



*Moving lives forward,
one step, one day & one person at a time.*

A Guide for Families & Caregivers



www.collagerehab.com

Aimed at family members and caregivers, this guide is designed to be a resource that can be used now and again ... a place where information can be found as needed. Our hope is that you find it easy-to-read, practical and truly helpful.

We would like to acknowledge lead contributor to this guide, M.J. Schmidt, MA, a dedicated professional and family member.

Copyright ©2011, ©2016, ©2023 Collage Rehabilitation Partners
All rights reserved. This book, or parts thereof, may not be reproduced in any form without permission.
Exceptions are made for brief excerpts in published reviews.

Published by
Collage Rehabilitation Partners
16 Industrial Boulevard
Paoli, PA 19301

TABLE OF CONTENTS

Introduction	Page 5
Traumatic Brain Injury: The Basics	Page 7
Recovery: What Happens and How to Help	Page 11
Barriers and Strategies	Page 15
Back to Life	Page 30
TBI: The Impact on the Family	Page 36
Other Valuable Stuff	Page 40
An Afterword	Page 44

INTRODUCTION

If you are reading this guide you have unfortunately and unwillingly been thrown into the world of brain injury rehabilitation. As a family member or friend you are looking for answers to your questions, practical information, and clues as to how to prepare for the journey ahead.

The purpose of this guide is to provide some information on the basics of brain injury and its consequences. We've included information about:

- the changes individuals experience,
- available and recommended treatment options,
- suggestions regarding getting back to life, and
- tips for moving forward are included.

This guide is designed to be a resource that can be used now and again, a place where information can be found as needed.

Traumatic Brain Injury: The Basics

What is a Traumatic Brain Injury (TBI)?

A traumatic brain injury is an injury to the brain that comes from the outside. Car accidents, falls, hits to the head (as in sports injuries), and gunshots are some of the most common causes of TBI.

There are two primary types of TBI: Closed Head Injuries and Penetrating (Open) Head Injuries

Closed Head Injuries occur when the brain is damaged without the skull being opened. For example, imagine a woman is in a car accident. She hits the dashboard with her head. The closed head injury occurs as the brain (a jello-like substance) is thrown around in its container (the skull) as a result of the hit and sudden stop.

Damage to the brain is then caused by the tearing and stretching of tissue and cells, bruising, bleeding within the brain, and then from the swelling and build-up of extra fluid. You may hear the term *diffuse axonal injury* to describe this kind of all-over-the-brain damage.

Penetrating (Open) Head Injuries occur when something goes through the skull and enters the brain itself. Knife wounds or gunshots are examples. Most of the damage is to the tissue right around the site of the entry point. This is sometimes called a *focal injury*; however, additional damage to other areas may then result from swelling and bleeding.

There are two other kinds of brain injuries that deserve mention: *anoxic events* and *blast injuries*. Anoxic and hypoxic events often occur as a result of medical accidents and drowning. The resulting brain injury occurs because of the deprivation of oxygen to brain tissue. This is referred to as *hypoxia* (not

enough oxygen) or *anoxia* (no oxygen at all). Damage in these injuries is pervasive and can be seen throughout the brain.

Blast injuries are those injuries that many of the veterans of the Iraq and Afghanistan Wars are returning home with. In a blast injury an explosion occurs which causes a rapid and intense change in air pressure. Sometimes, these explosions propel fragments, vehicles, and even people causing severe injuries. Other times, just the shift in pressure is enough to cause a concussion or brain contusion with lasting results.

Brain injuries are also described by their severity. You may hear the terms: *mild*, *moderate*, or *severe* brain injury. The chart below shows how doctors and therapists come to decide how severe an injury is.

Mild	Moderate	Severe
Little or no loss of consciousness	Coma-more than 30 minutes but less than 24 hours	Coma of more than 1 day
Initial Glasgow Coma Scale of 13-15	Initial Glasgow Coma Scale of 9-12	Initial Glasgow Coma Scale of 3-8
Changes in "mental state"-can be temporary or permanent	Some long-term problems in physical abilities, thinking or behavior	Long-term problems in physical abilities, thinking or behavior
Changes in abilities may impact areas of home, work, and relationships	Changes in abilities impact areas of home, work, and relationships	Changes in abilities impact areas of home, work, and relationships
May be no medical evidence of injury on scans	Visible signs on EEG, CAT, or MRI scans	Visible signs on EEG, CAT, or MRI scans



Why is an injury to the brain so concerning?

The brain controls most of our abilities. It holds our memories, our secrets, our personalities. When it is changed, we are changed. A TBI inevitably will alter a person and the way he or she gets along in the world.

Some of the most common ways people are changed by TBI are in their physical abilities, their thinking or cognitive skills, and in the way they behave or show emotion. It is important to remember that a person is a mix of all of their skills/abilities, experiences, and personality. Any one ability or disability affects others. This is true especially in brain injury. Areas that are changed impact other areas and vice versa. As a result, the outcome of each brain injury is unique and based on the individual, the injury itself, and the *synergistic* (or all-together) impact of the resulting changes.

The table on the following page lists some of the many ways a person may be changed by a brain injury.



Physical	Cognitive	Behavior & Emotion
Balance	Orientation to who one is, the place and the time	Flat or restricted emotions
Fine and Gross Motor Skills	Attention and Concentration	Quickly-changing emotions
Endurance/Fatigue	Memory	Apathy (caring very little about things)
Pain	Information Processing	Exaggerated personality
Range of Motion/Flexibility	Problem-solving and Judgment	Anxiety
Seizure Disorder	Being able to initiate or start things	Denial of problems
Spasticity (stiffness)	Planning and Organization	Depression
Ataxia (shakiness)	Problem-Solving Reasoning and Understanding Abstract Things	Changes in Drives—Hunger, Sex, Temper
Coordination	Flexible Thinking	Impulsivity (acts before thinking)
Quality of Speech (slurring) and Ability to Swallow	Communication Problems (Finding the words, staying on topic, understanding others)	Disinhibition (says/does things that are "inappropriate")
Vision	Slowed Thinking and Response	Changes in Frustration Tolerance
Changes in other senses (taste, smell, hearing, and touch)	Lack of Awareness	Changes in Social Skills
Mobility		Decreased Self-Esteem

Recovery: What Happens and How to Help

Each person's recovery from TBI is different. The greatest amount of spontaneous or natural healing will occur in the first six months after injury. Natural recovery after that point may continue at a slower rate and is considered stabilized at about one year. After that, gains made are usually the result of relearning, adapting, and compensating.

Again, each person's recovery is specific to him or her. However, there are some hallmarks and facts that may be useful in thinking about recovery in general.

Coma--Altered or Loss of Consciousness

Most brain injuries begin with a period of altered or loss of consciousness (coma). Again, the length and depth of a coma is used to predict how severe the problems after the TBI will be. Initially professionals look for eye opening, movement, and even speech in response to stimuli. They measure progress on the Glasgow Coma Scale. With recovery, responses move from being spontaneous and unpredictable to being more meaningful—like nodding, following people with their eyes, or responding to commands.

While in a state of diminished consciousness, individuals need a great deal of care that can include both medical and rehabilitation efforts. Tube feeding/hydration, position changes to avoid bed-sores, physical therapy, sensory stimulation, as well as the care of other injuries that may have occurred at the time of injury (e.g. broken bones, etc.) are to be expected. While most TBI survivors move through this stage to further recover, some

individuals will remain this way for an extended period. This is sometimes referred to as a *vegetative state*. Obviously, individuals who are in this state require a great deal of care as they are unable to do anything for themselves. Many families in this situation are in the difficult position of finding a long-term placement for their loved one.

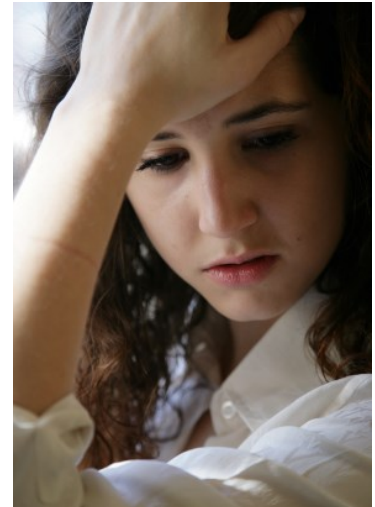
Confusion or Agitation

As individuals emerge from coma, they often experience a period of confusion or agitation. This is thought to be the result of the internal disorganization of the brain due to trauma and information processing and attention difficulties. They will often be confused about what happened, the date—even the year, where they are, and who others are. They can be agitated—even violent. Sometimes they appear paranoid. Many in this state have sleep-wake cycles that are disturbed and irregular. Behavior can be unpredictable and even bizarre. During this time, individuals cannot really learn new information. The main goal is to minimize frustration and disorientation while natural healing occurs.

Needless to say dealing with the challenges at this stage can be daunting for family members. It is important to remember that people with brain injuries very rarely remember anything about this time. Keeping them safe and promoting calm is the real task at hand, and family members may want to consider limiting visits and relying on professional caregivers during this stage.

Some suggestions include:

- Use a calm, quiet voice,



- Speak in short sentences,
- Limit touch,
- Provide frequent (yet simple) information about what happened and where the person is,
- Distract (For example, “I need to leave here now!!!” Response: Want some juice?),
- Discuss events from the past as memory here should be better—and this may be comforting.

Emerging Orientation

After a period of agitation, people start to have a better sense of what has happened to them and what is occurring now. Still, they are often unaware of the things that are changed about them as a result of the injury. As a result, they may be unsafe and require a lot of supervision. They will often have unrealistic goals and not be able to see why people are concerned. Specifically, you may notice poor frustration tolerance, communication problems, and significant difficulty with short-term memory (what happened in the recent day or days). Social behavior can be inappropriate or disinhibited and judgment and problem-solving can be poor.

Acknowledging Difficulties and Learning to Compensate

As individuals continue to heal and gain experience, they also begin to learn ways to improve or get around their problem areas. Most often, this process is facilitated by therapy. This is often a time when individuals are discharged from a facility to home yet still need support to be safe, self-sufficient, and productive. Individuals will begin to realize the extent of their problems yet may believe that their full recovery is still possible and imminent. Problems in thinking, behavior/emotion, and physical skills may persist and natural recovery/improvement tends to slow significantly.

Re-Establishing a Life

Of all of the stages of recovery, this one is the most important and the least explored. Once natural recovery has ceased and individuals are forever changed, the meaning of recovery changes significantly. Now is the time when individuals and their families must look at the realities of what has happened and begin to rethink what life might hold for them. Goals and dreams may need to be altered but shouldn't be ignored. This is a time when rehabilitation can make a real difference by establishing routines in the areas of home, work, and play. It is a time of adjustment and -to some degree- acceptance.



Barriers and Strategies

As mentioned, almost any area of functioning can be impacted by a TBI. Individuals can have physical/medical changes, cognitive, and/or behavioral/emotional changes and all of these changes truly impact who the person is and what he or she is capable of. Almost all people who have a TBI will tell you that they are not the same as they were before their injuries. They now have different strengths and weaknesses, changed outlooks and opportunities, and things that make everyday living a little (or a lot) harder.

In this section, some of the most common *sequelae* (things resulting from) of TBI will be discussed—along with some of the most common *compensatory strategies* (things done to help individuals get around their barriers and improve their level of functioning/independence).

PHYSICAL PROBLEMS

Problem Area: Movement

- Moves more slowly

- Weak, uncoordinated muscles with stiffness on one side or throughout most of the body

- Unsteadiness, loss of balance and disequilibrium

- Has trouble picking up small objects

Movement Strategies

- Allow more time to get places

- Talk to your doctor or physical therapist to see if a walker or cane might help. Some people may even consider using a wheelchair for long distances.

Keep things within easy reach when possible.

Consider meeting with a physical therapist who can help with balance and movement.

Also consider making modifications or using safety tools like tub benches and safety rails to prevent falls.

Problem Area: Vision

Blurriness

Double Vision

Trouble seeing things in some parts of space

Vision Strategies

Do not drive! Let a family member or friend drive until a doctor says you are safe on the road.

Talk to your doctor—perhaps ask to see an ophthalmologist. You may need a new prescription for glasses.

Beware—your old prescription for glasses may not be correct anymore. It may even make your vision worse.

Problem Area: Fatigue and Decreased Endurance

Feeling tired all the time

Sleeping more—could be at night or during the day

Getting tired after very short activities

Strategies for Fatigue

Understand that this is normal after a TBI.

Establish a consistent sleep routine and allow for extra time and rest.
Plan your days and activities to increase little by little as strength and endurance improve
Schedule activities and appointments for times when your loved one is most alert.
Consider what your loved one eats and drinks. Monitor use of caffeine and sugar which don't help to promote a constant stream of energy and can lead to "down" times.
Good nutrition and a regular schedule of meals and snacks can really make a difference.
Talk to your doctor about problems with sleep. Be specific. There may be medications that can help.
Eventually you may want to explore a fitness routine that promotes endurance and well-ness. This is best set up by a physical therapist or other professional and should be cleared by your doctor.

Problem Area: Changes in Senses

Cannot taste or smell food
Complains that everything tastes the same
Has difficulty being touched—overly sensitive to touch or pain
Feeling over-stimulated by things such as noise, crowds, or motion
Changes in ability to hear—cannot hear as well or is overly sensitive to noise

Strategies for Changes in Senses

Try adding more salt or spice to food to see if this is more satisfying.
Have adequate smoke alarms in your home so there is no need to rely on a sense of

smell.

Take your cues from your loved one and limit touch to necessary and pleasurable experiences as tolerated.

Limit exposure to noisy places and over-stimulating environments

Talk to your doctor about problems with hearing. A consult with an audiologist or other expert may be warranted.

Consider an evaluation with a PT or OT to assess sensory overload.

Problem Area: Eating and Swallowing

Chokes on food—has trouble chewing and swallowing without occasional difficulty

Has trouble drinking without choking or coughing

Wants to eat little or nothing

Wants to eat way too much

Strategies for Eating and Swallowing

Talk to your doctor about problems with swallowing. These can be dangerous and result in a true emergency. A consult with a speech therapist or other expert may be warranted. They may be able to provide safe guidelines and training for you and your loved one.

Explore different food choices as changes in appetite can be related to changes in taste.

Help your loved one keep a list of what he or she has eaten. Sometimes an increase in eating is related to a memory problem. Also explore the possibility that the eating is related to boredom or a lack of other pleasurable activities.

Strategies for Eating and Swallowing

Talk to your doctor about a loss of appetite. It may be a sign of other issues (like depression) that need to be addressed.

Explore different food choices as changes in appetite can be related to changes in taste.

Help your loved one keep a list of what he or she has eaten. Sometimes an increase in eating is related to a memory problem. Also explore the possibility that the eating is related to boredom or a lack of other pleasurable activities.

PHYSICAL PROBLEMS

Problem Area: Attention and Concentration

Has trouble keeping their mind on one thing—can't ignore things around them
Easily distracted by noises or other things which are not relevant to the task at hand

Has trouble completing a routine without getting lost—like starts cleaning the bathroom when supposed to be brushing teeth

Cannot do more than one thing at a time

Cannot focus on a concentrated task like reading or studying

Strategies for Attention and Concentration

Provide environments with limited distractions when possible—declutter spaces, keep things in the same places, choose quiet restaurants/movie times, etc.

Set up space that only includes things needed for the task at hand when possible—when cooking, only take out those things needed.

When giving important information or directions, turn off unnecessary distractions (TV, radio) and let your loved one know that it is an important direction. Ask if they are ready to receive it.

Checklists can help with routines and can be posted if this is agreeable.

Start critical activities (especially academic ones like reading) only when truly ready (not hungry, needing the bathroom, etc.) Limit expectations about the length of time your loved one can concentrate and allow for regular breaks.

Problem Area: Memory

Forgets appointments and critical events

Has trouble taking medication on required schedule

Frequently misplaces important items

Takes longer to learn new information

Repeats same story/information over and over

Strategies for Memory

Use a planner/calendar system which includes important dates and things to do.

Consider sections for other relevant information like phone numbers, addresses, and transportation routes/directions. encourage and assist use on a daily basis.

Write stuff down. Doctor's appointments—Encourage your loved one to make a note in their planner about the important info (or ask the doctor to do so for you). School—take notes or borrow/copy others. Keep these notes where they belong—the planner,

your notebook, etc.

Buy a medication box with labels for day/time. Fill with medications as prescribed and encourage your loved one to use it. Sometimes a cue in the planner or on a beeping watch/cell phone can help to remind individuals of dose times. Also, consider talking to your doctor about the medication schedule to explore if it can be simplified.

Keep household items in specific places—like keys on a hook by the door, therapy papers in an in-bin, wallet and phone on a table in the entryway.

Allow extra time for learning new things. Some approaches that help include repetition (you repeat the information often), writing things down (you can do this for-or have your loved one do it), using checklists and written directions, and review of the calendar/planner.

Encourage a daily routine. Anyone who has no rhythm to their life is more likely to forget things. Try to establish a routine whether it includes volunteer work or therapy, meals, exercise, support meetings, etc. Having a structure on which to hang memories and other details is very helpful.

Consider a personal signal to use when your loved one is repeating him/herself. Be sure to allow them to use it on you too!

Problem Area: Planning and Organization

Has trouble getting ready for daily appointments (therapy, work, school). Often does not have what he/she needs

Has trouble completing steps in the right order

Has difficulty organizing their time and getting things done

Has difficulty organizing their space and keeping things in order Has trouble setting goals, planning the steps to reach the goal, and completing them

Strategies for Planning and Organization

Again, help your loved one develop or use a planner/calendar system which includes important dates and things to do. Consider sections for other relevant information like phone numbers, addresses, and transportation routes/directions. Encourage and assist use on a daily basis.

Consider checklists and routines. Depending on need, checklists can break daily routines into steps and serve as an actual place to check things off or can be “templates” for regularly occurring events such as making the grocery list

Declutter spaces and have static places for things. Consider labeling spaces for easy retrieval of items. Truly consider getting rid of unnecessary items, less is really better!

Allow extra time to prepare for activities. Consider gathering needed items and packing the day before.

Identify goals and break down the steps. Record this information in the planner and review as appropriate. If appropriate, consider this activity at work or school.

Problem Area: Problem-Solving

Makes quick decisions without properly considering possible outcomes

Gets stuck on one idea and becomes unable to consider other ideas

Is unable to decide between choices

Tries to solve problems in ways that don't make sense

Can only see things in very concrete ways

Strategies for Problem-Solving

Strategies for Problem-Solving

- Talk to your loved one about your concerns about his/her ability to solve problems and make decisions. Encourage them to ask for you or a trusted friend for assistance.
- Help your loved one break down a problem into manageable pieces. Help them to generate possible solutions and their possible outcomes. Evaluate the choices together and choose one to try. Feel free to do this on paper.
- When describing options/solutions, be specific and precise in your language. Avoid abstract ways of describing things like analogies and metaphors
- Encourage your loved one to ask others for a “day or two” before making big decisions, allowing them time to seek assistance or think it over thoroughly.
- If your loved one is making choices/solving problems in a way that is truly dangerous (like giving money away recklessly or stopping medicines on their own), consider how much supervision they are receiving and whether or not they need oversight for some responsibilities or even a legal caretaker/guardian.

Problem Area: Language and Communication

- Cannot find the right words to say what they want
- Talks around a subject, never really getting to the point
- Doesn't fully understand what others are saying
- Has difficulty keeping up with a conversation, especially when there are a few participants or has difficulty starting a conversation
- Speaks about overly personal or embarrassing topics

Strategies for Communication

- Allow more time to express ideas. Encourage the use of gestures or signals if it helps.
- Develop a signal to let your loved one know he/she has gotten off topic or consider a phrase such as “We were talking about ...”
- Check in with your loved one during a conversation to make sure he/she knows what has been said. Recap if possible. Encourage your loved one to ask for clarification as needed. Let him or her know that we all do this in one way or another.
- Try to have only one person speak at a time.
- Praise your loved one for starting conversations. Offer them some starter lines (like “So, how have you been?”) or consider practicing other “scripts” to help.
- Gently discuss good topics and review those that make others uncomfortable. Encourage your loved one to observe how others respond to them—they might even ask others if this is an ok subject.
- Be direct in your communication and be clear. Don’t overburden someone with too many words

Problem Area: Slowed Thinking

- Takes longer to answer questions or respond as expected
 - Takes a long time to react to things, even physical emergencies or danger
 - Takes longer to understand things he or she would have easily understood before
- does help.
- Assess the situations your loved one engages in for safety concerns. If his/her reaction time is poor, driving or even crossing streets may be dangerous. Consider alterna-

Strategies for Slowed Thinking

Allow more time -to answer questions, to read/learn new things. Over time, some speed may return. Practice does help.

Assess the situation for safety concerns. If reaction time is poor, driving or even crossing streets may be dangerous. Consider alternatives—and seek advice from your doctor or a professional.

Review emergency procedures and post them in an obvious place.

BEHAVIORAL & EMOTIONAL PROBLEMS

Problem Area: Doing Nothing and Not Caring

Can do nothing for long periods of time

Fewer interests than before

Knows what needs to be done but cannot seem to start

Shows little to no emotions (flat)

Strategies for Doing Nothing and Not Caring

Accept that this is not laziness but the result of the injury

Develop a daily routine or activity pattern to stimulate doing things and develop that habit.

Offer a choice of 2 to 3 things to do when your loved one says he or she wants to do nothing

Use checklists to get through an activity or daily routine.

Reward activity and independence.

Allow adequate downtime and rest. This is important in recovery.

Ask your loved one how he/she feels. Tell them it is hard to tell when they are expressionless. Encourage expression of feelings either in words or by looks.

Problem Area: Unpredictable Emotions, Poor Frustration Tolerance, and Exaggerated Personality

Seems like they can be laughing one minute and then crying the next

Emotions may seem wrong for the situation—like laughing when someone gets hurt

Becomes angry or frustrated more easily than before—and over smaller issues

Seems “bigger than life”—may talk more loudly, tell too many personal details to others, and/or makes embarrassing or inappropriate comments

Strategies for Unpredictable Emotions, Poor Frustration Tolerance, and Exaggerated Personality

This is not their fault—it is injury-related

Try not to pay too much attention to over-emotionality. If possible, remove the trigger and change the subject.

Ignore things like yelling and using fowl language. Paying too much attention can increase these behaviors.

Set some rules for communication—let your loved one know what is not acceptable within your family. Encourage them to express their frustration in an acceptable manner and show your appreciation when they do.

Don't argue.

Problems tend to occur more often with stress. Limit stress when possible.

Consider discussing these problems with your doctor. There are times when medication or other interventions may truly help.

Problem Area: Denial of Problems

Seems unable to recognize that things are different, that they are changed.

Insists they can do things as well as before the injury—and wants to do things that they clearly cannot do.

Blames others for their problems and complains that doctors and professionals “don't know what they are talking about.”

Strategies for Denial of Problems

Your loved one is not ignoring their problems on purpose. Sometimes the brain injury makes it impossible for them to recognize these changes. Other times denial is a way of handling the pain of having lost so much.

Be honest about problems you see-- but in a kind and supportive way.

When it is safe to do so, let your loved one make mistakes on their own. Afterwards, review what happened and offer solutions for the next time.

Model admitting mistakes in a calm, easy-going, way.

Encourage your loved one to learn about brain injury—through reading, support groups, therapy, etc.

Problem Area: Depression and Anxiety

Seems sad a lot of the time and keeps to him or herself.

Has lost interest in things he/she once enjoyed
Changes in sleep, appetite or energy level
Says things like, "It would have been better if I had died in the accident."
Is nervous and worried a lot of the time. May pace, fidget, or even complain of a racing heartbeat or feelings of panic.

Strategies for Depression and Anxiety

- Understand that being sad about all that has happened is normal -it can be part of recognizing one's problems and moving forward.
- Show your support, acknowledge feelings and let them know that you recognize all of the changes as well.
- Get your loved one involved in activities he or she enjoys. A regular activity pattern is helpful as is exercise.
- Be honest about your concerns—offer your observations in a kind and supportive way.
- Encourage your loved one to learn about brain injury—through reading, support groups, therapy, etc.
- Talk the doctor about depression and anxiety. There are medications that might be appropriate. Also, a psychologist (with brain injury experience) may be able to help.

Problem Area: Impulsivity and Disinhibition

Says or does whatever comes to mind, often without thinking first

Does not consider the consequences of his or her actions—even dangerous things like walking into a street without first checking for cars

Makes embarrassing (often sexual) comments or gestures in public

Asks personal questions of others or offers too much personal information about him or herself.

Strategies for Impulsivity and Disinhibition

Stop your loved one when he or she is acting without thinking—explain the consequences of the action. Be sure, however, to be calm and discrete.

Consider developing a signal to use for times when he or she is acting impulsively or behaving in an embarrassing way.

Remove items that may be too dangerous for your loved one's level of impulsivity. Things like car keys, guns, alcohol or other dangerous items may best be removed from the house or his or her access.

Limit activities to those where you expect to have the most success. Consider audience, things to do, and your ability to stop impulsive acts or curb comments, etc.

Back to Life

GOING HOME

Going home-- it's the day that you have been dreaming of; what you have all been waiting for. Somehow, though, when the day comes it is often filled with anxiety and questions. Will my loved one be safe? Can our family give them what they need? What will happen next?

At one time, going home was the goal, the end, the "back to our old lives." When it happens, though, it is never quite that. It is a step on a journey that will be long. For many, getting "back to old lives" is just not possible. Instead, going home may be the first step in acknowledging the changes resulting from the TBI and adjusting everyone's expectations and goals.

In the first months after discharge from hospital, families can expect their loved ones to be more tired. Generally, there may only be 3 or 4 hours per day of "good" or "on" time. This is normal. To help, families can:

- Schedule important activities for these "good times;"
- Incorporate plenty of time for naps or downtime; and
- Limit activities until endurance increases.



Similarly, families often want to plan “welcome home parties” and family events at this time. Remember, evenings may be hard, and, again, time limits are often best. Consider:

- Limiting parties/visits to one hour or so; and
- Limiting the number of visitors at one time.

Another challenge of going home can be finding new roles that work for everyone. You may find yourself doting on your loved one, talking down to them or treating them with pity. They may seem to be a different person

altogether. Topics of conversation may be focused on therapy or medical things—and not encompass things you both are interested in, love, or used to enjoy together. Crafting new family relationships can be hard, but it may be helpful to remember how things used to be, to try old interests (perhaps in a new way), and to- as much as possible- treat your loved one as you always did.

Safety at home can be another consideration. When possible, make sure the rehabilitation hospital staff check out your home for any physical considerations and other recommendations for safety. In addition to looking at steps and bathrooms, they should consider things like:

- Will your loved one have too much access to dangerous items?
- Is furniture arranged in a way that best promotes independence and mobility?
- Are there area rugs or other tripping hazards?
- Will your loved one be able to access and use technology like the phone, remote control, computer?
- Would posting any reminder signs (like emergency info or checklists) be helpful?
- Would an alarm be helpful?

BACK TO WORK

Like going home, returning to work can be a big target in the rehabilitation process. It can also be a real challenge. For some individuals, going back to their job will be obviously unrealistic. For others, it may be a consideration. Either way, figuring out a meaningful way to spend time—through work, volunteering, or even school—is a critical part of recovery after a TBI.

If your loved one is considering going back to his or her job, you should talk to their rehabilitation team about planning for this. The team should be able to plan ahead for this by learning about the job and its demands, evaluating your loved one's ability to do all parts of the job, and making recommendations about a return-to-work schedule and any strategies or supports necessary. They might also recommend additional help from the vocational rehabilitation agency in your county or a conference with your loved one's employer.

If returning to a past job is not possible, your loved one may need to look at his or her life and begin thinking about how to spend time. Once formal rehabilitation services are over, it is important to identify an "activity pattern" that will keep your loved one engaged in the world. Most individuals want and need to be productive. Work (volunteer or paid) is one of the best ways to achieve this as well as maintain a social connection with others. Work is a way for individuals to continue to build skills and endurance, meet people, and feel independent.



Again, your state vocational agency and rehabilitation team can help with this.

BACK TO SCHOOL

Getting back to school is another hallmark for many people with TBI. For children and adolescents, it will be a way to get back into life and continue to rehabilitate. In fact, schools provide the greatest amount of rehabilitation to individuals with TBI under the age of 21.



Discharging rehabilitation teams and schools should work closely together to make sure the student's educational plan is well-suited to his or her abilities and needs. School-aged children with TBI are eligible for special accommodations and instruction in school. It is very important for families to realize that the school can and must provide services based on the unique needs of your child.

Returning to school can also be challenging for individuals in college or who are considering further education after their TBI. A number of the problems associated with brain injury make this so. Problems with thinking and memory make new learning particularly difficult. Fatigue and quick "overloading" may make a full schedule and the demands of a post-secondary school program difficult. There can also be considerations with regard to problems with behavior and social skills.

Colleges and other post-secondary schools are not obligated to offer special services, without cost, in the ways that public schools (to grade 12) are. There are some accommodations, however, that a post-secondary student can access through Section 504 of the Rehabilitation Act. These accommodations include things like untimed tests, tape-recorded textbooks, and preferential seating. Regardless, the deci-

sion to pursue post-secondary education after a TBI is one that should be made with input from your loved one, rehabilitation professionals, and when possible the school itself.

RELATIONSHIPS

So much changes after a TBI that it is inevitable that relationships will change too. Family roles shift as care-givers become care-receivers, bread-winners no longer work, personalities change, and family needs change altogether. There is no model that can predict the changes that will happen in your family, but it is safe to say that *your relationship with your loved one will change*. It may never be the same as it once was; however, over time, many families do find a new way of relating that works for them and brings them satisfaction.

Other changes in family relationships often have to do with communication. In the time right after the injury family members have probably spoken of little more than the injured person and all of the details of his or her recovery. People may not know what is going on in each others' lives, let alone how other members of the family are feeling. Some may feel it is not okay to talk about these feelings and others will find a way to be understood. There are some ways that may be useful to improve communication:

- Set aside times for family members to share what is going on in their lives (dinner once a week).

- Make sure everyone knows it is okay to talk about what has happened and how they feel—even if those feelings are negative;

- Explore new ways to communicate like journaling



You may also find that your family seems less affectionate. This is related to communication and can often be helped in the same ways. It can also have to do with the problems that your loved one is having. Feeling less affectionate towards each other is not uncommon. It does not mean you love each other less. Sometimes, working with a psychologist or other rehab professional can help in this area.

Friendships are another kind of relationship worthy of mention. Immediately after the injury, friends often abound. They visit, send cards, and inquire about their friend. Over time, though, many of these friendships fade away. In fact, some even call this the 90% rule—over a one to two year period, people with TBI will lose about 90% of their friends. Friends often cannot deal with the changes they see and are not sure how to continue their relationship with your loved one. Understandably, this is hard on everyone. There are some things you can do to make a difference:

- Include/invite friends in small, short activities—ones where you anticipate success.

- Offer some TBI education to friends—they may not understand what is going on.

- Explore how they are feeling and share your feelings too.

- Acknowledge with them that their relationship may be different but can still continue—and let them know that it is important to you and your loved one.

- Accept and encourage new friendships—remember people just meeting your loved one don't have an "old friend" to compare him or her to.

TBI: Impact on the Family

HOW IT IMPACTS

Life after a brain injury is changed forever—for the survivor and for his or her family. Know that this is normal—and that over time, most families find a new balance and some predictability. However, you may feel stuck,

overwhelmed, unable to see a “way out.” Other common feelings include:

- Sadness

- Anxiety and Nervousness

- Anger

- Frustration

- Guilt

- Exhaustion

Some of the common changes in lifestyle that you might expect include:

- Less time for yourself

- Financial challenges

- Problems with communication

- Role changes

- Lack of understanding and support among friends and other family members

COPING WITH STRESS

After a brain injury, families often find their lives turned upside down and completely focused on the person with TBI. Families try to make sure their loved one has everything he or she needs. They also have to continue the critical components of their own lives—like work and household responsibilities. This leaves little if any time for attending to personal needs. Unfortunately, this is a recipe for disaster.

Recovery from TBI is a long journey. It requires family members to be there over the long-run. Burn-out, or exhaustion, comes when family members do *everything* for or with their loved one to the exclusion of rest and personal rejuvenation. Burn-out often leaves family members so overwhelmed and exhausted that they are

unable to be helpful. For this reason, it is recommended that family members arrange support early in the game. Family members have reported the following as those strategies they found most helpful:

- Accepting help from friends and other loved ones
- Seeking out and attending a family support group
- Taking breaks from the hospital or rehabilitation setting
- Finding someone to share your feelings and concerns with on a regular basis
- Maintaining a sense of humor
- Being more assertive
- Trying to see things realistically
- Being careful not to blame everything on the injury
- Learning to relax

Relaxation deserves special mention, yet this advice is rarely heeded. Since the injury, you have probably been under a great deal of stress. A little stress is natural-and can even be good for us. However, too much stress over an extended period of time can wreak havoc on your body and mind. Stress has been linked to heart disease, cancer, stroke, headaches, and other medical problems. It can also cause your performance in other areas to suffer. You may find you are less organized or unable to concentrate and think clearly. Your temper may flare up easily, you may be less patient, and you may even find yourself lashing out at others. For this reason, stress often has a negative effect on your relationships.

Learning to relax, especially during a time of high stress, is not easy. Some tried-and-true techniques to try include:

Muscle tensing and relaxing

Lie down in a comfortable place with your eyes closed.

Tense one of your feet as you breathe in.

Release as you breathe out.

Continue with your other foot and then other areas of your body.

Focused breathing

Lie down on your back in a comfortable place.

Put your hands just below your belly button.

Close your eyes and breathe in, forcing the air into your belly.

Exhale slowly and imagine the stress leaving your body.

Visual Imagery

Lie down on your back in a comfortable place.

Imagine yourself in a place where you usually feel relaxed. Perhaps the beach or the mountains.

Imagine the sights, smells, and sounds—relax.

Use a word to help you focus

Choose a word or short phrase that has a positive meaning for you. (An example might be "Peace.")

Take full deep breaths from your diaphragm.

Say the focus word each time you breathe out.

Other Valuable Stuff

A MEANINGFUL LIFE

It is almost too hard to think about all that a person loses after a TBI. From not being able to play a certain sport or drive or get a date or even remember yesterday, the losses are sometimes too many to count. And in rehab, the focus is often on little parts of a person—how he or she steps, a calendar system, a checklist for hygiene—often without a genuine acknowledgement of the real concerns and big goals.

One of ReMed's founders, Dr. David Strauss, believed that looking at the whole person and his or her real life was of the utmost importance. He believed that each person's life was his or hers to live and that each person had a different vision of "happiness" and "quality of life."

People with traumatic brain injuries have fewer options for work and play. They are often alone, depressed, and more likely to turn to drugs and alcohol. Yet most rehabilitation programs work from a perspective of treating individual problem areas without considering a person's ability to define what makes them happy. Rehabilitation programs need to do a better job of asking people with TBI what they want. No one wants rehab for the sake of rehab. They want to regain meaningful relationships, go back to work, and enjoy activities that make them feel good.

The first step in therapy should be helping a person to develop his or her own definition of "quality of life." The answers to "What is important to you?" and "What makes you happy?" are cornerstones for good therapy. They are more important than any data, treatment plan or model.

Remember this: The goal of every life is to have meaning—not for the rehabilitation program, but for the person.

INTERACTION TIPS

Sometimes getting along with your loved one is harder than you could ever imagine. David Strauss, one of ReMed's founders, insisted that staff learn ways to interact with those they serve that were real, respectful, and positive. Here are some of his tips to people working in the field. They are easily applicable to family members and friends:

- The first thing to do in a stressful situation is nothing.

- Listen to what you say and how you say it. Are you supportive? Punitive or Critical?

- Remind folks that you are there to help.

- Give criticism or feedback privately. It's a matter of respect.

- Be aware of your non-verbals. What signals are you sending?

- Always say what you will do before you do it.

- Ask permission before you ask a question or disagree.

- Don't expect immediate change.

DEALING WITH DOCTORS

Your relationship with your loved one's doctors will absolutely affect the kind of care you receive. Working with a doctor who is experienced in TBI will make your life easier and your loved one's treatment more efficient and effective. Having a great doctor, though, is not enough. It is important for you and your loved one to be good reporters, communicators and evaluators.

Here are some tips for making the most of your relationship with your doctor:

- ◆ Prepare for your appointment. Bring a complete list of your concerns and observations. Be specific when possible, especially about how severe problems are and how often they occur.
- ◆ Take medication as prescribed!!! If there is trouble tolerating a medication, call your doctor. Do not stop a drug without consulting him or her. Stopping a medication cold can cause medical problems and it may change the kinds of medicines a physician is willing to prescribe. If your doctor does not think you will follow through with his or her recommendations, he or she may be less willing to try new things.
- ◆ Be sure to report progress, too. Your doctor absolutely wants to hear about what is going well.
- ◆ Make sure that each doctor knows about any other treating physicians, any other medications that have been prescribed (or discontinued). It is helpful to sign releases in each doctor's office so that the doctors can talk to one another and get each other's paperwork.

RECORD-KEEPING

What do you need to keep track of? What is the best way to do that?

Many family members have found that it is very helpful to start a formal record-keeping system to track all of the important papers and information they receive about their loved one. What will work best for you is a matter of preference. Some suggestions include:

- ◆ Get a portable file carrier. Keep several folders in it for things you may need to take with you. Folder titles might include: Rehabilitation Reports, a Folder for each Doctor, Bills, Disability Claims, TBI Information, and Contact Information. Carry this with you to important appointments so you don't have to search for just the right document.
- ◆ Keep notes on your contacts with social workers, case managers, employers/school contacts, and the like. Sometimes short notes on your calendar will do. This is a way to track promises made and the need for follow-up.
- ◆ Ask for a copy of prescriptions, recommendations, and important meeting minutes on the spot! This will help you track what you need to do.



An Afterword ...

The rehabilitation process can be a difficult journey for both the person who has experienced a brain injury and their family. In the days following, the focus in the hospital setting is generally on medical issues and in many cases, survival. As your loved one becomes medically stable the rehabilitation process begins. Your family member will likely be moved to the acute rehab unit in the hospital, and a multitude of therapies will begin. This can be a time of deep frustration and loss for your family member as they become aware of all the skills they have lost as a result of this injury. As a family member you may also experience a feelings of loss and that this is not the same person. After a few weeks of inpatient rehab, the doctors and therapists will begin to talk to you about the next steps in the rehabilitation process; post-acute rehabilitation. That's where we at Collage will become a part of your journey.

At Collage, there are many access points for continued recovery. In some cases, your family member may need to live in one of our residential settings in order to receive the continued medical care and supervision they need. For others the post hospital journey may start in their own home with our home and community program or in one of our outpatient settings. Regardless of where your loved one enters our system, it's our goal to move their recovery forward and help them regain their life and for you as a family to find your new normal.

This guide is intended to help you understand and support your family member. It's also important that you care for yourself during this process. I experienced this first-hand last year when my mother experienced a brain bleed. In the early days the fear and anxiety were overwhelming as we waited to see what

damage the bleed had caused and even if my mother would survive. We were incredibly fortunate that my mom became stable within about a week. She was confused, had word finding issues, very poor balance and lost a significant portion of her eye sight. After a short period of rehabilitation in the hospital we were able to take her home and have her receive her rehab services in our home. I was very relieved, but this part of the journey was very difficult for my highly independent mother. She struggled with depression as it became apparent to her that she needed assistance with the most basic tasks and could no longer engage in her favorite hobby, reading. She received therapy for many months and over time regained her skills, but her eye-sight did not improve. Through vision therapy she learned to make accommodations for her vision loss and is now fully functional in her home, however she can no longer drive.

I share this personal story with you to let you know that we understand what you are going through as a family member. Brain injury affects the entire family. It's our goal to help you, as well as your loved one through this process. We hope this family guide will give you some basic information about what to expect during recovery and some guidance on how you interact with your loved one when challenging situations arise.

Shannon Swick, MA, LLP
Chief Executive Officer
Collage Rehabilitation Partners



1-800-847-3633
www.collagerehab.com