Transitioning Home After Rehabilitation

This factsheet offers tips to help you transition from rehabilitation to home after a TBI. It also includes links to helpful resources.

Going home after inpatient rehabilitation can be a challenge for many people with traumatic brain injury (TBI) and those close to them. It is good for you and your family to start planning as early as you can to help make this transition as easy and effective as possible.

What Do I Need to Know Before Going Home From Rehabilitation?

Keep a Balanced Mindset

Everyone hopes for the best possible recovery after TBI. While most people do see improvements after their TBI, many continue to experience issues related to their TBI. This makes it important for you and those close to you to take part in rehabilitation. You can learn the skills you need for life after TBI and how to manage challenges you might face at home.

Learn About Your TBI

It is only natural to have questions about TBI. Don't be afraid to ask questions. But keep in mind that health care providers may not have all the answers, especially at first. Outcomes of TBI vary from person to person. And long-term outcomes may be hard to predict during your rehabilitation.

- Read Understanding Traumatic Brain Injury: https://msktc.org/tbi/factsheets/understanding-traumatic-brain-injury

Have a Good Discharge Plan

Each person has unique needs. Your rehabilitation team can help prepare you and those close to you for your transition home. You may not be able to prepare for every situation that you will face after discharge. But here are some tips for a good start.

- ✓ **Have a clear plan to identify and take advantage of your support network.** Rehabilitation helps you learn how to do as much as you can on your own. Still, everyone needs some type of help. Work with family, friends, and community resources on ways to get the help and support you need.
- ✓ **Educate yourself about health insurance coverage for recommended rehabilitation services following inpatient rehabilitation discharge.** Most rehabilitation units have case managers that can help you with insurance questions.

The Model Systems Knowledge Translation Center works with Traumatic Brain Injury Model System (TBIMS) centers to provide free research-based rehabilitation resources for people living with traumatic brain injury (see https://msktc.org/tbi for more information). This factsheet has been approved by experts from the TBIMS centers.

- ✓ **Identify your key health care providers for your ongoing care.** You will likely need to follow up with several different health care providers within a few days or weeks after going home and over the long term. This may require identifying a primary care provider if you don't have one, and a rehabilitation specialist.
- ✓ **Keep <u>all</u> medical documents you receive together and in one place.** Then give these documents to your health care providers to help them treat new and ongoing medical issues. Plus, it helps them understand what you have been through. Make sure that you and those close to you have a visible list of your health care providers and their contact information.
- ✓ **Make sure you have a plan for how you will get to and remember all your appointments.** After discharge, you may continue your rehabilitation at home or in an outpatient setting as well as have medical follow-up appointments Commonly, individuals who return home from inpatient rehabilitation are not able to drive immediately. Finding transportation resources and support is critical to get to outpatient therapies and medical appointments.
- ✓ **Make a list of state and local community resources.** Ask about state-funded programs, local brain injury support groups, state brain injury associations, and other community supports and services.
- ✓ **Work with your therapists and nursing staff to safely carry out daily activities.** This can help you maximize your independence while avoiding setbacks.
- ✓ **Ask about a home evaluation.** This is when an occupational therapist, physical therapist, or other rehabilitation professional goes to your home to assess your needs in a real-life setting. They may look at your ability to access your home, do activities of daily living, your mobility skills, and your need for assistive technologies. They may also identify general safety concerns, like the need for railings, grab bars, ramps, or other changes to your home environment. If it's not something the team can do in person, you might consider virtual options or taking pictures. Either way, talking with your team about the set-up at home will be helpful.

What Do I Need to Know After Going Home?

Transitioning to the Home Environment

Inpatient rehabilitation is a highly structured and supervised environment. Returning home provides desired independence but also increases risk. In the first year following discharge, persons who sustain a TBI are 10 times more likely than those without a TBI to have an injury that requires hospitalization. You may care most about your independence. Often family members will care most about safety. It's important for you and your family to work together, and here are some tips:

- ✓ Commit to keeping a balance between increasing independence in activities and avoiding a setback. No one wants to see you back in the hospital.
- ✓ Following TBI, individuals may not be aware of new impairments and changes in mood or behavior. Trust family members and friends to provide feedback on how you're doing, even if they see changes that you don't.
- ✓ Slowly ease back into your daily activities. Start by doing easier activities that you enjoy first, then tackle harder activities as you recover further. It takes time to regain your strength and stamina.
- ✓ Remember to celebrate daily and weekly gains, no matter how small.

Find Ways to Reduce Stress

Adjusting to life changes after you go home takes time and can be hard. It can feel overwhelming and stressful. But those feelings usually fade as you work through challenges and learn how to best manage your daily routine. Here are some tips for managing stress when you return home:

- ✓ **Limit the number of activities you do each day.** This includes rehabilitation appointments and exercise.
- ✓ **Set limits with visitors.** People often want to visit you after you get home. But they may not know the difficulties you may have after TBI. You may find visitors to be more tiring now than before your TBI.
- ✓ **Set quiet times.** It is usually best to set quiet times during the day as you slowly establish a daily routine.
- ✓ **Keep a journal.** You may find it helpful to keep track of your symptoms and how you are feeling when you feel stress. This might help you find things that often cause stress so you might find ways to avoid those stressors.
- ✓ **Keep a schedule.** You likely had a strict schedule during rehabilitation. That schedule may or may not work for you at home. It is important to create a schedule that works for you and to follow that schedule. This includes setting times for daily activities and for sleep.
  - You might keep track of your schedule using a planner, notebook, or smartphone app. Use what you are most comfortable with. You can use it to remind you to take medications and do daily activities and chores. It can also remind you of birthdays, appointments, and other activities.

Establish Healthy Habits

Having a healthy routine can be challenging. Managing medications, eating well, avoiding alcohol and drugs, and maintaining positive mental health are just a few key aspects of living a healthy lifestyle.

Here's a factsheet to help you understand how TBI can affect your health and tips for staying healthy.

- Read Staying Healthy After TBI: https://msktc.org/tbi/factsheets/staying-healthy-after-tbi

Use Your Support System and Available Resources

If you are a person with TBI or close to someone with a TBI, you are not alone once you leave rehabilitation. You're not expected to have everything figured out as you transition to your new daily routine. It's normal to need help after you get home.

- ✓ **Family and close friends can be a great support system.** They can provide emotional support. They can also provide transportation and/or attend appointments and activities outside of the house. They can help manage social situations or provide reminders and other support for memory or decision-making.
- ✓ **Individual or group peer support.** Your rehab team can arrange for you to talk with others in your area who have had a TBI and learned how to manage day-to-day activities.
- ✓ **988** is the national three-digit phone number for all mental health, substance use, and suicide crises.
- ✓ **Local brain injury organizations.** The Brain Injury Association of America (www.biausa.org) is a great resource that has local chapters in most states. You can call or email to connect with experts at the National Brain Injury Information Center for answers to your questions and help finding local resources.

- ✓ **BrainLine** (www.brainline.org). This provides a sense of community. It is a place where you can go 24 hours a day for information, support, and ideas. BrainLine also offers resources to meet the unique needs of military families. Visit www.brainlinemilitary.org for more information.
- ✓ **State Vocational Rehabilitation Agencies.** These State Supported Employment Services are in all 50 states, the District of Columbia, Puerto Rico, and four Territories. Visit https://rsa.ed.gov/about/states for a complete list.
- ✓ **Statewide independent living councils** (SILCs) (https://acl.gov/programs/centers-independent-living/list-cils-and-spils). SILCs provide resources that help people with disabilities to live independently in their communities.

Note to Those Caring for a Person with TBI

Providing care for someone with TBI can be stressful. Taking care of yourself is just as important as caring for a loved one. It allows you to provide the best care for you and your loved one.

- The available resources above can help you find respite services in your area.
- Family or close friends can also be a great support system. They may help with tasks around the house, or brainstorm to solve problems, or help you to get much needed breaks from caregiving.

Additional Resources

- Read Relationships After Traumatic Brain Injury: https://msktc.org/tbi/factsheets/relationships-after-traumatic-brain-injury
- Read Stress Management for TBI Caregivers: https://msktc.org/tbi/factsheets/stress-management-tbi-caregivers

Authorship

Transitioning Home After Rehabilitation was developed by Phil Klebine, MA; Sean Hollis, PhD; Kelli Talley, PhD, MPH, OTR/L, CBIS; Daniel Klyce, PhD, ABPP; and Thomas Bergquist, PhD, ABPP, in collaboration with the Model Systems Knowledge Translation Center (MSKTC).

Source: The content in this factsheet is based on research and/or professional consensus. This content has been reviewed and approved by experts from the Traumatic Brain Injury Model System (TBIMS) centers, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, as well as experts from the Polytrauma Rehabilitation Centers (PRCs), with funding from the U.S. Department of Veterans Affairs. The content of the factsheet has also been reviewed by individuals with TBI and/or their family members.

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 90DPTB0029, 90DPTB0021, 90DPTB0031, 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.

Recommended citation: Klebine, P., Hollis, S., Talley, K., Klyce, D., & Bergquist, T. (2026). *Transitioning home after rehabilitation*. Model Systems Knowledge Translation Center (MSKTC). https://msktc.org/tbi/factsheets/transitioning-home-after-rehabilitation

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