

# The Missouri Greenbook

## Living with Brain Injury



**A guide for survivors, families and caregivers.**



# Life after rehabilitation: home, work and school

---

This section offers a number of suggestions that can help individuals with TBI move forward after formal rehabilitation ends and gradually resume their daily activities.

## Being home

- Work with your family to divide duties, including breaking jobs into smaller tasks that you can manage safely.
- Develop a schedule and routine that includes participating in home-care activities every day.
- Set a routine and schedule for self-care activities.
- Identify any home modifications or adaptive equipment that might be helpful in your ability to participate or complete tasks.
- Regularly talk with family about your progress on tasks and increase participation over time.
- Recognize that tasks may take more

time and energy and allow ample time for completion. At least initially, periodic brief rest breaks may be useful.

- Modify the environment to be quieter or slower paced when you are working on tasks. This will help prevent you from becoming overstimulated by noise and activity.
- Keep a family calendar for tracking important dates. Get a large calendar with room for recording daily events that may be important to recall later.
- Keep paper and pens by all phones and develop the habit of keeping notes of calls.
- Keep an organized house so that frequently-needed items have a set place.
- Declutter work areas and avoid visual overstimulation.
- At the beginning of the week, meet with family to plan for the upcoming week.

“Allow people the blessings of helping you. You can’t do it alone. Tell them what you really need when they ask.”

- Debby Beffa, Chesterfield, Mo.  
Mother of a TBI survivor

- Begin every day by reviewing the calendar and planning the use of your time to complete the day's tasks.
- Build in time for social interaction daily.
- Incorporate physical exercise into each day.
- Make reading an important part of every day. Also, participate in intellectually stimulating activities that may include puzzles, crafts, games and mental challenges.

### Attending college or vocational training

- Your first task should be to speak with staff in the student services office about available accommodations and services for students with disabilities.
- Choose a school/program that offers smaller class size and easy access to instructors.
- Begin with a conservative (part-time) course load. Use the first semester to focus on school success.
- When scheduling courses, try to achieve a balance between intense classes and less demanding classes.
- Include classes of great interest to you even if at a pass/fail level.
- Speak with instructors individually to let them know of your learning needs and establish a plan to address your needs. Make sure the instructor has a copy of any accommodation plan prepared by the student services office.
- Always sit close to the instructor or other learning source to avoid distractions.

- Plan to tape record lectures for possible later review as needed to enhance learning.
- Determine the need for a note taker. You may want to exchange notes with a peer.
- Use tutorial labs frequently to review material and reinforce learning.
- Establish a quiet study environment and a set a daily study period.
- Monitor grades routinely and meet with your instructor immediately for assistance if you receive a poor grade.
- Carry a planner/calendar to class and record upcoming assignments and tests. Break down assignments to indicate when you plan to study and complete all or parts of the task.
- Schedule plenty of rest breaks into your day.

### Driving

- Speak with your treating physician about your readiness to complete a driving evaluation.
- Once released to complete an evaluation, explore available driving evaluation programs with expertise in TBI.
- Do not return to driving unless released to do so by your treating physician.
- Upon release to return to driving, make appropriate modifications to your vehicle and change your driving habits to ensure the safety of yourself and others.
- When returning to driving, avoid heavily congested traffic areas and time periods.

- Keep distractions out of your car when driving. Don't use a cell phone when driving or engage in distracting social behaviors.
- Recognize fatigue and do not drive when tired.
- Address any visual limitations related to driving.
- Never use alcohol or illicit chemicals and drive.
- Always wear a seat belt in the vehicle.

### Attention

- Avoid distractions that may include noise, lights or movement around you.

- When taking notes, repeat back what you have written to ensure that you have all of the details.
- Use a highlighter marker to draw attention to specific areas on a page.
- Study or read in a quiet environment.
- Look directly at people during a conversation.
- When studying, take notes on what you are reading.
- Be an interactive listener by periodically rephrasing what the other person is saying during a conversation.
- Avoid multi-tasking, which taxes your ability to give your full focus to tasks.
- Plan before beginning. Think about what you want to learn or know and be focused on those areas as you study or read materials.



- Avoid unnecessary visual clutter that may affect your ability to find things.
- In your wallet or purse, carry a list of your medications, medical conditions and emergency contact information.
- Develop a system for having necessary items always placed in set places.
- Repeat back what you are told and use large and colorful labels to write it down to ensure that you organize and mark materials to make have all the details.
- Turn down or turn off the TV or radio when trying to talk on the phone or have a conversation with others.
- Develop a routine for regular activities including taking medications, home tasks and self-care.
- In restaurants, ask for a table in a quieter area and seat yourself in a place where you are less distracted.
- Keep a central calendar in your home and write down all appointments and upcoming events.
- Ask people to speak up and be

Develop memory strategies that help you learn new things. ”

- Begin the week and day by reviewing upcoming activities and planning attention.
- When studying or reading, take brief breaks about every 15 to 20 minutes.
- Ask for call reminders of appointments.
- Keep sticky notes available for quick work, review and proceed.
- Review sticky notes to remind you of a task that is undone. Get rid of notes that are no longer current.
- Make a daily “to-do” list. Then make a pencil and paper for keeping notes.
- Use a small notebook, calendar or single piece of paper for note taking.
- Consider carrying a small tape recorder for taping notes for list at the end of the day and decide which tasks need to be carried over into the next day.
- Call your voice mail and leave notes and reminders for yourself.
- You will likely need to practice new learning to maintain the information.
- When you go to the doctor, take your calendar and diary/journal.
- Understand your preferred learning mode. Some people learn better of your injury, medical history and current medications.

by reading or hearing whereas others learn better by watching, seeing and doing. Use your preferred mode for new learning.

Avoid distractions and interruptions

- that interfere with your ability to encode information into memory.
- Use cues to trigger memory. A cue is something that will remind you and help your brain know where to find the information.

Take responsibility for your memory rather than expecting family and

- friends to be your memory for you.
- You will remember more easily if it is important to you.

Develop memory strategies that help you learn new things: turn a list into song; make a mental picture; develop a word cue for an idea.

- Pair a learned activity with a new task that needs to be part of your routine. For example, pair taking a medication with brushing your teeth in the morning.

Use a weekly medication tray to help keep track of medications.

Keep a medication log and check off when each dose is taken.

- Use timers in your house to cue you of an upcoming task that you need to do.
- Use the alarm on your watch to cue you.
- At night, prepare everything you need to take with you the next day and place it all together.

▪

▪

- Accept that remembering things may be more challenging and ask others for assistance with new learning or reminders.

Develop specific strategies for

- your needs with the help of family, a speech pathologist, or neuropsychologist or rehabilitation psychologist.

## Judgment

- Find a mentor to help you think through important decisions.
- Use a decision making strategy that includes:

- Collecting all important data
- Determining potential solutions
- Assessing how realistic each option is
- Examining the pros and cons of each decision
- Thinking through possible consequences to you and others

Take your time in making decisions and avoid acting impulsively.

- If you make a mistake, review your decision-making strategy and learn from your mistakes. Also, figure out a way to correct mistakes.

It is typically very useful to talk out decision-making because it will help you understand how you feel and think about a situation.

- Decisions are best made when you are calm and not when you are distressed or angry.

▪

“It is important for families to remember that when their survivor seems to be different they are not the same person they once were. The original person may peek out from time to time, but TBI can cause a great change.”

- Andrea Buening, Seneca, Mo.  
TBI survivor

- Keep good friends who are willing to be honest and supportive. Good counsel leads to better decisions.
  - Lean toward decisions where you are the main person responsible. Practice empathy, putting yourself in someone's shoes and thinking about how they would feel. Think first before talking or acting.
  - Think about your comments or actions. Ask yourself:
    - How will the other person feel?
    - How will the other person react?
    - Is this how you want to behave?
    - Will this obtain the desired effect?
    - Are you willing to accept the consequences?
- Behave and make decisions consistent with your value system.

### Processing speed

- Allow enough time to complete tasks.
- Think about how much time will be needed to complete a task before beginning.
  - Learn to slow down the flow of information so that you do not feel overwhelmed. Tell people to slow down if they are talking or moving too fast. Look for work settings that match your preferred work pace.
  - Keep track of how long it is taking to do a task. This will help you readjust your internal sense of time. Choose times to go to the store or office when the staff is likely to have extra time and not rush you.
  - If you drive, choose times and routes that are less busy or rushed. Leave

early to allow extra time to get to your destination.

- Talk to your doctor about safety using power equipment (lawn mower, all-terrain vehicle, power tools, etc.). Help your family understand your need for time so that you and they do not feel as rushed completing routine tasks such as getting ready to leave or completing daily chores.

### Your health

We all function better when we take care of our health. TBI may create specific health issues, and you are encouraged to work closely with your physician to manage any chronic health conditions. Some general health recommendations include:

- Have annual examinations.
- Comply with medication recommendations (take only as prescribed). Do not discontinue a medication without discussing the decision and process with the doctor prescribing the medication. Tell your doctor about all of the prescription medications that you are taking and your use of over-the-counter medications (ibuprofen, acetaminophen, etc.), and vitamins and supplements. Your doctor needs to know about possible interaction effects in order to provide good care. Tell your doctor if you are using alcohol, street chemicals (such as marijuana or cocaine) or tobacco.
- These substances affect your overall health and the effectiveness of your

medication.

- Have recommended preventative procedures (annual PAP, mammogram, colonoscopy, prostate exam, etc.).  
Have annual eye exams and annual dental cleanings and exams.  
Report to your physician immediately if you think or know that you have
- have had a seizure or seizure-like episode. Seek emergency care if a seizure involves lost consciousness or possible injury.  
Practice safe sex to avoid social diseases and unwanted pregnancy.
- If you use tobacco, talk to your physician about medications and programs to help you stop.
- Tobacco affects your brain as well as your lungs.  
Limit use of caffeine (coffee, tea, energy drinks, sodas, etc.).  
Develop a regular and sufficient pattern of sleep.
- Adults usually require seven to eight hours of sleep per night.  
Talk to your physician if you
- have trouble falling and/or staying asleep or if you continue to feel sleepy or tired during the day despite an adequate amount of nighttime sleep.  
Fatigue is a common effect of a TBI. It can be related to many factors including lack of activity, poor quality or quantity of sleep, medication side effects or over activity, to name a few.  
Fatigue limits a person's ability

or drive to accomplish tasks. You and your family are encouraged to speak with your physician if fatigue is a noted barrier to your plans.

- Talk to your physician about developing a suitable regular exercise program that fits your needs. Exercising 20 minutes, three times a week can have a positive effect on your physical and emotional health.



- Know your best target weight and develop a balanced and regular eating pattern to maintain your weight. Gradual weight gain can occur when you become less

- Seek medical care for health concerns early to avoid protracted problems, complications or more invasive care.

“ Seek medical care for health concerns early to avoid protracted problems...”

### Substance abuse

Unfortunately, alcohol and substance abuse has played a major role in the incidence of TBI. Many individuals who abuse alcohol or illicit chemicals return to abuse after the TBI, to the greater detriment of their health and ability to reach their goals.

physically active. However, obesity has many negative effects on health and self-esteem.

- Manage chronic health conditions in conjunction with your physicians' help. Uncontrolled diabetes, hypertension, heart disease, sleep apnea and similar conditions can affect your long-term health and current ability to function at your highest level.

Chronic pain is not common but can follow TBI. Post-concussive

- headaches rarely become chronic. Spasm and contractures, among other things, can cause pain.

Untreated chronic pain is correlated with depression. You are strongly encouraged to work with your physician to identify an effective treatment approach to eliminate or significantly decrease the impact of pain. Treatment options may include medication, counseling, acupuncture, physical/occupational therapy and biofeedback, separately or in some combination.

Alcohol and illicit chemicals affect the brain differently after TBI. Alcohol and illicit chemicals can increase seizure risk and the risk of additional brain injuries.

Long-term negative effects of alcohol use on the brain have been documented. The use of alcohol and illicit chemicals can magnify changes that may follow TBI, such as problems with initiation and drive; memory; attention; and emotion and behavior control.

Studies connect alcohol and substance abuse to poorer overall outcomes as related to success in returning to work, school, social and home life. Individuals who have had a pre-injury history of alcohol or substance abuse are strongly encouraged to seek consultation with a substance abuse counselor to develop a plan to avoid relapse into alcohol or substance abuse.

It is important to appreciate that you may need to make lifestyle changes to avoid relapse or abuse. Friends and families, work and recreation environments often

influence our decisions about alcohol and substance use. Speak with your physician, a rehabilitation psychologist or substance abuse counselor about strategies to maintain a healthy lifestyle.

### Dating and intimate relationships

TBI can have an impact on intimate relationships including dating and marriage. Single adults with TBI report challenges to dating after their injury. Physical changes can influence one's self-image and confidence. However, cognitive changes can impact social skills as well. Brain injury is a unique experience and poses individual challenges.

As you move back into dating, do a self-assessment on your:

- Social skills
- Dating expectations
- Self-image
- Plans regarding sexual intimacy

Use your trusted friends and family to give you important feedback about your choices in dating.

A word about victimization: Unfortunately, individuals with disabilities are at increased risk of being taken advantage of in many areas including sexual exploitation. Never accept or allow physical, emotional or sexual abuse under any circumstances. Partners who do not accept your personal

choices or who demean or hurt you in any way do not have your best interests in mind.

Married individuals who have experienced a TBI sometimes experience role changes in the marital relationship. Spouses become caregivers, at least initially, and often take on many of the roles of the family.

As you return to family participation, you and your spouse may need to openly talk about your role as a spouse and parent and your contributions to home care and your sexual relationship. You are encouraged to understand that your spouse has acted in love by assuming additional roles and may be reluctant to relinquish or change roles, partly out of concern for your well-being.

Family members are encouraged to understand and appreciate that the individual with TBI may function in prior roles in a different way. While different, their new or amended approach is not necessarily wrong.

It is imperative that couples frankly discuss the changes in their relationship through the recovery process and beyond. This can be uncomfortable and cause those involved to feel threatened and defensive. Advocate for yourself and your marriage by seeking professional help from a counselor familiar with TBI.

“Make decisions based on your gut feelings. Don't let anyone push you into a decision you are uncomfortable with.”

- Debby Beffa, Chesterfield, Mo.  
Mother of a TBI survivor

## Friendships

It may be difficult for your friends to understand TBI, as it has been for you and your family. They may not have received much information about TBI and its effects. In the absence of information, they may struggle to find a place in your life or a way to connect with you.

You and your family are encouraged to keep close friends educated and involved from the injury forward. Help them to understand your needs for friendship and how they can connect with you.

When initiating social contact, consider selecting specific and time limited tasks with one or two friends. An example would be going to a movie. It may be helpful for you to talk to your friends before going on outings as to your needs for accommodations.

As you feel comfortable, you can expand social outings. You are always encouraged to advocate for yourself by taking rest breaks, shortening activities, asking for accommodations (such as help getting out of the car) and putting limits on the types of social activities you prefer. Remember the things that make your friendships special and strive to be a good friend.

Some friends may not feel comfortable continuing the friendship, or you may find that some friendships were not as close as you may have thought. Look forward, and begin the process of reinforcing strong and positive friendships and making new friends.

## Coping with change

Change is often a challenge for people regardless of the cause. There are three important things you can do to help yourself in navigating change.

- Be patient with yourself.
- Share your feelings and thoughts with your family and friends.
- Use your available resources of family, friends, agencies and professionals.

The injury event can create stress for you and your family. Remember that this is unfamiliar territory for all of you. Stress can cause problems in many areas of your life. It can create a sense of guilt, worthlessness, hopelessness, or feeling completely alone, among other feelings. Stress can also contribute to depression and anxiety.

The following recommendations may help your family cope during different phases of your experience. Family members should:

### Take care of yourself

- Get plenty of rest, eat the right foods and get enough exercise.
- Take turns at the hospital with friends and family.
- Plan to resume some of your normal family activities.
- Ask friends to help with home tasks.

### Try not to isolate yourself

- Try becoming acquainted with other patients and their families.
- Ask friends to visit you at the hospital or home.

- Ask the hospital volunteers to call on you.
- Visit with the hospital chaplain.
- Spend time with your other children
- (if it is one of your children who has the TBI).

### Depression

Depression is defined as having significant feelings of sadness, helplessness, hopelessness and dissatisfaction to the extent that it interferes with one's ability to function well in life. There are many factors that contribute to depression, including a sense of loss, lack of help or resources to deal with life and financial strain.

Individually, our own attitudes and approaches to problems play a major role as well. Depression is treatable. The best treatment for clinical depression includes a combination of medication and counseling. The goal of treatment is to help the individual learn new ways to handle problems, make life choice decisions to decrease problem areas and improve one's ability to face challenges.

Depression can affect the individual with TBI or family members, as all have experienced the injury event. Sometimes family members ignore their own needs for help due to a belief that they need to focus on their loved one with a TBI. In fact, depression robs us of our fullest ability to help others. If you experience depression, you are encouraged to seek treatment.

There are general strategies that can be used to help avoid or overcome depression.

These include:

- Maintain a problem-solving approach to problems and avoid being reactive.



Adopt a positive and hopeful outlook.

- Use your resources, friends, family, local agencies and professionals to help you manage challenges.
- Do not rehearse and replay negative thoughts or experiences.

“ Use your resources, friends, family, local agencies and professionals to help you manage challenges. ”

- Adopt a healthy lifestyle, including adequate sleep, a balanced diet and regular exercise.
- Avoid alcohol and illicit chemical use as this tends to exacerbate emotional problems.
- Participate in socialization opportunities on a regular basis.
- Be involved in meaningful life activities including volunteering, participating in faith-based activities and actively using your mind through reading and new learning.
- Establish short- and long-range goals to keep you directed and energized.
- Find something to look forward to daily.
- Be a thankful person.
- Establish mentors for all areas of your life and make it a point to learn from the good example and counsel of others.
- 

## Support groups

Dealing with the stresses of TBI can be difficult for families. The Brain Injury Association of Missouri (its local chapter and other various programs) can help through:

- Local support groups
- Information and referral
- Advocacy
- Social and recreation activities
- Educational programs and materials for people with TBI, families and caregivers

People who receive such services may:

- Collect useful information
- Gain support and understanding
- Learn problem-solving skills
- Enlarge their support system

Support groups are a place to share feelings and experiences with others who have walked in your shoes; a place to gain valuable information about TBI and resources; and even a place to have some fun. Support groups give families and people with TBI information regarding:

- Funding
- Legal protection
- Preparing a will
- Selecting a rehabilitation facility
- Planning for future rehabilitation, housing and employment
- Many other topics that are relevant issues to people with TBI

## Keeping essential records

After initial hospitalization, many professionals will ask for detailed information about:

- Medical treatment and diagnosis
- School performance
- Insurance
- Rehabilitation
- Employment history
- Financial resources
- Community service involvement

Records of the information are very important. Begin keeping records at the time of hospitalization. Start with information including contact information for:

- Doctors
- Nurses
- Social workers
- Other therapists involved in your care

Ask for and keep copies of the discharge papers.

### Save everything

Keep everything including:

- Insurance papers
- Benefits applications
- Responses and correspondence from important agencies, especially from your insurance company, Medicaid and Medicare
- Financial records (budgets, paycheck stubs, income tax records, bank statements, annual report on work history earnings)
- Educational records (assessment results and copies of individualized education plans - IEPs)
- Medical records

Build a file, making sure you note contact names on:

- Treatment programs and providers
- State and federal agencies
- Advocacy organizations

Organize information files. Suggested headings include:

- Medical history
- Insurance
- Financial resources
- Rehabilitation
- Education/work
- State and federal agencies
- Resources

Be sure to include information related to benefits:

- Eligibility for services
- Correspondence
- Services offered
- Log of interactions
  - Date(s)
  - Contact person
  - Address and phone number
  - Notes from conversations

### Ask for help

If you need assistance or have trouble, ask for help. Refer to the Resources section in this book for information about various supports and services.

“Keep a journal from day one. You will never know how important a name, hospital stay or medicine will be. Sometimes these facts are needed years later. A journal is also a way to record emotions and stages of recovery.”

- Sue Orton, St. Louis, Mo.  
Mother of a TBI survivor

[Read the full Missouri Greenbook.](#)

