021 www.msktc.org/tbi/factsheets TBI Factsheet

This fact sheet explains why it is important to vote. It includes tips for people with TBI on when, where, and how to vote. Options and strategies may vary by state and locality, so be sure to check.

People with traumatic brain injury (TBI) may experience challenges in voting due to a range of impairments in physical, hearing, vision, communication, cognitive, emotional and behavioral function. Obstacles may include registering to vote, remembering to vote, accessing transportation, physically navigating the polling place, understanding ballot design and utilizing technologies for voting. All that on top of deciding who to vote for! The information here is intended to help people with brain injury overcome obstacles in the voting process. Options and strategies may vary by state and locality, so be sure to check.

Why Vote?

- Voting gives you a voice in what happens in your city, county, state, and country.
- People with disabilities, including TBI, vote less often than people without disabilities. When this happens, people with disabilities have less of a voice.
- Your vote matters. If you do not vote, you are letting other people make decisions for you. Some of these decisions may affect your rights and access to health care, employment, and other services and opportunities.
- Voting is a privilege and a responsibility that is part of being a United States citizen.

What Are Your Responsibilities?

- It is up to you to ask for help.
- It is up to you to be fully informed about the voting process and the candidates before voting.

What Are Your Rights?

- You have the right to vote.
- You have the right to ask for help with voting.
- You have the right to bring a friend or family member with you to help you navigate the voting process.
- You have the right to have accommodations to help you vote.
- You have the right to ask a poll worker to explain how to use the voting machine.
- You have the right to ask for a voting machine you can reach.
- You have the right to ask for a seat while you are waiting to vote.
- You have the right to take your time while voting.
- You have the right to use curbside voting.
- You have the right to be treated with respect.
- You have the right to speak up for yourself.

The Traumatic Brain Injury Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See http://www.msktc.org/tbi/model-system-centers for more information.)

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How Do I Prepare to Vote?

- Register to vote.
- Decide where/how will you vote and how you will get there if voting in person.
- Confirm your voter registration.
- Even if you have registered before, you should verify your registration status and make sure the address listed is up to date.
  - Infrequent voters are more likely to be removed from voter rolls.
  - When you go to vote, if you are told that you are not registered or not allowed to vote, you have the right to ask for a provisional ballot.
  - In order for your provisional ballots to be counted, you must follow-up with the appropriate officials to provide proof of registration status.
- Set helpful reminders leading up to election day to remember to vote.
  - Write important dates on your calendar, set a reminder on your cell phone, and/or or ask someone to remind you as the dates approach.
  - Important dates include the deadline to register to vote and to request and turn in an absentee ballot. They also include the dates for early voting and for Election Day. These dates may be differ by state and precinct (voting region).
- Decide which elections matter to you.
- Become informed. (See suggestions on page 3)
- If you plan to vote absentee, request an absentee ballot to vote. Follow the directions that come with the ballot to complete it and turn it in. Consider having a family member or friend check that you completed it correctly and signed in the right places.
- If you plan to vote at the polls:
  - Make notes and take your notes with you when you vote.
  - Check on your state election board website to find out what kind of identification (ID) you need to vote.
  - Find out which polling place is your assigned location for voting.
  - Figure out how you will get to the polls. Plan for a ride if you need it.

Lines may be long on election day. Allow yourself plenty of time. If needed, bring things like water, medication, or food.

Where Can I Register to Vote?

You can register to vote at a variety of places. Locations and processes vary by state. Check before you go to make sure that the location is doing voter registration. Find out what documents to bring. There are several registration options. Chose the option that is right for you. These options may include:

- In person.
  - County board of elections office.
  - Public libraries.
  - Department of motor vehicles.
  - State and county public assistance offices.
  - Post offices.
  - Town halls or municipal offices.
- Online.
  - Visit https://www.usvotefoundation.org/. This portal walks you through the process for each state. You can also check your county or state board of elections website.

How Do I Become an Informed Voter?

- Decide what you care about. Learn about the issues. Learn about the candidates' positions on the issues and his or her leadership skills.
  - You can read newspapers, listen to the radio, watch debates on TV, and talk to other people.
  - Visit each candidate's website. These sites may list the candidate's views on different topics.
  - Read the Guide to Informed Voting. (https://www.aascu.org/programs/ADP/VotingResources/InformedVoting.pdf).
- Know who is running. Know what issues are on the ballot.
  - Get a sample ballot.
    - » You can get a sample ballot from your county board of elections office, early voting sites, libraries, or online.

Where Do I Go to Vote?

Choose the way that is best for you. Options include:

- Vote from home using an absentee ballot or vote by mail.
  - You must request an absentee ballot before the election.
  - Follow the directions that come with the ballot to turn it in.
  - Start the process early to allow enough time for you to receive and submit your ballot.
  - Absentee ballots should be completed and placed back in the mail as soon as possible to be received by election day.
  - Most states also have options for drop-off boxes or in-person early drop-off.
- A place that offers one-stop early voting. This often starts 2–4 weeks before Election Day.
- Your assigned polling place on Election Day.
- Curbside at the polling site or your local elections office.
  - If you can't get out of your car or walk into the polling place, a poll worker can bring your ballot to your car.
    - » You will need to have a friend or family member go inside the polling place and tell a poll worker that you need curbside voting.

What if I Need a Ride to the Polls?

- You can take public or private transportation to the polling place. Examples may include:
  - State-funded disability transportation
  - Transportation services for seniors
  - Churches
  - Private transportation services, such as taxi cab, Uber, and Lyft
  - Party headquarters (e.g., Democrat, Republican, or other) in your county
- Ask a family member, friend, neighbor, or someone else you trust if you can go with them to the polling place.

What if I Need Help Voting?

- You can ask a poll worker for help.
  - **Poll workers can’t ask you if you need help, but you can ask them for help.**
  - You can ask the poll worker to help you read the ballot and use the voting machine.
- You can ask someone to go with you and have that person ask the poll worker for help on your behalf.
- You can ask someone to go with you to the polling place and into the voting booth to help you.

How Can Families, Friends, and Care Partners Help Me Vote?

- Talk about current events, political issues, and candidates with others.
- Think about obstacles that may keep you from voting.
  - These obstacles may include a lack of desire to vote, fatigue, and a desire to avoid crowds. Other examples include problems with memory, not being able to drive, and having a tough time moving around or communicating.
  - Plan each step of how you will vote, from getting your ballot to turning it in.
    - » If there are parts of the process that you don’t know how they will work, research these issues and make a plan.
- Think about how you can get help to overcome obstacles to voting.
- Tell others that you want to register to vote, your preferred method of voting, and ask for their help if you need any. Ask for help with
  - registering to vote.
  - remembering deadlines (such as, dates for registering to vote and getting an absentee ballot).
  - gathering information.
  - learning about the candidates.
  - getting a sample ballot.
  - making sure you have the right ID to vote.
  - requesting or turning in an absentee ballot.
  - getting a ride to the polls.
  - getting into the polling place.
  - reading the ballot.
    - » Someone else can read the ballot and ask you to pick one of the choices. They can’t pick for you.

What about voting and COVID?

- If you vote at the polling place, bring a mask, hand sanitizer, and remember to social distance.
- You could request an absentee ballot if you are concerned about voting in person.

Where Can I Get More Information?

- National Disability Rights Network
  - https://www.ndrn.org/issues/voting/
- American Association of People with Disabilities Voter Resource Center:
  - https://www.aapd.com/advocacy/voting/voter-resource-center/
- U.S. Vote Foundation online portal for registration, absentee ballots, election dates, and other information:
  - https://www.usvotefoundation.org/
- Election Protection coalition:
  - Toll-free at 866-687-8683 or online at www.866ourvote.org
- USA gov:
  - How to Register to Vote: www.usa.gov/register-to-vote
  - Voting and Elections: www.usa.gov/voting
- Guide to Informed Voting:
  - https://www.aascu.org/programs/ADP/VotingResources/InformedVoting.pdf
- U.S. Election Assistance Commission:
  - Resources for Voters with Disabilities: https://www.eac.gov/voters/resources-for-voters-with-disabilities/
  - Voter's Guide to Federal Elections: https://www.eac.gov/voters/voters-guide-to-federal-elections/

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Authorship

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