

# ***S.A.I.L.***

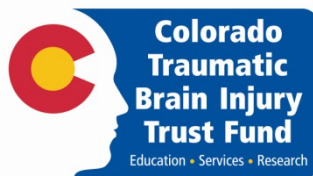
## **Self-Advocacy for Independent Life**

*Empowering people with brain injuries and their families  
with the skills of self-advocacy*

A Project of the Brain Injury Alliance of Colorado

*Edited by  
Lenore A. Hawley, LCSW, CBIST*

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Brain Injury Alliance of Colorado

This workbook is dedicated to

*Jan Nice, LCSW*

For her contributions and leadership



## ACKNOWLEDGEMENTS

*SAIL was conceived by a committee of the Brain Injury Alliance of Colorado in 1990. Committee members included **Pat Breese, Catherine Graca, Karen Hildebrand, Susie Hyde, Jane Letsinger, Jan Nice, George Richardson, and Alan Welch**. The goal of this committee was to empower people with brain injuries and their families with self-advocacy skills, knowledge, and beliefs. A workbook was published, self-advocacy workshops were held, and three peer advocates were hired. The project was funded through support from the **Rocky Mountain Regional Brain Injury Center, the Colorado Developmental Disabilities Planning Council and the Colorado Department of Health**.*

*In 2007, BIAC board member **Franny Mazone** suggested updating the SAIL program and workbook. The **Colorado Traumatic Brain Injury Trust Fund Program** provided funding for that project. The 2007 SAIL Committee members included: **Christy Dittmar, Kathryn Rohan Hague, Ann Levis, Joe Lewis, Karen McAvoy, Eileen McLaughlin, Elizabeth Meschievitz, Jennifer Olson– Madden, Theodora Pappas, and Diane Vigoda**. (Elizabeth Meschievitz, Ann Levis, Eileen McLaughlin, and Jennifer Olson-Madden also provided many hours of time in helping to edit and format the workbook). In 2014 the workbook was once again updated. **Megan Vance** contributed many hours of her time, energy and insight to the 2014 revisions. This latest edition would not be possible without her.*

*We appreciate the efforts of the many individuals who have authored and updated the chapters in this workbook. The SAIL project is a collaborative effort involving individuals with brain injury, family members who advocate with them, and professionals who serve them, all working together. Thank you to everyone who has contributed to this project over the years.*

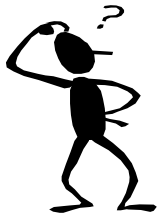
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*We would also like to acknowledge the authors who contributed to the original workbook, whose work does not appear in later editions: Sue Barker, Pat Carman, Randy Chapman, Nita Cherry, Karen Chilson, Janet Fox, Barbara Handler, Billy Jones, Helen Kellog, Sue Kirton, Joan Krim, Kathy Leonard, Kay Potter, Barbara Ramsour, Becky Saver, Giles Schofield, Bryan Thurston, Mark Voth, Alan Welch.*

## INTRODUCTION



### ***What is the SAIL Workbook all about?***

This workbook is about self-advocacy after acquired brain injury (ABI). Self-advocacy involves:

- ✓ **knowing what your needs are,**
- ✓ **knowing what resources are out there to help you meet your needs, and**
- ✓ **having the beliefs and skills to get your needs met.**

Sometimes the injured person may advocate for himself; sometimes the person and a family member may advocate together as a team; and sometimes a family member is an advocate for the injured person. This workbook was *developed for both individuals with brain injury and other people who advocate for and with them*. When we use the term “self-advocate” we are referring to both types of advocates.

The Self-Advocacy for Independent Life (SAIL) program was developed to provide a roadmap for people with brain injuries and their families as they navigate the sometimes bumpy path of life after brain injury. The SAIL program includes **this workbook and a series of SAIL workshops**. The chapters in the workbook are written by people with brain injuries, family members, and brain injury rehabilitation professionals.

*We hope this book will:*

- **give you information about successful self-advocacy.** Section 1 is aimed at answering the question: What is self-advocacy and how is it done?
- **help you know you are not alone.** In Section 2, you can read about the experiences of other people whose lives have been affected by

brain injury. These individuals have been down the same road and are willing to share some of the things they've learned along the way.

- **provide you with information about brain injury and the skills of self-advocacy.** We think it can be helpful to gather information about brain injury as you prepare to advocate for yourself. This knowledge will help you ask the right questions, and look for the right resources. Section 3 provides this kind of information.
- **give you information and resources to enable you to get your needs met and be a successful advocate.** After a brain injury, you may find that you need things in your life that you never needed before. For example, you may find that you need help with transportation, or need legal assistance. You can find this information in Section 4.

The format used for this workbook was recommended by people with brain injuries. The pages have open space for notes and for easier reading. There is also a **Self-Advocacy Information Sheet** at the very end of the book (page 459). You can make copies of this sheet and keep an updated form with you as you advocate for yourself. There are blank pages in the back of the book for additional notes. This workbook may also be accessed through the internet at the BIAC website [www.biacolorado.org](http://www.biacolorado.org).

We hope that you and your family will use this workbook as a resource as you advocate for your needs after brain injury. Please share it with other people on your advocacy “team”. These may include members of your family, friends, or professionals such as a case manager. We wish you and your team the greatest success!

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## **Self-Advocacy after Brain Injury: A Roadmap**



## **SELF-ADVOCACY AFTER BRAIN INJURY**

Lenore A. Hawley

Lenore A. Hawley, LCSW, CBIST, has worked in brain injury rehabilitation since 1978 providing clinical services, advocacy, and clinical research.

Self-advocacy involves **knowing what your needs are, knowing what resources are available to help you meet your needs, and having the beliefs and skills to get your needs met.** We advocate for ourselves by gathering information and resources, negotiating for resources, and letting others know what we have to offer as workers, citizens and friends. Our need to self-advocate increases dramatically when we face problems in our lives and need to seek special assistance and services.

Although we may need to advocate for ourselves at different times in our daily lives, most of us are not prepared for the job of self-advocacy following brain injury. In fact, many people are not familiar with the term acquired brain injury until it becomes part of their own life. The injured person and his/her family are suddenly expected to navigate through a catastrophic event which involves a new vocabulary, piles of reports and test results, legal and ethical dilemmas, and a number of potential disabilities -- many of which are difficult to see or measure.

When a person sustains a brain injury and faces long-term changes in life, he may find it difficult to self-advocate for at least a period of time. This may be because the person is unable to communicate, remember, or make decisions. However, it also may be because other people look at the person as disabled and assume the person cannot self-advocate.

Other people may initially take on the role of advocate for the injured person. The

## NOTES

Self-advocacy involves:

- *Knowing what your needs are*
- *Knowing what resources are available to help you meet your needs*
- *Having the beliefs and skills to get your needs met*

hospital discharge planner, the physician, or a case manager may become involved in this role. Advocacy agencies such as the state chapter of the Brain Injury Association may join in. However, as good as their intentions may be, the job of advocacy eventually falls back squarely upon the shoulders of the injured person and his/her family and friends.

Here are a few examples of things you may do as a successful self-advocate:

- Make a list of questions for your doctor and bring them to your appointment,
- Take a class on social security benefits so that you know what your rights are,
- Ask assertive questions during a meeting with your attorney,
- Write an email to your case manager to summarize what was discussed in a meeting.

You take on the job of self-advocate at a time when you may be least able to do so. You have experienced an unanticipated event which has drained your family of energy and has strained emotions. The non-injured members of the family -- particularly children -- may not be getting the attention they need. If you are the spouse of an injured person, the person you leaned on in times of need and who helped you make decisions, may be less able to help. Friends may back away because they do not understand the new

## NOTES

behaviors or the appearance of your loved one. If you are the injured person, your body and your brain may make it difficult to accomplish daily tasks, let alone make life decisions or advocate for your needs. This book, and the workshops that go with it, do not hold all the answers. However, you no longer need to seek your way alone, without benefit of the experiences of others. We can learn a great deal from other brain injury self-advocates, as well as from self-advocates living with other types of disabilities. You will advocate for yourself in your own style, utilizing tools and techniques that feel most comfortable to you. There is no one right way. However, there are some road maps to help you along the way.

## **THE PRINCIPLES OF BRAIN INJURY SELF-ADVOCACY**

### **1. TAKE CARE OF YOURSELF**

When a brain injury occurs in a family, it may seem that other matters need to be pushed into a back corner to be dealt with at a later time. Unfortunately, it may be difficult to figure out when that “later” time has come. The effects of brain injury may impact your family for the rest of your lives.

The injury may initially put your life into high gear. You might not be able to sleep or eat, and might find that you cannot do enough to immerse yourself in the rehabilitation process. The kid's activities go unattended, you can't get to the grocery store, bills pile up, you miss weeks of work and it may

### **NOTES**

There are 4 core principles to keep in mind as you advocate for yourself and your family:

- **TAKE CARE OF YOURSELF**
- **GATHER INFORMATION - KNOWLEDGE EMPOWERS**
- **ORGANIZE AND PREPARE**
- **COMMUNICATE & NEGOTIATE ASSERTIVELY**

seem that you will never be able to catch up. As time passes, the demands continue as the bills increase, decisions need to be made, and the reality of the long term effects of the injury settles in. At a time when you need the most energy and resources that you have ever needed in your life, you may find yourself physically and emotionally depleted.

If you are going to succeed in your new job as advocate, you must first take care of yourself.

If you are the person with the brain injury, there may be people around you who are encouraging you to take care of yourself. If you are a family member, you may be missing out on this encouragement from others since the focus is on the injured person.

If you are the family member, remember: you will not be able to advocate for your injured love one if you do not take care of your own physical and emotional needs. The job of advocate requires energy, endurance and emotional well-being.

#### **\* Physical Health**

Take care of yourself physically, so that you have the energy to do this job. Take care of any medical needs as they arise. Try to get adequate sleep and to eat nutritiously. Get some exercise. Exercise will help you feel more energetic, will give you an emotional boost, and will help keep you healthy. It is not a luxury - it is part of your job!

## NOTES

### \* Emotional Health

You have the right to feel overwhelmed, sad, angry, or stressed after a brain injury. However, you also have the right to take the time to do something to feel better. Taking care of your emotional health will help you be a better self-advocate. There are several things you can do. Make time during the week for activities that you find enjoyable and stress relieving. This is not a luxury, it is a necessity. Dig in the garden, spend time with a friend, read a novel, or take a walk. Discover what works best for you. If you find that your emotional symptoms are persistent, it may be a good idea to seek professional help. A mental health therapist can help you assess what is going on and develop a plan of treatment.

Your emotional health is important not only because you need the energy to complete the job, but because you **need to approach self-advocacy in an emotional style which will help you get your needs met**. If you are angry and hurting, you will come across as aggressive rather than assertive. This will not help you successfully communicate your needs and negotiate to get your needs met.

## **2. GATHER INFORMATION**

Gather the information you need. Knowledge empowers you to:

- Decide what your needs are,
- Communicate effectively,
- Negotiate for your cause -- to let other people know that what you have to say is important and deserves attention.

Some of the information you will need for self-advocacy includes:

- ✓ Information about your injury and your strengths and challenges;
- ✓ Information about what resources and skills you need as you cope with life after brain injury;
- ✓ Information about community resources that could help you;
- ✓ Information about the skills needed to communicate and negotiate with others.

Information can sometimes be overwhelming, particularly when you have so much going on in your life, and so much to digest. Be systematic in gathering information:

- Develop a system for keeping track of information.
- Don't let anyone rush you – take your time.

If you are getting information from someone over the phone or in a meeting, don't allow yourself to be rushed even if the other person seems to be in a hurry. Your time is important too. If you take the time to get the information correctly, the conversation will be more productive for both of you.

### **3. ORGANIZE AND PREPARE**

Being organized and prepared involves:

#### NOTES



Additional information on organizational tools can be found in Chapter 14 which begins on page 192.

- Organizing the information you gather,
- Documenting information and events so that you can substantiate what has been said,
- Arriving prepared for meetings and interactions.

If you are organized and prepared, the people you interact with may pay more attention and feel more accountable.

In this chapter, we will discuss the importance of being organized and prepared. In Chapter 17, we will talk about specific strategies for organizing your information. Be sure to read Chapter 17 carefully and decide which strategies may work best for you.

*Organization* can be difficult for some people. It may feel like too much work at first. However, if you are organized you will actually save yourself time and energy. Use only those strategies that really work in your life, ones that make sense to you, and that you will follow through on. If you spend a few moments each day getting organized, you will reduce the level of stress in your life and will spend your time more efficiently.

*Documentation* allows you to substantiate your position. (For example, "According to my notes from our last meeting, you said my evaluation would be in May. Is that correct?"). You can document information or interactions by:

- Writing things down

## NOTES



Chapter 17 will discuss strategies on becoming organized, prepared, and informed. This chapter begins on page 252.



- Audio-taping
- Having a friend or family member write things down for you

When you pull out your pen and paper, or turn on your tape recorder, you will find that people will sit up and pay attention. Your documentation encourages the people around you to feel more accountable for what they say.

The following points can be helpful when documenting meetings or phone calls.

1. At the beginning of an interaction, note the names of all the people attending, the date, the place, the purpose and the time of the meeting.
2. Write down only key words or abbreviations rather than whole sentences.
3. Remember: you have a right to document information. If it takes time, or slows the meeting down, that's okay. Take your time and document as thoroughly as needed. Don't be timid about asking someone to spell their name, or to repeat a statement so that you can document it.
4. Before ending an interaction, review your notes and ask for any clarification you may need. Clarify who will be doing what and when.
5. Keep track of your documentation. Some systems that have worked include: smartphone, mini-recorder, dayplanner/organizer, or a notebook. Find a system that works for you! See Chapter 17 for ideas.

## NOTES

**Review and ask for clarification before you end an interaction**

6. Write letters or emails to follow-up your conversations. A letter serves as a reminder and as documentation of your interaction.

#### **4. ASSERTIVELY COMMUNICATE AND NEGOTIATE**

Most of the work of a self-advocate involves communication. You will advocate for yourself and your family through phone calls, meetings, and emails. The people you are communicating with are often people who have too much work to do in too little time. Your life, or the life of your family member, may not be their priority. You need to make it a priority.

Changes in how a person interacts and communicates can be one of the most difficult problems after brain injury. We need good social skills if we are going to successfully communicate our needs and advocate for ourselves. Our ability to communicate and interact with the people around us depends on many different skills. It requires speech and language skills, awareness of others, memory, picking up on cues that people give us, initiation, emotional control, and awareness of social boundaries, among other things. A brain injury can cause problems in any of these skills, resulting in changes in our ability to socially interact.

A brain injury can cause a person to have problems with any type of social skills, including:

#### NOTES

- Listening
- Maintaining eye contact
- Taking turns
- Asking questions
- Respecting social boundaries
- Bringing up interesting topics
- Initiating conversation
- Giving feedback (nodding your head, smiling, saying things like, “I know what you mean”)
- Communicating assertively, not passively or aggressively

**Here are some suggestions for good communication as you advocate for yourself and your family:**

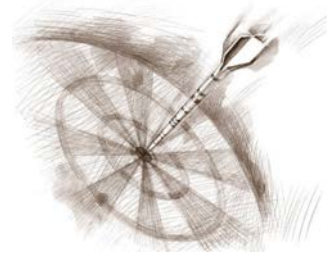
1. **Be Prepared.** Have essential information written down before-hand. You may want to develop a fact sheet about yourself/your family member, including date of birth, social security number, date of injury, current abilities and needs, chronological timeline listing past treatment, etc. (see the self-advocacy information sheet at the end of this workbook). Write down questions ahead of time.
2. **Clearly state who you** are, your reason for calling/visiting and ask if you are talking to the right person. When you get the right person, write down the person's name, number and title.
3. **Be empathetic.** Empathy means seeing things from the other person's perspective, and putting yourself in the other person's place. Being empathetic towards others is a great way to help others become

## NOTES

empathetic towards you, This can be difficult when your needs are so great. However, showing empathy to others will help you communicate and will increase your influence. The more you understand the agency and the people that you are dealing with, the easier it is to become empathetic. Seeing that person as *a person*, may help him/her see you more as a person -- rather than a case or a number.

4. **Be goal directed.** What do you want and what is the end goal that you are striving for? It can be easy to stray off topic and not get to the point of your phone call or meeting. Keep the conversation focused on your goal so that you can get your needs met
5. **Build relationships.** Knowing people *does* help. It helps when someone sees you as a person, not just as "another client". Be helpful to someone who has provided services or information to you. Send the person a thank you note, or a copy of an interesting article, or connect the person with other contacts that have been helpful to you.
6. **Clarify and review.** Do not end the interaction without reviewing: what has transpired, who has agreed to do what, and what will happen next. Be sure to write this down. It can be helpful for the other person to know that you are documenting the conversation. It will help the person feel accountable. Remember, you have the right to ask for clarification, to

## NOTES



Stay goal  
directed

ask the person to explain technical terms, or to ask for the correct spelling of names, etc.

- 7. Be Assertive!** There are 3 basic styles of interaction. You can be Aggressive, Passive or Assertive. Most of us use all 3 styles of communication at one time or another. We may be more aggressive in some situations or with some people, and more passive or assertive in other situations. Here is a description of the three styles of communication:

- A. The Aggressive Style:** The aggressive person attacks people not problems. When someone is aggressive, s/he points a finger, finds blame, and feels that his/her rights are more important than the rights of others.

*Example: "I don't care how many patients you have waiting, Doctor. I have some questions I want to get answered and I'm not leaving until you answer them!"*

- B. The Passive Style:** The passive person does not let his/her needs be known. This person feels his/her rights are not as important as the rights of others.

## NOTES

**The assertive person attacks problems, not people!**

*Example: "I wanted to ask my doctor some questions about my medications, but she seemed so busy. She just didn't give me a chance."*

**C. The Assertive Style:** The assertive person attacks problems rather than people. The person may be angry or upset, but the anger is up front and appropriate, and is usually directed toward the problem, not at a person. The assertive person stands up for his/her rights, but without stepping on the rights of others.

*Example: "Doctor, I have some questions about my medication that I need to discuss with you. Would you like to discuss them now or at the end of the appointment?"*

Being assertive is not always easy. It is especially hard when you are frustrated, when your self-esteem is low, and when you feel that life is unfair. It involves practice, and there will be times when you will blow your cool, or times when you find yourself intimidated by "the professional". Learn from these experiences and then move on. If you find assertiveness particularly difficult and would like more intensive training, there are a number of Assertiveness Training courses offered through

## NOTES

**Self advocacy is not easy – don't give up!**

community colleges, etc. There are also a number of assertiveness training books available.

Remember, assertiveness is not just what you say but how you say it. Your body position, the tone of your voice and even the way you dress can all influence how you communicate your message to people.

Here are some more examples:

**Aggressive communication:**

"Stop bothering me! You treat me like a child. If it wasn't for you I'd have a job by now!"

"You people don't know anything about my son. I can't believe you claim to help people. You'll be hearing from my lawyer!"

**Passive:**

"Whatever you think is best, Mom".

"Well you're the experts. I guess whatever you think is best for my son is what we should do."

**Assertive:**

"I know you worry about me, Mom. But I've decided to go on this trip with my friends. Let's sit down and I'll go over my plans with you."

"I appreciate your opinion about my son. I'll think over what you've recommended. I'm frustrated because you have suggested several things that I don't agree with. I'm going to talk this over with my family, and then I'd like to meet again

NOTES

next week. How about next Thursday?"

8. **Negotiate.** Negotiation is an important part of communication. You will get farther faster if you are willing to negotiate or to “give a little”. Negotiating let's people know that you are willing to work on a problem as a team, that it is not you against them. It allows the other person to let down his or her defenses and to become much more flexible. Negotiating does not mean giving in! It means that you both win in the long run.

**Self-advocacy is not an easy job!** It requires physical and emotional energy, persistence, communication, negotiation, emotionally keeping your cool, and keeping track of lots of information. It involves gathering information, finding resources, influencing resource providers, and following up to make sure that things are accomplished. You will become more and more proficient at the job as you gain experience, and as you share your experiences with other self-advocates who are looking for a better life for themselves and their family members. The SAIL workshops cover the information in the chapter in more detail.

## NOTES



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## **COMMUNITY ADVOCACY**

Kathy Rohan Hague

Kathy Rohan Hague, J.D., sustained a TBI in 1990. She has been an active advocate for brain injury survivors.

## WHAT IS COMMUNITY ADVOCACY?

**Description:** Community Advocacy involves working to improve your community by changing national, state, regional, and local laws, regulations, rules, and policies. For us, that means the brain injury (BI) community. Many BI survivors and family members feel a strong need to "give back" to others by making the way smoother for those who follow. Many others want to "educate the world" because so few people really understand life after brain injury. This chapter is addressed to those BI survivors and family members.

People with brain injury have been surviving in large numbers since the early 1980s, due to advances in medical care, safety equipment, and helicopter rescues. As it became clear that many of those survivors struggled to find support for basic survival, dozens of individuals in Colorado and several other states came forward to work toward solutions.

In Colorado, this was a broad-based, grass-roots effort by rehabilitation hospital representatives, social workers, medical providers, family members, survivors, state and county government representatives, and state legislators. That spirit of cooperation still exists, and has produced many improvements in the lives of survivors. Many other states followed similar or quite different paths.

**Community Advocacy Is Relationship Building.** All lobbyists agree that the

## NOTES

*"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it is the only thing that ever has."*

Margaret Mead

key to success in this endeavor is building relationships. For us, that includes relationships with the brain injury community, with other disability and medical/service provider organizations, and with elected representatives at the city, regional, state, and national level. In addition, when you are an advocate, you educate every person you meet regarding brain injury and its impact on lives. The lack of community understanding of TBI is a major problem affecting brain injury survivors and families.

**Community Advocacy Includes:**

- Representing BI survivors and families on private, government and non-profit boards, either specific to brain injury or including other disabilities;
- Writing or calling your legislators or city council representatives;
- Showing up at the State Capitol building to support TBI related legislation, to show how many BI survivors there are, and to support other disability groups and other causes;
- Speaking one on one with your legislators and city council members;
- Testifying at legislative or city council meetings, or at state, local, and national government committee meetings;
- Taking part in public demonstrations.

All of these opportunities will be further discussed below. As you will see, very different personalities and abilities are needed to contribute to these activities.

NOTES

***Believe in  
yourself, even  
when others do  
not.***

Some examples in Colorado of the diverse personalities involved are:

- The person with Cerebral Palsy who crawled up the steps of the Colorado Capitol Building, with news cameras in attendance, after the Governor refused to let her ride the elevator to committee hearings.
- The person who spent seven years learning the Medicaid rules to be able to advocate for people with disabilities on the Medical Services Board.
- The several people who use wheelchairs that chained themselves together at the intersection of Colfax and Broadway because there were no accessible busses.

**What Community Advocacy is not:**

Community Advocacy is not a support group. This is NOT the place to re-tell the whole story of your former life, or of the injury and the rehabilitation. It is the place to tell how the issue being discussed affects your life. It is also the place to tell the stories of other BI survivors affected by the issue being discussed.

True-life stories are the most compelling when trying to form the decisions or change the minds of public figures. They ask for our stories, in our own words. Please tell them when appropriate. You will learn when it is appropriate to tell your entire story, and when it is not, by paying close attention and asking for input.

## NOTES



Information on Self Advocacy can be found in Chapter 1, beginning on page 9.

The chapter on Advocating for Productive Activities can be found on page 337.

## **HOW TO BEGIN**

- 1) **Study and understand Self-Advocacy (Chapter 1).** The principles and recommendations in that chapter are essential to master for yourself in order to be an effective community advocate.
- 2) **Carefully explore the chapter on Productive Activity.** Community Advocacy is very empowering to the individuals who commit themselves to making life better in their communities. It can also be stressful and demanding, and often moves very quickly.
- 3) **Honestly evaluate your abilities and deficits.**
  - Learn how your brain injury affects your life. This keeps changing for years, as you improve, adapt, grow stronger, learn new compensations, and as new therapies are discovered and you practice them.
  - Ask for clear and honest feedback from several different sources, particularly other advocates. Almost all BI survivors lose self-perception. We don't know how we come across to others, either positively or negatively. We also don't know how we might react under stress, or how we would respond to verbal challenges.

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***Believe in your  
cause***

- Learn to recognize and work with your energy limits. Keep expanding your energy limits, when you feel safe to do so.
- Develop a network of people to support you. Be sure to use your skills to help them in return. This is building your own circle of support.
- Go – Make a difference! All attempts at advocacy will yield rewards.

### **HOW TO COMPENSATE FOR TBI-RELATED DEFICITS WHEN YOU ARE ENGAGED IN COMMUNITY ADVOCACY**

Consciously practice using compensatory techniques first in a safe place, such as support groups, church groups and volunteering. Especially around people in power, it takes repetition to be comfortable using the techniques you have learned. Practice on everyone, often. Notice and make notes of what works. Soon, your life will flow easier from using these strategies.

**(1) Plan ahead.** Recognize that you may become overloaded at some point while advocating. You may have to spend many more hours at the Capitol building than you anticipate. Plan ahead in order to take care of yourself.

- Always carry healthy energy bars and boxed juice, or some other energizing snacks

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- Pack a lunch for any late morning meetings or hearings
- Always carry taxi fare for emergencies. Have someone you can call for help if possible. Double check for their availability on days you go to the Capitol.
- If you drive, consider giving yourself time to rest/sleep in your car before driving home.

**(2) Carry a tape recorder.** Record reminders, observations, and meetings to yourself. Listen carefully to your tape after you are rested. Add or modify as needed.

**(3) Ask for help from other advocates when needed.** There is a very supportive camaraderie in these settings.

**(4) Explore your state capitol building with another advocate or a supporter before you go to advocate.** Look for potential problems and strategize solutions. Be sure to find all committee rooms for Senate and House, as well as bathrooms and cafeteria.

**(5) Compensate for vestibular overstimulation.** Many state capitals and state office buildings have ceilings higher than 30 feet, public seating high above the floor of each chamber, hallways next to 100 foot atriums, and wide, circular stairways. This can add to the overstimulation.

- If you are overwhelmed when walking through these areas, hold the arm of a supporter with your

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***Seek always to empower and to be empowered.***



eyes on the floor, and run your hand along the wall way from the openings

- Wear balance bands on wrist acupressure points
- There are few places to sit where you can rest quietly and regroup, so find an office with a kind staff member, and ask for assistance
- To observe proceedings on the floor of a chamber, ask to stay in the back of the room or in the doorway
- Be aware that seizures can occur in these settings.

**(6) Compensate for auditory and visual over-stimulation.** Most capitol buildings have marble floors, wall, and ceilings, so sound echoes. During legislative sessions, the hallways are crowded with talking people.

- Wear ear filters and/or amber-tinted glasses.
- Find a quiet place to get away to rest as often as possible.
- Most lobbyists conduct business in this setting. If you find this difficult, let them know, and meet by phone or in a quieter place.

**(7) Wheelchair accessibility.** Since the passage of the ADA, and the activism of previous advocates, government buildings have ramps and elevators. You will probably need to search for them, or find a guard to unlock doors.

**(8) Behavior and emotional control.**

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The State Capitol may not be the place for you if you get angry and yell at people when they don't "get" what you are saying. Public building guards are extremely cautious about security. You may frighten them and police may be called. You may be much more comfortable, and effective, at public demonstrations, making phone calls or e-mails, or attending meetings which you can easily leave when frustrated. (Don't give up on going to the capitol. Keep trying as you make progress.)

**(9) Choose activities which you enjoy.**

It is exhausting to put ourselves in challenging situations. Becoming overwhelmed is frustrating and embarrassing. Having passion for your cause provides a lot of energy.

**(10) Learn to say "No".** Practice saying, "Thank you for asking for my help, but my time is already fully committed." Once you become known as an advocate, many people will be asking for your help. While flattering, it is very easy to over commit yourself.

**(11) Take care of yourself.** Schedule physical exercise first, then fit in your advocacy time. Physical exercise improves cognition, and makes you a calmer and more effective advocate.

**LEGISLATION**

**The Big Picture.** The path of legislation described here is for the state of Colorado. However, most elected bodies

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use similar procedures. Since this information is public, most have offices to educate the public about interacting with them. In Colorado, many publications with more details are available from the Legislative Council.

1. There are 100 members in Colorado's General Assembly, 35 Senators and 65 Representatives. During the legislative session of 120 days (from early January into May), they are involved with legislative work throughout the days and evenings, Monday through Friday, and have minimal staff support. The rest of the year they have other careers, in addition to legislative work. Therefore, individuals and groups are typically the source of legislative initiatives and at times serve as staff to our elected representatives. As a result, one person or one group can make a big difference in changing Colorado's laws.
2. Hundreds of "bills" (proposed state laws) are introduced every year, but only a few are passed and signed into law. Here is why:

Each senator and representative can sponsor only a certain number of bills per "session." A bill must clear several hurdles to become a law. It must be voted for by 33 House Members, 18 Senators and signed by the Governor. During the Legislative process, legislators,

## NOTES

advocates, and opponents examine every word and try to anticipate all possible meanings.

This work takes place in committee hearings, oral debate in both Houses, and through private conversations, phone calls, and e-mails.

3. Between legislative sessions, many formal and informal study groups, Task Forces, and committees meet to plan for bills to introduce in the next session. It is extremely valuable to your cause to join one of these groups.

### **What is Needed to Pass a Bill**

1. It may take several years to pass your bill. Work as if each session is THE session.
2. Start planning six to nine months before the next legislative session.
3. First, you must find a sponsor for your bill.
4. You must build coalitions to support your bill. (Remember "relationship building.") Think broadly to develop like-minded groups to support you, for example: disability advocacy organizations, medical organizations (therapists or hospitals), Mothers Against Drunk Driving, (AARP). State agencies often have legislative liaisons (a/k/a

### NOTES

***Failure can be positive - if we are able to learn from it.***

"policy analysts"), who may be very helpful with guidance and potential supporters.

5. The sponsor must request the Legislative Drafting Office prepare the bill by December 1.
6. The Legislative Services Office and Legislative Council can be helpful in providing historical information and answering your questions. They are especially helpful between sessions when they have more time available.
7. To find potential witnesses to testify for committees, ask your state's grass roots organizations and the bill's sponsors. These groups are also helpful to maximize the volume of calls and e-mails to committee members and all legislators when the bill is on the floor of the houses.

### **Step by Step**

1. A bill is first introduced in the House or Senate by its sponsor, called First Reading. (Only the Title of the bill is read.) The leader of the majority party then assigns it to a committee, based on the subject matter and politics.
2. During committee meetings, legislators on that committee review the bill carefully. This is the first public place where advocates

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and opponents of the bill testify, under oath, to the legislators and where the committee members debate with each other. The bill may be, and often is, amended or changed in the committee meeting.

3. Any bill that might have a financial impact on the state is next sent to the Appropriations Committee. This is a very powerful committee, where only the bill's sponsor can testify. If the bill passes out of the first committee and Appropriations Committee (where applicable) it returns to the house of origin for "Second reading" and floor debate. Further amendments and changes are made during this debate. The bill is then voted on.

3. There is little further action here, but the bill is put into final form, and returned to the same house, for Third Reading, where it is usually approved. The bill then goes through the same process in the other chamber.

**The Governor.** After a bill has successfully passed both houses, it goes to the Governor for his/her signature or veto. The Governor may allow the bill to become law without his/her signature. If the General Assembly is in session, the Governor has ten days to sign or veto the bill. If the General Assembly is not in session, the Governor has thirty days to

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sign or veto the bill. If the Governor vetoes a bill, however, the General Assembly can override the veto with a two-thirds majority in each house, if it is still in session.

**Applying the law – Rule Making.** After the law is passed, it must be turned into rules or regulations. This is the place where many laws gain or lose their teeth. Make sure you are on the committee to write the rules or regulations. Ask the law's sponsor how to accomplish that.

### **MANNERS AT THE CAPITOL.**

- 1) The most important rule is to be respectful and polite. Individual legislators represent our democratic way of life and deserve your respect.
- 2) The second rule is to always tell the truth. All of the legislators and staff work together daily, and compare notes about who is trustworthy.
- 3) Be accurate on facts. Don't exaggerate.
- 4) Each Legislature has its own etiquette. Guidebooks are available from the Office of the Legislative Council.
- 5) Always be polite and respectful to other advocates and lobbyists. Your present opponents will almost certainly be future partners, and you may disagree in the future with present partners.

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***Don't take the  
world too  
seriously -  
particularly your  
brain injury.  
Laugh at yourself.***

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- 6) Always use proper titles in letters, phone calls, in personal conversation, and e-mails. Address them as "Senator Smith" or "Representative Jones." Even if you know them personally, address them formally in business settings.

### **LOBBYING**

**In 2008, lobbying has a very bad reputation.** However, it is the overall term used for educating your elected representative about what you believe is very important.

**There are paid and volunteer lobbyists.** Paid lobbyists must register with the Secretary of State and file monthly reports. Volunteer lobbyists must register with the House of Representatives, but no reports are required. Anyone can testify before a committee or express an opinion on your own behalf without registering.

**Your first step is to learn the names of your state and national senators and representatives and their contact information.** You can find this information from your county clerk and recorder, or local political party, or the Legislative Council, as well as web sites, described below.

**There are many ways to find out the progress of any bill.**

1. Most states have very helpful and easy to use web sites. In Colorado, go to [www.Colorado.gov](http://www.Colorado.gov), and link to



the General Assembly. Other states have similar web addresses: for example: [www.nebraska.gov](http://www.nebraska.gov), and link to Legislature, or [www.ny.gov](http://www.ny.gov). On these sites, you can learn what committees exist, who is on them, read the text of bills, find the progress of each bill through each house, as well as get contact information.

2. You can find the phone numbers for learning the progress of a bill (In Colorado-303-866-3055). You can obtain a copy of the bill either online or at the Bill Room. In Colorado, the Bill Room is located across from the capitol at 14th and Sherman, basement.

### **Meeting your legislator.**

1. You will make the most impact if you introduce yourself to your own representatives before you ask for their help.
2. You can contact your legislators at the capitol offices during the legislative session, and in their home districts on weekends and the rest of the year.
3. It is also helpful to meet the legislator's staff, as they have great influence, particularly in Washington DC.
4. Know your issues. Think about them objectively. Anticipate objections and opponents.
5. In advance, make notes or write out what you want to say.
6. Be very clear and brief about your information and position:

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7. Give the number of your bill,
8. Say what your bill is about,
9. Say why you are for it.
10. Ask what their position is. Listen carefully and ask questions.
11. Send a Thank You note after meeting with them.

**Writing your legislator.** Legislators welcome your calls, letters and e-mails. Politicians pay attention to their mail. Many state legislators say that 15 letters on a single issue will get their attention. E-mails are less impressive, but still valuable. Forwarded e-mails are barely counted.

1. Write personalized letters and e-mails.
2. First, identify the bill number, name of the bill, or the general subject.
3. Say whether you support or oppose it, and why.
4. Give reasons for your position. Personal reasons and your own experiences or observations work best.
5. Keep sentences short and to the point.
6. Limit the letter to one page or less.
7. Ask for a reply. Ask for her/his views.
8. Include your name, address and phone number.
9. Always, thank them for their time.
10. Never send letters that are anonymous, abusive, or threatening.

### **TESTIFYING BEFORE A LEGISLATIVE COMMITTEE**

#### NOTES

Legislators need you to develop their understanding of your issue. No one knows it like you do.

1. Everyone is nervous before testifying. Being well-prepared will help a lot.
2. Carefully read the bill you are testifying about. Be clear on your goal.
3. Check the legislative status sheets for both the House and the Senate.
4. Find out who sponsored the bill, and the committee to which it is assigned.
5. Check the legislative calendar for the exact date of the committee hearing. Check the calendar often in the days before the hearing, as things move very quickly and change frequently.
6. Prepare your testimony and practice it. Limit your comments to 3 minutes. Many BI survivors use extensive notes or write out their full testimony. Legislators prefer that you do not read, so explain in advance that you must to read your notes due to memory loss.
7. Get help. Ask others in your group or other groups for assistance in making your points clearly and briefly.
8. Don't assume the legislators have read your bill. Pretend they have read it, but give all necessary information.
9. Listen carefully to others who speak before you. Also listen carefully to the questions the legislators ask. If it is clear the legislators have read the

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bill, cross out any redundant information from your testimony, unless it is necessary to make your point.

10. Be prepared to answer questions from the committee members. If you do not know the answer, SAY SO. Offer to find out the answer to the question, and e-mail it to all of the members on that committee. Make a note immediately so you don't forget.
11. Arrive early at the hearing room. There is a sign-in sheet on the table where you will sit to testify. Write your name clearly. You will be called in order.
12. When you speak, speak persuasively, even if you must read.
13. Begin with: "Thank you, Mr./Madame Chairman/woman, I am \_\_\_\_\_."
14. At the end, say, "Thank you. Do you have any questions?"

## **WORKING ON COMMITTEES AND BOARDS**

**Committees and Boards are often the most effective place to change public systems.** Ideas for future bills are proposed in meetings or by individuals. Such meetings are also excellent places to practice using Compensations, as non-disabled members learn to understand you better.

**Decisions are made by those who show up.** If you commit to being on a committee, do it. If you are not able to

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maintain your commitment, tell the chair and find a replacement, if possible. If you are the only representative of the BI community on the committee, definitely find a replacement.

**Listening is not just hearing.** To truly listen, one must use ALL of her/his body, including the eyes, heart and undivided attention. This is where a tape recorder will be very helpful for memory loss and distractibility. Check out your understanding with others.

**Find out your purpose.** What is the purpose of the committee? Where does it fit in the big picture? What is your role on the committee?

**Ask people to try things a new way.**

Never take "no" or "we can't" or "it doesn't work that way" as an answer. When you are excited about finding new solutions, that energy is contagious, even to the most jaded bureaucrat.

**Celebrate your differences but recognize your commonalities.** Chat with others before and after meetings about their weekend, family, and hobbies. Tell them about yours. Friendliness breaks down barriers of misunderstanding and fears.

**Expect specific actions from others in the organization and trust they will follow through.**

**Volunteer to do only what you can complete within the time frame available.**

**Ask for accommodations if needed:**

1. Ask to meet with a long time member for the history of this group.
2. Be clear about the purpose of this

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***Be creative.  
There are always  
five or more  
RIGHT ways to do  
everything.***

- group. Is it fund-raising, advisory, action?
3. Be clear why you are working with this group:
  4. If they want a token disabled person, decide if that is what you want to be. You may learn and teach a lot in that capacity, as well as make good contacts. Be aware, however, you are very unlikely to make serious change.
  5. Fundraising is the main purpose of many boards. Many BI survivors are superb at marketing, obtaining donations for silent auctions, asking strangers to do things. Make it clear if you are personally unable to donate more than a few dollars. 100% participation of Board members may be more important than the amount of money you can give.
  6. Don't worry about thinking slowly. Tape record the meetings, listen to the tape soon, and make notes of your thoughts as you listen. Then send your comments by e-mail to the rest of the group.
  7. Ask to always receive the agenda, and any materials that will be discussed, several days prior to the meeting. Review them carefully and make your notes.
  8. Speaking slowly is not a problem. There is no need to apologize for it. People will learn to listen to you.
  9. Non-verbal members are as important as verbal members. If you are not able to speak or cannot be understood, know that many

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- advocates use a speech board or a translator.
10. Be respectful of all members of the group. Speak to them, not to a translator.
  11. Greet the group members as you enter the room.
  12. Introduce yourself to the people sitting near you and learn who they are.
  13. Many BI Survivors & family members introduce themselves as a "brain injury advocate."
  14. If you need additional support, ask the group leader, staff assistant, or another advocate, to help you problem solve. Before the meetings, you could arrange some signal techniques if you think you may need a prompt during the meeting, such as: one or two taps on the arm, or sliding a colored paper in front of you. Examples of when you might need a signal are:
  15. If you begin to go on too long on a topic
  16. If you start to over-react to a comment
  17. If you consistently bring up issues which are off-topic
  18. If you interrupt other speakers
  19. People without brain injuries also do these things, and I have often seen improvements in the behavior of the whole group when BI advocates use these supports.
  20. Ask to attend 2-3 meetings before you decide if this group is a fit for you. Tell the group leader if you decide not to continue - do not just

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***Assume nothing - particularly about what other people are thinking or feeling about you – or about themselves.***

stop going. Remember, this is about building relationships.

## **COLORADO BOARDS AND COMMISSIONS**

A. Governor Appointed. Look at <http://www.colorado.gov/cs/Satellite/GovHickenlooper/CBON/1249674847715>

Traumatic Brain Injury Board  
Developmental Disabilities Council  
Statewide Independent Living Council  
Medical Assistance and Services  
Advisory Committee  
Medical Services Board  
Governor's Advisory Council for Persons  
with Disabilities  
Workforce Development Council

B. Not Requiring Governor Appointment.

Your local town or county disability  
councils  
Denver Regional Council of  
Governments  
Regional Transportation District (RTD) -  
Access-a-ride Board  
Colorado Brain Injury Advisory Board  
Colorado Cross Disability Coalition (local  
and state)  
State Rehabilitation Council  
Mental Health Advisory Board (local and  
state)  
Human Services Board  
Interim Legislative Committees  
Local Independent Living Center Boards  
The Legal Center for People with  
Disabilities and Seniors  
(local and state Protection and  
Advocacy Center Boards)

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**You Are Not Alone**

## **SURVIVOR PERSPECTIVES**

with insights and suggestions from

Mark Condon  
Mathew Doty  
Richard Spears  
Noanie O'Brien Geistert

This chapter includes the comments, suggestions and insights of several people who have lived with brain injury. They hope their experiences can be useful to others who travel this same road. *Information in this chapter was compiled through interviews and summarized by Lenore Hawley.*

***“Sometimes I felt like they could be having a meeting without me, that I really wasn’t saying anything and didn’t have anything to offer. But now I realize that it’s important just to be there. It keeps everyone aware that this is your life and you have a say in it.”***

Matt Doty, brain injury survivor

For some people, advocacy after TBI is a joint effort between the injured person and his or her family and friends. Other people may find that family or friends are not available. Whichever situation you find yourself in, remember this:

***It is hard to go it alone.***

If family/friends are not available, you may want to connect with other people who have brain injuries or with an advocacy agency, such as the Brain Injury Association, in your advocacy efforts. Other people who have been down the same road may have experiences and ideas to share with you. Some of these may be useful to your individual situation; some may not. But the act of sharing your journey with others allows you to realize that you are not alone. Someone else out there has been in a similar situation and understands and accepts your feelings. Here are a few suggestions from people who have lived life after TBI and are at various points along that road.

***Be aware of your strengths and deficits.***

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Mark John Condon sustained a TBI in 1981. Mark states that you have to begin with being honest with yourself about the deficits you face. He says that his family pointed out his deficits to him and helped him see what he needed to work on.

***Become knowledgeable.***

Mark also points out that you should find out everything that you can about brain injury and about the resources available to you. Write down what you have learned and keep the information organized in a way that makes sense to you.

***Ask questions.***

Richard Spears sustained a brain injury in 1998. Rich states that one of the most important things he has learned is that it's good to ask questions. You may hesitate sometimes because you feel like you are asking a question that you should already know the answer to, or because the person you are asking knows a lot about the topic (for example, a doctor or an attorney). However, asking questions shows that you are very interested in the information and want to get it right.

***Write everything down.***

Noanie O'Brien Geistert sustained a mild to moderate TBI in 2000. She says that although her memory has improved over time, she finds it helpful to write everything down so that she can remember all the information in her day. She suggests using a big calendar, and investing in lots of post-it notes. And, don't forget to use them!

***Give yourself time to process information, and then respond.***

Matt Doty sustained a brain injury in 1989. He says that sometimes there is a lot of information given to you in meetings and other situations. He suggests that at the end of a meeting, you should let people

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know that you will think about what was said and get back to them with any comments or feedback. This gives you time to gather your thoughts, think things over, and then respond.

***Ask for help when you need it.***

Another important thing that Rich has learned is that it's okay to ask for help when you need it. This was hard for Rich at first. Before his TBI, he was very independent and enjoyed doing things on his own. However, he realized that asking for help when he needs it allows him to be less frustrated and to then do other things more independently. Rich finished college after his TBI and emphasizes that he could not have finished without asking for help. Asking for help from others allowed him to achieve his goal.

***Don't be ashamed of your brain injury.***

Noanie says that you can spend a lot of energy trying to act "normal," energy that you can't afford to waste. She points out that because people cannot see her brain injury, some people expect her to be able to do all the things she could do before. Sometimes, this tears away at her self-confidence. However, she has now come to a point where she knows, "I do the best I can and that's good enough for me."

***Cut yourself some slack - don't be too hard on yourself.***

Rich notes that it is easy to start to put yourself down for not being more independent, or not being able to do all the things that you used to do. Being too hard on yourself can make you feel down and make it difficult to get motivated. Set small goals for yourself and celebrate when you achieve them.

Noanie adds that you won't be able to do everything that you did before and **that's okay!** If you're tired, take a nap. If you need to be alone, that's okay too. If projects take longer than they used to, or if you

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can't handle as big a project as before, that's fine. Cut yourself some slack.

***Never quit – don't give up hope!***

Mark points out that you will come upon many roadblocks as you advocate for yourself. You may feel lonely, not have the money to pay for all the things you need, have difficulty finding transportation, etc. Don't give up. Some problems you face may not have an easy solution. Take one problem at a time, connect with other people, become knowledgeable, and ask for help. If a good solution is not available, there may be an alternative solution that will do for a while. There may be another route you can take to getting your needs met.

Noanie adds that you should never give up hope that you will get better. The timetable is different for everyone but you'll get there – don't give up hope!

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## **FAMILY PERSPECTIVES: BRAIN INJURY IS A FAMILY AFFAIR**

Ann E. Levis

Ann and her husband Bill are the parents of Jon, who suffered a severe brain injury shortly after celebrating his 19th birthday.

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My son, my only child, suffered a severe brain injury shortly after celebrating his 19<sup>th</sup> birthday. My husband and I were immediately thrust into the frightening, unknown world of brain injury. As we picked our way through the shards of our days and nights, we learned, piece by piece, many of the things we needed to do to protect our son as well as ourselves through the process of recovery and acceptance. We certainly did not learn everything there is to know, but we learned enough to get us through, and perhaps by sharing some of the lessons we learned, we can spare others from having to start from scratch.

This chapter is written from the perspective of my own family's experiences. Incorporated into it are the experiences of two other families who were generous enough to share their own personal stories.

Having someone you love suffer a traumatic brain injury (TBI) can be a devastating, life-altering event. One of the first things you will probably hear is, "Every brain injury is different." Just as every brain injury is different, every family is different and so is every situation. The issues involved when the injured person is your child are different from those involved when the injured person is your spouse, but there are many similarities among those who have traveled this road. We are all survivors, the injured person and all those who love him. A brain injury does not just happen to one person; it happens to a family. If you have felt grief-stricken, lost, overwhelmed, and disoriented, you are not alone. This is a normal response to a traumatic experience.

When you first learn that your loved one has suffered a TBI, is in the hospital, probably in a coma, your initial reaction may be shock. You may think that this is the kind of thing that only happens in other



families. You may even believe that a terrible mistake has been made, and that it is not actually *your* son/ daughter/ spouse/ sibling lying in that hospital bed. Seeing him in the hospital, possibly on a ventilator, with tubes and lines snaking in and out of his body, totally unresponsive, can knock you to your knees. You may watch him go through medical procedures that you have only seen on television.

When someone you love is seriously injured, worry and fear can make it very difficult to leave his bedside. Everything else is put on hold, as the injured person becomes the central focus of your life. Like a broken clock, time can seem to stop. Days can go by without your being aware of it. You may start out running on adrenaline and end up running on empty. You will probably be exhausted, unable to sleep, and you will not be thinking clearly enough to absorb what you are told.

In the hours and days following the injury, you may not be sure that your loved one will survive. If you know he is going to survive, you will have no idea what “survival” means. It will be a while before the reality sinks in that survival can mean anything from eventually living an independent life to existing in a persistent vegetative state. Everything you learn about brain injury will come to you slowly, over time, because it is so new, much of it incomprehensible, and you may feel as though you are living in an alternate universe from the one you knew before. If possible, have a family member or good friend with you who can take notes, ask questions, hold your hand, and maybe even make you laugh. This can be a great comfort at a time when you are feeling isolated and overwhelmed.

Your loved one needs your support, and at the same time you have a life of your own to keep living. Over time, hopefully you will realize that, although your life

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has forever changed, it is a worthwhile life and, although your loved one may be forever changed, he also has a right to as fulfilling and independent a life as he can manage. He may always need you to make decisions for him, or help him make decisions if he is able to participate, and he will always need to know that you are there for him. You will need to be an advocate for him, and you will need to be an advocate for yourself. You will constantly have to balance his needs with yours, and if you don't take care of your needs, you will not be able to help him.

Eventually the phrase, "Every brain injury is different" will become frustrating, because it means that no one can predict how much this person will recover, or what recovery will look like. Even if the survivor has few obvious physical injuries, a severe brain injury can cause profound changes in his physical and mental abilities, his ability to process information, his emotional responses, and his personality. You will crave reassurance that your loved one will be alright, and you may believe that when he recovers, everything will be the same and life will get back to normal. But a brain injury is not like a broken leg that heals. A brain injury can change what a person is able to do, how he is able to think, speak, eat, walk, and care for himself in the most basic ways. It can change who he is.

If the injured person is your child, your dreams for what might have been may be shattered. Your child may not graduate from high school or college, have a career, get married, have children, or live independently. Even though many personality traits may persist, the person you knew and loved may seem to be gone. If the injured person is your spouse, you may feel as though you have lost your best friend, and find yourself having to take care of the person who has always shared family responsibilities with you.

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## NOTES

These are extremely difficult realities to understand and to accept. As the hours turn into days, the days into weeks, the weeks into months, and the months into years, you will eventually come to understand that your life may never be the same as it was before the injury, and you will need to begin the process of accepting this fact.

The anxiety you feel over the injury itself can be debilitating. If you don't take steps to take care of yourself, to make things as easy on yourself as possible, it can be completely overwhelming. Do not try to handle this on your own. It is too big. In the early days in the hospital, the focus of the medical staff is necessarily on the patient. But you need support, too. Gather your family and friends around you. Be willing to ask for help when you need it and to accept help when it is offered.

Whenever you meet with the doctors, therapists, and other health-care providers, take notes, or ask someone to go with you to take notes. This allows you to go back later and review what you have been told. You may think at the time that you will remember everything you hear, but you will not. In fact, you may remember very little. Information will be coming at you through a filter of grief and disbelief. Sometimes the very air around you will seem to be permeated with strange words and phrases – ischemic, inability to initiate, dystonia, ataxia. Even the common word “coma” can have confusing definitions. Write down the words you hear and look them up. They may not always mean good news, but you will be less likely to feel adrift in the land of “medical speak.” The Internet is a good source for definitions of words that might not be in your home dictionary.

You may go through every emotion imaginable. You

may feel grief, sadness, disappointment, frustration, anger that the injury happened, maybe anger at the injured person if you feel that he in any way contributed to his injury. You may even feel anger towards him simply because of the many ways the injury has impacted your life. You may wrestle with guilt if you feel there was something you should have or could have done to prevent the injury. As time goes by, you may find it helpful to read what other families and survivors have said about their own experiences. It can help you feel less isolated, provide a glimpse into what life is like for the survivor, or, if you are a survivor, what life is like for your family, and provide ideas about ways to handle your situation. You will realize that your reactions and emotions are not unusual. A list of some books that I have found helpful is at the end of this chapter. There are many more. You may also find that you need to read books about anything *but* brain injury, because you must get away from it for a while. Pay attention to what you need.

Trying to figure out why this happened is not a good use of your time and emotional energy. Sometimes things just happen. The greatest lesson that I and others I know have learned from this experience is that we do not have control over everything. Try as much as you can to deal with what is. Constantly thinking about what the injured person used to be able to do, or how you think their life should have been, will surely sap your energy. As much as possible, try to get to know the person he is now. You may find that the person before you now is different than the person you once knew, but has something about him that is delightful and endearing.

Your loved one will need a great deal of support in every area of his life. Just dealing with the financial aspects of the injury can become a full-time job. There may be insurance companies to deal with if he

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has private health insurance – and they will not be jumping up and down with joy at the prospect of paying large medical claims. There may be government agencies from whom you may need to obtain funding. When your loved one is in the hospital, the hospital social worker or case manager should deal with these matters, but he will continue to need the services provided by private insurance, Medicaid, Medicare, SSI, SSDI, the Brain Injury Waiver, or the Colorado Brain Injury Program. These matters are addressed in detail in other chapters of this book, but keep in mind that once your loved one is discharged from the hospital, your family may no longer have help with these details, so learn as much about them as you can. Obtaining funding often does not go smoothly. This may be a good time to contact the Brain Injury Association. They may be able to refer you to someone who can help guide you through this process. If you have contacts, use them. For example, if you know a physician, a legislator, or a person who works in a government agency, ask for their help. You will find that most people who are in a position to help will be more than happy to do so.

When you do contact insurance companies or government agencies, keep a detailed record of your conversations, including the names and phone numbers of everyone you talk to. If you find a receptive person, try to make that person your contact at that organization. That way, you will not have to go over everything again and again, or feel like you are always talking to a stranger. Follow up your conversations with an email or a letter, so that you have a written record and will not have to try to remember everything you have told them.

Above all, be persistent. Just because someone tells you they will send you the necessary forms, make the necessary phone calls, or contact the appropriate agencies, do not assume that they will. Continue to

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follow up with your contacts. If you are not receiving the information or help that you have requested, ask to speak with a supervisor. Sometimes it is necessary to become a constant thorn in the side of someone from whom you need something. But be careful not to push yourself to the point of exhaustion.

Keep one file with copies of all important documents that you may need in a new situation, such as admission to a hospital, an appointment with a new doctor, or placement in a residential setting. These might include private health insurance and Medicaid ID cards, guardianship papers, and records from previous hospitals. Not having to look through files and piles of paper will save you time and anxiety when you need to provide this information.

If the injured person is over the age of 18, discuss with your family who will be responsible for making decisions for the survivor if the person is unable to do so himself, and have that person appointed by court order as the survivor's legal guardian. Otherwise, you will run into legal roadblocks when you try to make decisions or plans for, or obtain information about the injured person. For example, under HIPAA (the "Privacy Act"), if you are not the injured person's legal guardian, you will not be able to obtain information from a doctor or hospital about his medical condition. It is a relatively simple procedure. You can hire an attorney to do it or simply obtain the necessary forms from the clerk of the court where the injured person resides. Consider appointing a successor guardian in case something should happen to you. You may also need to set up a checking account under The Custodial Trust Act or get a court-ordered conservatorship to handle your loved one's finances.

Try not to let yourself become isolated. It helps to

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talk about what happened and its effects on your life. Talk to your family, your friends, or a mental health professional. It is easy to let this type of life change destroy your relationship with other members of your family. Try not to let that happen. You need each other. You need support from each other and from other members of your family. People grieve in different ways and have different ways of handling their feelings, and if you cannot find a way to support each other, seek professional help. Educate yourself and your extended family about brain injury in general, and about your loved one's brain injury in particular. Un-informed and unsolicited advice can cause unnecessary tension and misunderstandings.

Some routine things must be done – you have to continue to pay your bills so that your electricity and water do not get turned off, and you don't incur late-payment fees. But there are bound to be some things on your "To Do" list that can be put aside – that filing you have been meaning to do, some of the letters you have been meaning to write. You are only one person. You cannot be in two places at one time, and you will not have the energy at first to forge ahead with life as you have known it. Your energy and motivation will eventually return.

You may need to find interim hospitalization until your loved one is stable enough to begin rehabilitation. The social worker or case manager at the hospital should be able to help you with this. You can also call the Brain Injury Association and ask for the names of people who have already done this and gather information that way.

Once your loved one is well enough to leave the rehabilitation hospital, even if he qualifies for continued out-patient rehabilitation, you may eventually be faced with the very difficult decision of whether to take him home and care for him yourself, or find a residential

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setting where he can be cared for by trained professionals. Brain injury survivors may lack impulse control and judgment, are at risk of seizures, and may need constant supervision to be safe. They may be unaware of their own deficits and may think they can do things they cannot safely do. They may fight anyone who tries to help them.

When our son was discharged from the hospital, we had to acknowledge that his needs were too great for us to care for him, and we were fortunate to have him admitted to a residential facility where he received good care and was able to continue with his therapies. He received funding under the Colorado Brain Injury Waiver. He was close enough to home that we could see him nearly every day.

In April of 2007, with very little notice, this Brain Injury Waiver facility closed its doors, and we were left scrambling, with a significant number of other families, for a place where our son could live. With a tremendous amount of effort on the part of a small number of people, a new facility opened 65 miles from our home. It filled up quickly. Our son has lived there for almost a year. He is well cared for by good, caring people, but we are able to see him much less frequently and it has taken almost a year to reinstate his therapies. We are in constant contact with the staff. We oversee his medical needs. We are now trying to find a way for him to have some interaction with people his own age. He is only twenty-one years old.

We are older parents, and we constantly worry about who will care for him if he outlives us, or we become unable to oversee his situation, or the place where he now lives should close. At this time, there are no good alternatives.

As a result of his injury, our son lacks judgment and impulse control, and is unable to problem solve. It is

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very difficult for him to speak and be understood, and to use his hands. He has virtually no short-term memory, and the only new things he is able to learn are repetitive actions, such as how to get to his room or the dining room. He does not initiate interaction with other people or any other type of activity. He needs constant supervision to be safe, especially since he is unable to comprehend that he has these challenges. It can be very difficult to advocate for someone who does not believe that he needs any help.

Being a caregiver 24 hours a day, seven days a week, for a traumatic brain injury survivor can completely wear you out. Be honest with yourself about your ability to provide the type of care they require. Unfortunately, there is a lack of post-hospitalization resources for people with traumatic brain injuries. This is changing because more people are becoming aware of the devastating effects of this “invisible injury.” When you talk to someone in an attempt to seek resources, keep a record of the names of any people or organizations of which they are aware from whom you can gather additional information. Often someone who cannot help you knows someone who can. Networking works.

T sustained a brain injury and a spinal cord injury in November of 2006. Her husband, J, tried to care for her, but soon realized that it was simply too much for him to manage. He moved to Longmont, Colorado in the hope of placing her in a nearby residential facility for people with brain injuries, but she does not qualify because she is unable to manage her own care. J. ended up placing her in a nursing home. He has no help. He has two children who are grown and far away.

The nursing home has a ratio of about one staff member to ten residents. J is very unhappy with

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the level of care his wife is receiving; he says they just don't care, and does not understand why they cannot hire people who do. He visits her nearly every day, and feels that he has to be on top of things all of the time to make sure his wife receives the treatments she needs. She has had a urinary tract infection since she has been there, and he has had to argue with the staff about how to treat it. He says that he knows more than they do. He drives her two or three times a week to therapy. He says that it is "wearing him out."

While they still have money available for her care, their life savings will eventually be gone, and he is facing the prospect of going on welfare. His wife is a registered nurse, and J commented on the irony that she spent her working life being a caregiver, and cannot now receive appropriate care for herself.

J's wife's lack of short-term memory affects everything. She cannot remember to take notes to help her remember where she needs to be or when. She is unmotivated, "would be content to sit and watch television all day," and J is extremely frustrated by her lack of motivation, because he believes that if she would participate in her therapy, she could regain some of the abilities that she lost in the accident. He says that the biggest thing the accident took away is her motivation.

When asked what, if anything, he does for himself, J stated that he has a Harley Davidson that is his escape. He also knows that if he is going to survive, he must get his own life going, but that he, too, lacks motivation.

J feels that the biggest problem faced by people challenged by brain injury is the lack of resources. He believes that there simply must be more long-

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term care facilities run by staff with knowledge of brain injury.

Again, people will tell you that you need take care of yourself. This is much easier said than done. For one thing, you might not even know what “taking care of yourself” means under these circumstances. You may not feel like doing any of the things that previously gave you pleasure. Your physical and emotional energy will be depleted. But find something that does give you pleasure, even if it seems like a small thing, and do not punish yourself for being unable to do everything you could do before. If you wait to do the things you want to do until life returns to normal, you may never do them. “Normal” will never be what it was before, so do not wait. You only have one life.

S is a Denver area mother of three adult children whose youngest child, P, suffered a traumatic brain injury when he was not quite 15 years old. Since being discharged from the hospital, P has always been cared for at home. S emphasizes that you need to have something outside of the caregiving situation for yourself or you cannot be there for the injured person. She would not be of any help to P if she did not balance her own needs with his. In fact, she says that finding such a balance is “crucial.” Her family has been fortunate to have two caregivers in the home for P. P needs his mother to not be constantly worn out and depressed. She uses the analogy of being on an airplane when the flight attendant explains that if the cabin pressure drops and the oxygen mask appears, and there is someone next to you who needs help, put on your mask first, or you will not be able to help the other person.

S also has a supportive husband and two other children who are devoted to their brother, but P’s

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injury has had an impact on all of the choices made by her family. Her other children chose to stay close to home, go to school near home, and play a big part in P's life.

P's injury, says S, has brought blessings as well. He has an effect on everyone he meets. Although he has every reason to wake up every day angry, depressed, defeated, he instead wakes with a smile on his face and a cheerful "good morning." It puts things into perspective. If one of the other family members comes home after a difficult day, it is hard to interact with P and not think, "What do I have to complain about?" In addition, she says, her other children are not clueless about what life can bring. They became aware of the realities of life when they were young.

S believes that we need other people. We need support. She knows a couple of other mothers who have very positive outlooks. Such people have given her great support.

When people speak of their experiences since the injury, they talk in terms of how far "out" they are. When you say you are 18 months out, or 28 months out, it feels like it has been a lifetime. However, professionals and other families usually respond, "Oh, so it's a fairly new injury." That is when you really face one of the hardest parts of living with brain injury - the slowly-dawning recognition that you are in this for the long haul. Life as you knew it will never be the same. There will be times when you think, "I can't do this anymore. I can't go on." But you can, and you will. You will find strength inside you that you never knew you had. Acknowledge this strength and take pride in it.

It is a good idea to check on your loved one frequently when he is in the hospital, because you

know him better than anyone else and may catch things that the doctors or nurses may miss. If you walk into the hospital, or the post-hospital facility where your loved one is residing, and think, "I just can't do this," it is time to take a break. If you are not comfortable taking a day or two off, ask a trusted friend to look in on your loved one. Being with the injured person all the time is not good for him either, as what he needs most is rest.

There will probably be people who work in the hospital or post-hospital settings – social workers, case managers, psychologists – who can give you much needed support. But you will continue to need support, probably for a long time. Rely on the resources available to you – friends, other family members, religious organizations, mental health practitioners, and support groups – and do not be afraid, or too proud, to ask for help. You may often find a much-needed shoulder to cry on, or a simple hug, from the nurses and aides who care for your loved one. You may feel that you have been abandoned by your friends. If you do not hear from them, it does not mean that they do not care. It usually means that they do not know what to say. Tell them that there is nothing they can say that will make things better, that all you need to know is that they are still there and still care about you. Do not hesitate to contact them. You need people you can lean on right now.

Feeling helpless as you watch the survivor struggle to regain as much of himself as he can is a very difficult part of this experience. One way to feel less helpless is to get involved. Become involved in his rehabilitation. Become involved with legislation to provide more services and greater choices for people with brain injuries. Become involved with people who have been through what you are going through. The Brain Injury Association sponsors several events

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during the year to raise funds for various brain injury resources. Volunteer to help at these events. Even if there is nothing you can do to directly help your loved one, raising money for brain injury research and resources can help you feel useful. The Brain Injury Association has family support groups around the state that meet on a regular basis. Check to see if such support groups exist in your area. People who have never stood in your shoes cannot truly understand what you are going through, but when you spend time with other people who have been where you are, there is a certain unspoken connection that permits you to simply be yourself, to not have to put on a happy face or act stronger or more together than you feel. And if you need to talk, or cry, they will truly understand like no one else can.

As your loved one recovers, try to find things you can do with him when you visit, even if it is just watching television or a movie together. Eventually, you might be able to play games, go for walks, go shopping or out to eat. You can rebuild a relationship with him, even if it is not the same as it was before. It takes a long time to accept these changes in your life. Try to be patient with yourself

You will celebrate every small increment of progress – when your loved one begins to speak, when he is able to swallow and no longer needs a feeding tube, when he is able to chew and can eat regular food, when he begins to feed himself. You will be thrilled when he can move himself around in his wheelchair, or when he takes his first steps. As you watch him in his usual environment, you will be constantly aware of improvements.

Be realistic about the long-term effects of a severe brain injury, but do not give up all hope. We were told that at 18-24 months post-injury we would have a fairly good idea of how much our son would recover,

but we continue to see significant improvement after 2-1/2 years. S sees improvement in her son after 19 years. M also stresses the importance of holding on to hope. In addition, much research is being conducted on brain injury and eventually there may be more ways to help those who have suffered such a devastating injury. But balance this hope for the future with the facts as they are today, and do not build your expectations up too high. Research takes time.

Above all, try to be kind to yourself. There comes a point when we have to accept that there is only so much we can do. The survivor of a brain injury is a human being who has suffered a tragedy and deserves to be treated with dignity, compassion, and respect – and so do you.

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## **HAVING A PARENT WITH A BRAIN INJURY: A CHILD'S PERSPECTIVE**

Bradley Hague

Bradley Hague was 11 years old when his mother was injured in a head-on collision. After receiving a B.A. from George Washington University, he has lived and worked in Washington D.C. and London as a freelance journalist.



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I was on a soccer field when my mother was hurt. She was headed to pick up my twin brother when a truck ran a red light and slammed into her head on. She was in the ER for less than 12 hours. She doesn't remember much from the first two years post-injury and it's hard for me to remember as well. My recollection of the early stages of my mother's brain injury is a blur, a whirling meld of days and years crushed into a series of ill-defined memories.

She was a bit of a mess in the beginning; often in terrible pain, her head spun constantly and she was always sleeping. It put a huge strain on everyone. She also cried a lot, and was going to various therapy sessions several times a week. Her neck, head, and shoulder pain continued for 15 years, until she was finally able to get the therapies she needed. It's been nearly 18 years, over half my adult life, and she still isn't able to support herself completely on her own. She has a bookkeeper, a housecleaner, and a driver for errand days. Her injury has had a devastating impact on all our lives.

Having a parent with a brain injury eliminates the ability to have a normal adolescence. You grow up quickly. You have no choice in the matter and the process isn't pleasant. My brother and I were two days away from our 12<sup>th</sup> birthday when my mother was hurt. My sister was 14. All of a sudden, the mother we had, and the family that I was used to, ceased to exist as I knew them.

The routine dynamics of dealing with a brain-injured parent are extremely complex. My mother had wild mood swings for no apparent reason, a lingering tension, and anger at her circumstances. Feelings that she normally repressed were brought out in the open regardless of the emotional impact on us or on her. This emotion was raw, unfocused, unharnessed, and untargeted. The targets of anger

about her mental, physical, or emotional shutdowns were her children as often as herself, or at fate in general. Whether or not outsiders were present, when the "meltdowns" occurred, they were embarrassing for everyone involved; doubly, maybe triply so for a teenager in public.

Moreover, the mental agility of a mother whose brilliance I'd always respected vanished. She was suddenly befuddled by indirect statements. The ability to manipulate a parent, once sometimes enjoyable, lost all necessary effort, and with it all its appeal. It made the woman who taught me pride in thought and the value of speech, seem weak in both. The loss of mental ability was the hardest thing to accept at the time. To some extent, after more than a decade and a remarkable recovery, I still haven't accepted it.

In the early days, my mother could barely walk. The new physical limitations meant that my siblings and I were called on to shoulder a greater burden in maintaining and running the household than we would normally have adopted. Furthermore, rebellion became frequent, frustrating, and ultimately futile. Rebelling about helping with grocery shopping meant instead of facing mere opposition, we faced a potential emotional meltdown, and then, to top it off, the actual possibility of running out of food.

Moreover, my mother's physical limitations meant that actions like driving, attending school events, and the normal physical tasks that make up day-to-day existence, became massive trials, for her and everyone else. These limitations, combined with mental and emotional shutdowns, meant that I had to call 911 to rescue my mother no fewer than three times.

At the moment someone is afflicted with a brain

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injury, the life you knew is over. It is very easy to let a brain injury become the dominant factor in life, even if you aren't the one who was injured. Don't lock yourself into that world. Strengthening your connections to the normal, non-brain-injured world is extremely important. You have to try to maintain the links to the world you knew before. We didn't abandon our mother, or turn away from her when she was injured. But all of us focused on maintaining one section of our lives that was not intimately connected with brain injury. My father buried himself in soccer and ski patrol. My sister surrounded herself with friends, sometimes isolating or avoiding the family. My brother lost himself in his skateboarding. And I withdrew inside myself in order to create that space, becoming socially isolated and awkward. (I don't recommend it, but it can work.) These worlds were touchstones to our sanity allowing us to hold on to the outside world while our home life was in such turmoil.

One of the hardest things about having a parent with a brain injury was that there was no one we could ask for help. I'm sure there were other kids who went through it, but we didn't know any. And since every brain injury is different, other kids' experiences would have been different, too.

In Junior High and High School I wanted to be normal. But when a parent suffers a brain injury, your life becomes extremely *abnormal*. I didn't want my teachers, or anyone else, treating me in any way like I needed special attention. I wasn't a good student, but the activities and events in the high school world, a world so different from my brain-injury-affected home life, helped me to stay sane. It's important to have those touchstones of normality when a parent or spouse gets injured.

There were some good times, and especially as she

progressed there were things my mother did that I was really proud of; in large measure because I knew what she overcame in order to do them. But it was harsh and it was brutal, especially at the beginning.

As my mother built back her life, our family adapted to the changed circumstances. My sister rejoined the family day-to-day, my brother likewise, and I became social once again. But it took years, and my parents' marriage couldn't handle the strain. Though their marriage ended, our family is incredibly close, and living with my mother's brain injury created an independence in every member of the family we would likely not otherwise have had.

My mother's limitations are still there. The severity that once made her brain injury the defining fact of our entire family's existence is gone, but she is still not the mother I had as a child. I will not try to deny that enduring the brain injury of a parent is an unfair and chaotic situation. To be honest, the best that can be said for the first several years is simply this: it gets easier. The trick is to endure the difficulties until life does what life always does...evolves.

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## **Understanding Brain Injury**

## **THE BRAIN AND BRAIN INJURY**

Lenore A. Hawley

An original version of this chapter was published in "A Family Guide to the Rehabilitation of the Severely Head Injured Patient" by Lenore Anne Hawley, copyright Healthcare International, 1984.

## THE BRAIN AND HOW IT WORKS

You may have received information about the brain from your doctor, therapists, or others. The information below is intended to provide a brief overview of the brain and how it works.

The brain is the control board for all of the body's functions, including thinking, moving and breathing. It receives messages, interprets them and then responds to them by enabling the person to speak, move or show emotion. The brain is protected by a thick layer of bone called the skull and is surrounded by cerebrospinal fluid. This fluid allows the brain to "float" slightly within the skull. The cerebrospinal fluid also fills the open areas within the brain called the ventricles.

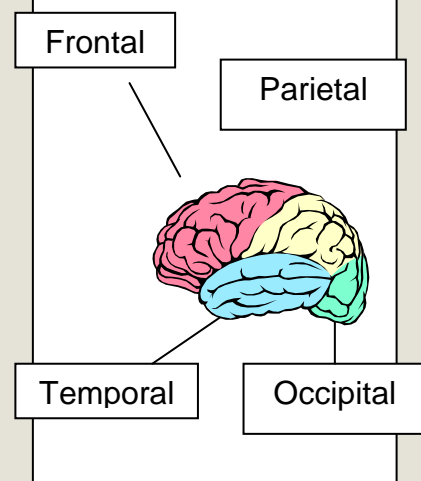
The brain is comprised of the cortex, where most thinking functions occur; the cerebellum, which coordinates movement; and the brainstem, which controls consciousness, alertness and basic bodily functions such as breathing, respiration and pulse.

The cortex is the largest part of the brain and is divided into 4 lobes, each of which specializes in particular functions and skills.

Frontal Lobe: emotional control, motivation, social functioning, expressive language, inhibition of impulses, motor integration, voluntary

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#### LOBES OF THE BRAIN



movement

Temporal Lobe: memory, receptive language, sequencing, musical awareness

Parietal Lobe: sensation, academic skills such as reading, awareness of spatial relationships

Occipital Lobe: visual perception

In addition, the cortex is divided into two hemispheres. The left hemisphere controls verbal functions (speaking, writing, reading, calculating), while the right hemisphere generally controls functions that are more visual-spatial in nature (visual memory, copying, drawing, rhythm).

Damage to the brain may occur at the time of impact, or it may develop sometime after the injury due to swelling or bleeding. When the head is hit with sufficient force the brain turns and twists on its axis (the brain stem) causing a loss of consciousness.

If the person remains unconscious for more than a brief period of time, he or she is considered to be in a coma. While in a coma the person is unable to open his or her eyes, speak or follow commands. If the injury is severe, the area of the brain where the impact occurred may be bruised and damaged. Also, the brain may rebound against the opposite side of the skull resulting in further damage, referred to as contra-coup. Because of the twisting and rebounding which may occur, the person usually also sustains damage to other

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parts of the brain, referred to as diffuse damage.

Hemorrhaging or bleeding inside of the brain may also occur, causing a mass of blood to accumulate. This is called a hematoma. This mass of blood may put pressure on the brain tissue around it leading to further damage. Blood flow to other parts of the brain may also be cut off due to the bleeding. This is called anoxia. Some brain injuries are due to anoxia alone, such as in the case of drowning or cardiac arrest. Swelling, called edema, may also occur following a brain injury, and can cause further damage because the skull does not allow the brain to expand.

### **COMMON CHANGES AFTER BRAIN INJURY**

Physical, cognitive, sensory and personality changes may occur following a brain injury. For many people it is the "unseen" cognitive and personality changes which are the most difficult to live with. When something is difficult to see, it is difficult to understand, accept and explain to the people around you.

Each person's recovery is unique due to pre-injury personality and learning style, location and severity of the injury, time elapsed since the injury and the individual's psychological reaction to the injury. Therefore not all of the problem

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*For many people it is the "unseen" cognitive and personality changes which are the most difficult to live with. When something is difficult to see, it is difficult to understand, accept and explain to the people around you.*

areas listed here may relate to you or your family member.

Some of the changes that occur following a brain injury will resolve over time. Others will get better over time as the healing process occurs and the person develops skills through therapy. Still other problems may remain for the rest of the person's life. It is generally accepted that the most significant recovery will occur early post-injury, in the first 18 to 24 months. However, it is important to remember that people who have sustained brain injuries can continue to grow and develop throughout their lives, just like everyone else does.

### **Motor Changes**

The person may experience paralysis or weakness of one side of the body (hemiparesis), paralysis or weakness involving both legs and both arms (quadriparesis), poor balance, lowered endurance, a loss of ability to plan motor movements (apraxia), and/or abnormal tone and muscle stiffness (spasticity). The individual may also lose the ability to stabilize his or her trunk even though his or her limbs function (proximal instability). Direct damage to the muscular and bony tissue may be sustained resulting in orthopedic problems.

### **Sensory and Perceptual Changes**

All sensory systems may be affected, producing changes in hearing, vision, taste, smell and touch. Such changes may involve an increase in sensitivity or a decrease or loss of sensitivity. These changes may include a heightened sensitivity to touch, resulting in

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tactile defensiveness; a loss of sensation to parts of the body; inability to perceive items on one side of the visual field (visual field deficit); neglect of items located on one side of the body or ignoring one side of the body (unilateral neglect); double vision (diplopia); difficulty perceiving how far away something is (depth perception); decrease in visual or auditory acuity; and loss of the sense of smell or taste. Sensitivity to movement might be heightened resulting in vestibular problems, and the person may have difficulty understanding where her limbs are in relation to her body and the space around her (proprioception).

### **Speech and Language Changes**

The person may have difficulty understanding what other people are saying (receptive aphasia) or difficulty expressing him or herself (expressive aphasia). Some people have a specific difficulty recalling nouns or names, (anomia). People with brain injuries may also have difficulty pronouncing or articulating words (dysarthria).

### **Cognitive Changes**

An individual may be disoriented after a brain injury, confused about the time, where he is, who he is and who the people around him are. For many people this condition resolves, but in severe cases it may remain a problem. If a person is disoriented it is very difficult to engage in any other cognitive function. A

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*Cognitive changes may make it difficult for the person to be self-aware – to assess what he or she is capable of doing or how successful he/she is at a task.*

*It is our personality that identifies us and makes us unique.*

person with a brain injury may have attention and concentration problems, finding it difficult to focus on a task for a period of time without being distracted. He or she may find it difficult to remember information, particularly new, day-to-day information. The person may display poor judgment, not seeming to learn from past experiences. He or she may have difficulty planning events or tasks, drawing conclusions, making decisions, solving problems. He or she may perseverate on one topic or task, finding it difficult to switch from one thing to another, and may have great difficulty adapting to changes in daily routines. The person may find that he or she is more concrete, seeing things at face value and not being able to think abstractly. The person may be unable to pick up on social cues that other people give, so that he/she doesn't "catch" that someone is bored, offended or frustrated in a conversation. Cognitive changes may make it difficult for the person to be self-aware -- to assess what he or she is capable of doing or how successful he/she is at a task.

## **Personality Changes**

Following a brain injury, a person may experience changes in emotion, social skills, social interaction style, and other changes in what we commonly refer to as personality. It is our personality that identifies us and makes us unique. Therefore, personality changes are often very difficult to accept and to live with. The person may become apathetic and unmotivated. He or she may become

## **NOTES**

emotionally labile, that is, showing rapid and extreme emotional changes - crying easily, laughing when it is not appropriate. He or she may be irritable, depressed, or may not have as much initiative. The person may have difficulty inhibiting impulses or emotions, doing or saying things that prior to the injury may have been thought but not acted on. This dis-inhibition may result in angry outbursts, aggression towards people or property, and a generally lowered frustration tolerance. A person who is disinhibited may act upon sexual impulses as well. Some people may become more socially immature by making overly friendly or "silly" comments, not recognizing social boundaries.

## **Seizures**

Seizures may occur immediately following the injury, or may develop months or years post-injury, or may not develop at all. One fourth of people who have early seizures will also experience late onset seizures. Two types of seizures may occur. Major motor or generalized seizures involve rapid body movements, loss of consciousness, and irregular breathing. The person may regain consciousness after a few minutes, feel confused and complain of soreness. In some cases the person may require medication to stop the seizures. A second type is called a focal motor seizure, where the person experiences twitching or jerking movements. The person is usually conscious and the event is not long. Sometimes the person and those around him are unaware that a seizure has occurred. Some people are placed on

## **NOTES**

*People with brain injuries may easily become fatigued and need rest periods throughout the day.*

anticonvulsive medications.

### **Other Changes**

Often people with brain injuries become easily fatigued and require rest periods throughout the day. A person may find it difficult to sit through long tasks and may be able to do things better at certain times of the day than others. Headaches can be a significant problem as well. In addition, the person may experience changes in sleep patterns, or in the ability to regulate body temperature, as well as consumption of food and liquid. Some people may lose control of bowel and bladder.

### **REFERENCES**

A Family Guide to the Rehabilitation of the Severely Head Injured Patient by Lenore A. Hawley, MSSW, copyright Healthcare International, 1984

### **NOTES**

## **THE PLAYERS ON YOUR TEAM**

Jody Newman

Jody Newman, M.A., CCC-SLP is a speech-language pathologist who has been working with individuals with traumatic brain injury since 1977.

Due to the complexity of brain injury and the resulting problems, a team of specialists may be required to meet the needs of an individual with a TBI and his/her family. In most hospitals and rehabilitation facilities, a multi-disciplinary team provides an individualized treatment program, with the goal of teaching skills that improve an individual's level of independence and lead to a greater satisfaction with life. Each specialist brings to the team expertise in a different area of brain injury rehabilitation. The roles and responsibilities of the team members may vary depending on the needs of the individual, the length of time since the injury, and whether a person is an inpatient, an outpatient, or living in a community setting. The person with a brain injury and his/her family are at the center of this team.

## **FAMILY and FRIENDS**

Families and friends are an integral part of the brain injury rehabilitation team. They provide valuable information about the interests, habits, academic and vocational background, and pre-injury behaviors of the individual with a TBI. Family members are encouraged to actively participate in the rehabilitation process because they are a great source of support and motivation to the injured individual. In addition, when families are involved in the treatment process, they have the opportunity to observe, ask questions, and learn how to provide the ongoing care that will be needed at

## **NOTES**

*When families are involved in the treatment process, they have the opportunity to observe, ask questions, and learn how to provide the ongoing care that will be needed at home.*



home.

A physician, (usually a physiatrist or a neurologist) leads the treatment team and is responsible for managing the medical issues of a person with a TBI. The physician also monitors a person's treatment progress, and together with the other team members makes decisions regarding long-term and discharge plans.

## **NEUROLOGIST**

A neurologist is a medical doctor who specializes in disorders of the brain and problems such as moving, thinking, speaking, and pain. A neurologist may be involved in making the initial diagnosis of brain injury and may continue to monitor a person's neurological recovery during hospitalization and later as an outpatient.

## **PHYSIATRIST**

A physiatrist is a medical doctor who specializes in physical medicine and rehabilitation. In hospitals and rehabilitation settings, a physiatrist often coordinates the rehabilitation team, creating a unified approach. The physiatrist is instrumental in sharing information with family members about an individual's medical status, level of recovery, and prognosis.

## **NEUROSURGEON**

The neurosurgeon performs brain

## **NOTES**

surgery and has expertise in diseases of the nervous system. The role of the neurosurgeon is critical early on in assessing the need for surgery, and performing brain surgery in order to save an individual's life.

## **NURSE**

The responsibilities of a rehabilitation nurse vary depending on the stage of recovery and the level of care required. The nurse closely monitors an individual's physical condition, vital signs, level of alertness, nutrition, bowel and bladder functioning, and reactions to medications and treatments. In addition, the nurse administers prescribed medications, assists with routine self-care, and regularly communicates an individual's medical status to the physician and other team members. Families often find the nursing staff a great source of information about how their family member is doing and how to participate in his/her care.

After discharge from an inpatient hospital or rehabilitation setting, your doctor may order home health nursing for monitoring blood pressure or other vital signs, drawing blood, providing education, etc.

## **PHYSICAL THERAPIST**

Physical therapists focus on improving an individual's motor functioning and mobility. They assess and treat the areas of strength, range of motion, balance, coordination, endurance, and motor

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planning. They provide instruction regarding positioning, walking, or wheelchair mobility. The P.T. identifies special equipment that may be needed, such as a walker, cane, or wheelchair and provides instruction on how to use it safely. Prior to discharge from an inpatient facility, the physical therapist may do a home visit to assess safety in the home and any needed modifications. They may also develop a home exercise program to be followed after the individual is discharged.

Physical therapists providing outpatient or home-based services may focus on functional activities, such as setting up an exercise program at home, how to use exercise equipment in a recreation center, or how to get around in the community.

## **OCCUPATIONAL THERAPIST**

An occupational therapist's role is to assist an individual in regaining the physical, perceptual, and cognitive skills needed to perform activities of daily living, (i.e. self-care, home maintenance, and community skills). An occupational therapist evaluates an individual's balance, motor skills, posture, visual, perceptual, and cognitive abilities within the context of functional everyday activities. Use of adaptive devices and strategies may be practiced to achieve the maximum level of independence.

Occupational therapists often provide

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hand therapy or upper extremity therapy to improve functional use, coordination and to reduce spasticity and other upper extremity complications after brain injury. Many OTs are also trained in specific techniques to improve ocular-motor and vision difficulties.

Occupational therapists often are involved in the evaluation and preparation for return to driving.

Occupational therapists working within a home and community based setting may focus on activities such as shopping and meal preparation, organization at home, productive activity, money management, how to access public transportation, etc.

## **SPEECH-LANGUAGE PATHOLOGIST**

Speech-language pathologists are responsible for the diagnosis and treatment of cognitive-communication disorders. They address a range of areas including:

- Language – listening, talking, reading, writing
- Cognition - attention, memory, reasoning, planning, problem solving
- Speech – how one sounds when he/she talks and the motor movements necessary for speech production
- Swallowing
- Social skills

When speech production is not an

## **NOTES**

option, an alternative or augmentative communication system, such as a computerized device may be recommended.

When working in a community-based or home health setting, a speech-language pathologist may work on areas such as conversational skills, setting up daily routines and schedules to assist with memory, planning and organization, problem solving at home, or specific academic or vocational strategies. Education regarding specific strategies to help a person compensate for cognitive and communication problems is often provided by speech-language pathologists.

## **SOCIAL WORKER/CASE MANAGER**

The social worker serves as a link between the injured individual, the family and other team members. The social worker's role may vary depending on the facility; however duties often include providing education and emotional support to individuals and families, problem solving issues related to financial resources, applying for benefits and working closely with the rest of the team in reviewing discharge options. The social worker assists the family in selecting an alternate discharge setting, should a discharge home not be an option. In addition, the social worker may act as an advocate for the injured individual and the family by intervening in problematic situations. Social workers

## **NOTES**

often arrange for any services that will be needed after discharge. In the community, a clinical social worker may provide individual, group or family counseling. A social worker or case manager may provide assistance with information and referral to community resources and services, advocacy, financial and benefit planning and coordination of care.

## **PSYCHOLOGIST**

A clinical psychologist assesses an individual's emotional status, coping systems, intellectual abilities, and behavior. Psychologists also provide counseling to individuals and their families addressing the physical, emotional, and cognitive changes resulting from a brain injury. When behavior problems arise following a brain injury, the psychologist develops a behavior management program to be implemented by the entire team. Psychologists also provide education in stress management and coping strategies to reduce anxiety. Depending on the specific setting, psychologists may provide cognitive therapy.

## **NEUROPSYCHOLOGIST**

A neuropsychologist is a psychologist who has extensive training and expertise in the area of brain/behavior relationships. In addition to providing the services described above under the role of the psychologist,

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neuropsychologists administer a comprehensive evaluation of a person's emotional, intellectual, and cognitive skills. The neuropsychologist's role on the rehabilitation team is to assist in the identification of specific cognitive, social, and emotional skills that require treatment and to monitor changes in those areas.

When working in a community-based setting, a neuropsychologist administers a comprehensive assessment of an individual's intellectual, emotional, and cognitive abilities to help determine whether a brain injury has occurred and to document the extent of any psychosocial and cognitive impairments. They may also provide counseling and psychosocial support.

## **DIETITIAN**

Dietitians are responsible for recommending a daily diet that meets an individual's nutritional needs. They review a person's current and prior dietary restrictions, patterns of weight gain and loss, and prior eating habits. When an individual has chewing or swallowing problems, the dietitian works closely with other team members in the selection of food consistencies that can be safely swallowed. Prior to discharge from an inpatient setting, the dietitian may provide information to the individual and family regarding any specific nutritional needs, as well as, how to maintain a balanced diet at home.

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## **RESPIRATORY THERAPIST**

The respiratory therapist is usually involved early in the rehab process and works together with the physician and nurse in caring for individuals with breathing difficulties. Some of the duties of respiratory therapists include: administering breathing treatments, maintaining trachs, and monitoring breathing equipment, such as ventilators. The respiratory therapist works together with the nursing staff and the physician to educate the individual and his/her family about the use of any special equipment that may be required.

## **THERAPEUTIC RECREATION SPECIALIST**

The certified therapeutic recreation specialist (recreation therapist) provides the opportunity for an individual to plan and participate in leisure activities. Due to cognitive or physical limitations following a brain injury, the recreation therapist may assist an individual in modifying previous leisure activities to address his/her specific needs. In addition, a recreation therapist helps individuals identify and explore new leisure activities. Therapy is often group oriented and may include a wide range of activities, such as horseback riding, swimming, gardening, crafts, community outings, and special events. The recreation therapist acts as a resource to the individual and family in

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identifying activities within the community that the whole family can continue after discharge.

## **VOCATIONAL REHABILITATION COUNSELOR**

The vocational rehabilitation counselor's goal is to assist an individual in resuming appropriate and realistic employment or other productive activity. They assist an individual in determining what he/she would like to do, and whether he/she is capable of performing the job. Vocational rehabilitation counselors review academic and medical records, interview individuals with TBI and their families, and talk with other team members to determine the current capabilities of an individual. They also work closely with employers to locate appropriate positions, provide education about any job accommodations needed, facilitate placement in positions, and monitor an individual's performance. After working with a vocational rehabilitation counselor, individuals may seek further training or education, return to a previous job, be assisted in finding a new competitive job, a volunteer opportunity, or in finding supported employment or a program where job skills training is provided.

## **HOME HEALTH SERVICES**

Your physician may recommend Home Health Services such as physical therapy, occupational therapy, speech-

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language therapy, and/or nursing care when a person with a brain injury is discharged from an inpatient setting. These providers will continue to be monitored by a physician and should continue to work as a coordinated team.

For additional information about your team members, the following websites may be helpful:

American Physical Therapy Association  
– [www.apta.org](http://www.apta.org)

American Occupational Therapy Association – [www.aota.org](http://www.aota.org)

American Speech Language and Hearing Association [www.asha.org](http://www.asha.org)

American Psychological Association – [www.apa.org](http://www.apa.org)

American Dietetic Association – [www.eatright.org](http://www.eatright.org)

American Rehabilitation Counseling Association – [www.arcaweb.org](http://www.arcaweb.org)

American Therapeutic Recreation Association – [www.atra-online.com](http://www.atra-online.com)

## **PLAYERS ON YOUR TEAM AT SCHOOL**

When your child returns to school after a brain injury, an Individualized

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Educational Plan (IEP) may be developed. An IEP is a written plan that documents the nature of the disability and whether or not your child is eligible to receive special education services. If your child is eligible, an IEP outlines a plan of services based on your child's current abilities and needs and includes specific goals and objectives as well as the access to state funding for the recommended services. Following a brain injury, a child may be placed in a regular, general education classroom with very structured and concrete instruction of academics. In addition, that same child may receive services such as physical therapy, occupational therapy, or speech-language therapy. A child may also be placed in a smaller, more structured classroom, depending on the severity of the injury and the specific needs of the child. It is important to stay in touch with your child's school to provide education about your child's brain injury, share medical records with his/her teachers, and discuss any specific problems areas. Some school districts have a designated brain injury team, but many do not.

Your child's team may include any of the professionals discussed earlier in this chapter as well as any of the following professionals who work in schools:

### **CLASSROOM TEACHER**

The teacher provides information about how a child with a brain injury is performing in the classroom in areas

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such as, reading, following directions, math, writing, behavior, etc. Specialists on your child's team may assist the general education teacher in adapting teaching strategies to meet the needs of your child following a brain injury.

### **SPECIAL EDUCATION TEACHER OR LEARNING DISABILITIES SPECIALIST**

Learning disabilities specialists and special education teachers are teachers with a degree in the area special education and/or learning disabilities. They are experts in helping children with learning differences perform successfully at school. While they may need some information about the specific effects of a brain injury, their skills lend themselves to helping children learn and achieve success at school following a brain injury.

### **CASE MANAGER**

The case manager at school is the leader of your child's IEP team and is responsible for scheduling IEP meetings with you. They also communicate important information about your child's progress and needs to the entire team. In most schools, when a student has a brain injury, there is not a specific team member that is automatically assigned as the case manager. Any of the main team members may assume that role, depending on their caseload and the needs of the child.

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## BEHAVIOR SPECIALIST

The behavior specialist is a staff member with additional training in the area of behavior management. They are experts in helping children with behavior or emotional challenges perform successfully at school. Behavior specialists observe the child during class and transition times, develop a behavior management program based on teacher reports and their own observations, and then educate teachers and parents about how to consistently implement the behavior program. If one of the main problems following a TBI is having behavioral outbursts that interfere with learning, then the behavior specialist may be the case manager of your child's special education team.

## LIFE SKILLS SPECIALIST

The life skills specialist (sometimes called by another name depending upon the district) has special training in serving the needs of a child with multiple disabilities. The life skills specialist helps manage the care and education of students that are often more severely affected by a brain injury. They provide assistance with the daily routines such as toileting and eating.

Other members of your child's team at school may include a hearing or vision specialist, para-professional (or teacher

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*Each and every member of your child's IEP team has an important role and contribution. We know that a healthy partnership between a child's home and school team facilitates a smooth transition.*

assistant TA), counselor, dean, principal or assistant principal, in addition to any of the professionals described earlier in this chapter. Each and every member of your child's IEP team has an important role and contribution. We know that a healthy partnership between a child's home and school team facilitates a smooth transition. It is important for you to provide general information about brain injury, as well as, specific information about the needs of your child to the team at school, since experience working with students with brain injury varies among teachers and schools.

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## **UNDERSTANDING EMOTIONAL, INTERPERSONAL, AND BEHAVIORAL CHANGES AFTER BRAIN INJURY**

Lenore A. Hawley

This chapter was originally published in the first edition of the SAIL Workbook. It has been updated and is published here with an additional section on

### **SUICIDAL THOUGHTS AND BEHAVIOR**

by

Jennifer Olson-Madden

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Emotional, interpersonal and behavioral changes may occur after a brain injury. These changes can make it difficult for a person to successfully return to previous roles in the family, in the community, and at work. Family members may experience emotional changes after the injury as well. Understanding these changes can help you be a better self advocate.

## **EMOTIONALCHANGES**

There are a variety of emotional changes or challenges that may accompany brain injury. Some of these are related to changes in the brain. Others may be related to your emotional reaction to the injury. You also may find that emotional problems you were experiencing before the injury seem more troublesome now.

### **Emotional Lability**

An injury to the brain may lead to emotional lability. This means the injured person may have sudden or extreme emotional responses that are difficult to control. The person may cry more quickly, or become angry more easily. This can be difficult for other people to understand. Emotional lability may improve over time. However, sometimes these emotional outbursts become worse over time when they are reinforced. It can be helpful to let family and friends know if this is a problem for you or your loved one.

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- Ask people to respond to emotional lability in a calm manner
- Reduce the noise and activity in the environment
- Redirect – change the subject, or change the activity

### Depression

Depression can be a problem for both the injured person and for loved ones. For the person with brain injury, depression may be difficult to separate from some of the neurological changes that have occurred. These neurological changes can lead to low motivation, a flat affect, and reduced drive. If you are depressed, you may notice a loss of interest and enthusiasm, changes in eating, changes in sleeping, and increased irritability. You may notice a change in how you care for yourself -- not paying attention to personal grooming, letting housekeeping and other chores go unattended, etc. You may also withdraw from other people.

These problems may remain over time. It is best to seek professional help when you or your loved one may be suffering from depression. A psychiatrist, psychologist or clinical social worker can evaluate the problem and facilitate treatment. Treatment may involve therapy, anti-depressant medication, or both. Because the symptoms of depression can be similar to other symptoms related to brain injury, it is

**important that the mental health professional is knowledgeable about brain injury** as well as general mental health.

### Anxiety

A person may feel more anxious after brain injury. He/she may feel nervous and not know why. Sometimes a person feels a loss of confidence after brain injury and begins to doubt his decisions or actions. The person may become easily overwhelmed by noises or multi-tasking which can add to a feeling of anxiety. If anxiety becomes a problem for you or your family member, seek professional help from a mental health professional knowledgeable about brain injury. Take a look at your lifestyle and activities. Are you doing too much? Are you often multi-tasking? Do you leave time for a cognitive break in your day? Do you do stress relieving activities such as yoga or meditation? Review the chapter on Alternative Medicine for additional information.

### Grief

Grief is a natural and difficult process that follows a major loss. When that loss is final, such as when there has been a death of a loved one, the process seems to continue through a series of stages: denial, anger and frustration, depression and withdrawal, and acceptance. However, when someone is living with a brain injury the course of grief can be more complex and may not follow this same series of stages. You or your family member may be grieving the

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*Grief is a natural and difficult process that follows a major loss.*

loss of a former job, the loss of relationships, the loss of cognitive skills, or the loss of the future plans. People have described it as a process from one stage to another and sometimes back again as recovery occurs and new challenges, plateaus, and successes are reached.

There are no simple answers for dealing with grief. Sometimes people find that it is helpful to set new goals for oneself – goals that are realistic and can be accomplished in a short period of time. Many people find that it helps to be around other people who are going through the same thing, whether that is other members of your own family, or other families who are living with brain injury. Early in the recovery process, some people find that they are not ready to talk with others who have experienced brain injury. However, later in the process, many individuals find this to be helpful.

Everyone experiences grief differently and finds comfort differently. Members of the same family will experience grief differently as well. Children may "act out", getting in trouble at school or in the community. They may isolate themselves, or experience a drop in academic performance. Some people, children or adults, may experience extreme guilt which the person may not share with the rest of the family. Spouses may feel particularly isolated from the injured spouse. The person whom he/she would usually turn to in a

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*Each person may experience grief in his or her own individual way, and may find comfort in different ways as well.*

time of need now has a brain injury and may not be able to be as supportive. The non-injured spouse may find that suddenly there is no time to deal with his or her own grief as the bills pile up, children are in need, and decisions need to be made. Friends may seem less available, especially if they were friends of “the couple” and now the couple has changed.

Pay attention to changes in behavior in any member of the family, or to responses that don't seem "normal", such as someone in the family who is not showing any emotional response to the injury. Don't be afraid to ask for help. Family members sometimes feel that because they are not the injured person, they do not have the right to seek help for themselves. Or family members may feel that so much time has passed since the injury that they "shouldn't feel this way" and don't want to "bother" anyone with their problems. If you feel that grief is having an ongoing effect on your life, seek professional help.

## **INTERPERSONAL OR SOCIAL CHANGES**

There are also interpersonal or social changes that can occur after brain injury. These may be related to changes to the brain or changes in your work and social situation. Social problems may also occur because of the attitudes and fears of people in your community. They may not know how to approach someone who has a brain injury. Some of these

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interpersonal and social changes are described here.

### Loneliness

Loneliness can be a problem for family members *and* for the injured person. After brain injury, marriages can become strained, friends may not know what to say, and work relationships may no longer be available. You may find that you need to put more effort into friendships and socialization in a way that you did not have to before. You may need to take a class, join a group, or use a dating service, in order to meet people. All of these things take initiative.

Some people do not want to socialize with other people who have had a brain injury. They may feel that this is a group they do not want to be identified with. This is a personal choice. Just because you have sustained a brain injury does not mean that you will enjoy the company of someone else who has as well. However, you may want to consider every avenue for friendship, support and social contact. Other people who have sustained brain injuries may be more open to your needs, and may help you to realize that you are not alone.

Some people find that church activities, volunteer work, or organized recreational activity is helpful. Volunteering has been found to improve well-being, and provides a way to meet new people. It is important that you choose strategies that are of interest to you and feel right.

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Ideas for increasing socialization can be found in Chapter 24 which begins on page 391.

### Intimacy and Sexuality

Along with loneliness, many people find a loss of interpersonal intimacy and sexual intimacy following brain injury. Intimacy refers to a close, confidential, sharing, trusting, affectionate relationship.

Intimate relationships include sexual and romantic relationships, as well as close intimate friendships. In either case, the loss of intimacy following brain injury can be very difficult. We all have a need to be touched, to be confided in, to have someone with whom we can share our deepest thoughts and emotions, and to love and be loved.

Sexuality does not just mean the act of sex. It involves intimacy, touch, and our own concept of who we are as a sexual being. The social losses that lead to loneliness can lead to problems in sexuality. In addition, there may be neurological or physiological problems which interfere with a person's sexuality. These problems can make it difficult to perform sexually, and can lead to a decrease or increase in desire for sexual intimacy. Impaired communication skills may make it difficult for a couple to communicate about intimacy and sexuality. The psychological responses to the injury may also affect sexuality (anxiety, depression, grief, etc.). A person may also experience a decrease in self-esteem, feeling unattractive and untouchable.

Treatment providers must address our own "hang-ups" about discussing

sexuality as a valid concern for a person who has had a brain injury. People who have sustained brain injury and their families should be open about discussing sexuality and not brush it aside, to be dealt with later. Sometimes, it is a problem that requires professional intervention. Your needs are real and you have the right to get help.

*Below are some tips for developing and maintaining relationships:*

1. **Start simple:** Some relationship skills are the same, whether you are trying to begin a casual friendship or a romance. If you are frustrated in your efforts to find the perfect romance, start by working on developing new friends. It can give you the practice and the self-confidence to develop more intimate relationships down the road.
2. **Evaluate your current interpersonal skills:** How are you doing? Are you a good friend/brother/wife etc.? Do you talk too much or too little? Do you bring up new topics to keep conversations interesting? Ask your friends to give you feedback regarding what you do well socially and what could be improved. Use this feedback to help you succeed at new relationships.
3. **Be active:** Get out and be where other people are. Do activities that are fun and that make you feel good. An active and confident person is more attractive and easier to interact with.

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4. **Practice good social communication skills:** People love to be around people who listen. A good listener maintains eye contact, asks questions, remains attentive and is empathetic. Read the newspaper, take up a hobby, or become involved with other activities so that you have new and interesting topics to bring up in conversation.
5. **Be comfortable for others to be around:** Observe boundaries -- standing too close to someone or touching someone you don't know may make the person uncomfortable. Pay attention to any mannerism or habits you may have that may make people uncomfortable, And remember to take good care of yourself and your personal grooming.

## **PROBLEMATIC BEHAVIORS**

Sometimes after brain injury, people develop changes in their behavior that become problematic. These are often referred to as behavior problems. These behaviors may break social rules, or may be potentially dangerous. Behavior problems can get in the way of successfully reintegrating into relationships, work and society. Some behaviors become so problematic that the person needs to live in a structured setting. The purpose of this section is to give you information so that you can help manage some of these behaviors, and become a more successful and

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*A good listener maintains eye contact, asks questions, remains attentive, and is empathetic.*



independent self-advocate. If you are the person with a brain injury, you can use this information to manage your own behavior. If you are a loved one, you can support your injured family member as he manages his own behavior.

Where do behavior problems come from? Where the problem comes from tells you a lot about how you should respond to it. Behavior problems following brain injury often stem from three sources: 1) the neurological changes after brain injury, 2) the person's psychological reaction to the brain injury, and 3) how the environment responds to the person. A behavior problem may be linked to one or all of these sources.

1. **Neurological Changes:** There are a number of cognitive (or thinking) skills that can be disrupted following brain injury, such as attention, memory, judgment, etc. There can also be changes in a person's ability to regulate emotions. The combination of these cognitive changes and decreased control over emotions can lead to a person becoming easily frustrated, overwhelmed, or irritable. People often describe a lack of patience or lack of tolerance that they did not feel before the injury.

2. **Psychological Changes:** Most people who sustain a brain injury

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experience a range of normal emotional responses. The person may feel *anger* that such a thing has happened, *sadness* over the losses that have occurred, *anxiety* and fear of the unknown, *frustration* due to the difficulty of daily tasks that were once simple. These psychological reactions can contribute to a person feeling frustrated, overwhelmed, or irritated.

3. **Environmental Response:** The environment is the physical and social world in which the person lives. The environment responds to the person's behaviors. How the environment responds can lead to behaviors increasing, or decreasing. For example, if someone wants to be left alone, he may yell in frustration. The people around him may then leave him alone. Yelling got the person what he wanted, so the next time he wants to be left alone he may try yelling again.

These three sources of behavior change can interact with one another. If we take the time to understand where a behavior comes from, we have taken the first step to positive behavior change.

### DECREASING BEHAVIOR PROBLEMS

Whether you are concerned with your own behavior or the behavior of a family member, here are some tips for decreasing behavior problems:

1. **Evaluate:** Where is the behavior coming from? Am I feeling overwhelmed, confused,

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embarrassed, or sad? Am I tired, or am I trying to do something that is too hard? Or, why is my loved one acting this way? Is there too much commotion in the house? Have we changed his routine too much? Always start by looking at the behavior and figuring out where it may be coming from.

**2. Be Consistent, Repetitious, and Structured:**

When someone sustains a brain injury the person loses some of the internal structure that helps him or her organize information and make decisions. The person may need to get that structure from the environment. You can help by keeping to a routine, putting things in the same place every day, labeling drawers and cabinets, writing things down, and having a list of things to do during leisure time. The person who has difficulty learning will need lots of repetition to learn new information. If you are a family member, be consistent in how you respond to the injured person and in what you expect of him or her. If there is a problem behavior, decide how everyone is going to respond to it, and stick to it.

**3. Monitor the Stimulation in the**

**Environment:** Are there too many distractions, too much going on? Is the T.V. on all the time, too many people coming by to visit, or are the kids making a racket? People who have brain injuries need to learn to tolerate noises and activity, but they need to do so gradually and they will probably reach a ceiling in their tolerance level. Watch how you or your loved one responds to different stimuli, particularly when fatigued, and then change the environment accordingly. Perhaps there are certain times of the day

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when the phone needs to come off the hook, or when the T.V. needs to be off.

4. **Be Respectful:** Be respectful of the injured person's privacy and his or her ability to make decisions. Respect the person's right to be in charge of his or her life, and to learn from mistakes. If you are the injured person, be respectful to yourself. Pay attention to the little things you say to yourself, and avoid putting yourself down. Know that you should be involved in any efforts to manage your emotions and behavior.

### **What Do I Do When a Behavior Becomes a Problem?**

Once a behavior becomes a problem, you can continue to use the prevention suggestions mentioned above, but you may want to also use the following strategies to help manage the behavior.

### **Increase Positive Behaviors**

**REINFORCEMENT:** Reinforcers are events following a behavior that increase the probability that the behavior will occur again. The main way in which we increase behaviors is by reinforcing them. We do this all the time. We do it for ourselves and for other people. If we want someone of the opposite sex to continue to pay attention, we smile and say nice things. Someone who wants to

### **NOTES**

*Respect the person's right to be in charge of his or her life, and to learn from mistakes.*

lose weight might promise herself a new outfit when she reaches her goal weight. Reinforcers can be tangible things, like food, or intangibles such as compliments or smiles. An important key to reinforcement is finding the right reinforcer. What works for one person does not work for someone else. It needs to be something that is worthwhile to you (if it is your own behavior you are trying to change) or to the friend or loved one you are trying to help. For example, you may decide to quit your job. Your boss offers you a raise to try to change your mind. For you, money may not be the primary reinforcer for working. You may be more reinforced by challenging work, responsibilities, or positive feedback from your boss. We learn what is reinforcing by watching our behavior/ the person's behavior. Be open and creative in finding reinforcers.

2. CATCH 'EM DOING GOOD: When someone does something that is problematic or irritating it usually draws attention. But when someone is doing something good, it may go unnoticed. Catch those good things, and catch them as soon as they happen. Give the person immediate feedback, ("you really kept your cool during that conversation", or "Did you realize that you used to get angry and yell when this happened and this time you didn't?"). If you are trying to change your own behavior, ask the people around you to give you immediate feedback when you are successful in managing your behavior.

3. SHAPE A SMALL BEHAVIOR INTO SOMETHING BIG:

Sometimes you may feel that reinforcement is impossible because the person is never doing the behavior that you want to reinforce. If you catch the person doing something that even slightly resembles the behavior, use that as a

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starting point. Reinforce any little glimpse of the behavior, and then slowly begin expecting more before you reinforce it again.

4. **CONTRACTING:** It can be helpful to develop a written contract, outlining what you expect of the person and why and how it will "pay off" for the person. You can even write a contract with yourself! You can write a contract where you agree to fulfill certain goals and agree to certain rewards or consequences. Everyone involved should sign the contract and have a copy of it, kept in a place where it will be a constant reminder. It can also be useful to keep charts and graphs of behavior changes as a form of feedback on progress.

### **Decreasing Behaviors:**

1. **TAKING AWAY REINFORCEMENT:**  
One way to decrease a problem behavior is to take away what is reinforcing it. What is keeping the behavior going? What do you (or your loved one) like about the particular behavior? Once you have figured out what is reinforcing the behavior, you need to *consistently* extinguish it. This is tough to do but very important. Reinforcement that occurs sometimes but not all the time is called "intermittent reinforcement" and it can be quite difficult to stop a problem behavior when there are intermittent bouts of reinforcers that keep that behavior going. For example, let's say

that you are attempting to ignore a person's problem behavior, but finally you just can't stand it any longer and you give the person attention for that behavior. This "reinforces" the problem behavior, and despite your best efforts, you have taken a big step backwards in extinguishing the problem. The key is to try to be consistent, even when it is difficult.

2. **NATURAL CONSEQUENCES:** This is also something we use all the time. If you speed down the highway, you eventually will get a ticket. If your spouse shows up late without calling, he may find himself eating a cold dinner. If your son gets angry and breaks a vase, you may tell him he has to buy a new one. This strategy works best when the consequence is something natural -- something that makes sense to the person. For example, if your son becomes angry and throws his cell phone against the wall, the natural consequence is that he has no cell phone.

Problem behaviors can be difficult and frustrating. What works for one person will not work for another. The ideas presented here are general principles and guidelines. In some situations you may find that you need an objective professional's help to deal with problem behaviors.

We hope that this chapter helps to outline some of the common emotional, interpersonal, and behavioral problems that

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you or your loved one might encounter, and provides some insights toward solutions to those issues.

## **Suicidal Thoughts and Behavior**

Jennifer Olson-Madden, Ph.D.

The emotional aspects of TBI can be difficult to deal with and may often lead survivors to think about ending their lives, in order to “end the pain/frustration/fear.” The fact is, millions of Americans have suicidal thoughts and each year thousands make suicide attempts. Suicide is a major leading cause of death in the United States, accounting for approximately 31,000 deaths per year (CDC, 2006). In the US each year, white males account for approximately 73% of suicide deaths (Maris, Berman & Silverman, 2000). Although proportionally the rate of *completed suicides* is highest for older White males (Maris et al., 2000), it is individuals between the ages of 15 and 24 who make the largest number of suicide *attempts*.

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*Be aware of the risk factors and warning signs for suicide.*



It is very important for survivors and family members to realize that suicidal behavior has been identified as a **significant problem** among those with a history of traumatic brain injury (TBI). The following are just a few statistics regarding the combination of TBI and suicidality:

- Simpson and Tate (2002) found that 23% of individuals with TBI receiving outpatient services thought about suicide.
- TBI survivors also have a significantly higher rate of suicide attempts than those without such injuries (Silver, Kramer, Greenwald, & Weissman, 2001; Simpson & Tate, 2007).
- Individuals with a history of TBI also die by suicide more frequently than members of the general population (Teasdale & Engberg, 2001).
- Also, individuals with severe TBI are at 3 - 4 times greater risk of death by suicide than the general population and are more likely to have significant suicidal thoughts.
- Individuals with histories of psychiatric diagnoses (like depression), emotional disturbance, and substance abuse problems were 21 times more likely to have made a post-injury suicide attempt than those without such histories (Simpson & Tate, 2005).
- Specific risk increases for those who have sustained a **concussion** (i.e., 3 times the risk), a **cranial fracture**

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(i.e., 2.7 times the risk), or a **cerebral contusion/traumatic intracranial hemorrhage** (i.e., 4 times the risk)

Paying attention to the potential for risk, considering both risk and protective factors, and knowing what to do to help yourself or your loved one is very important. Below is information about how to identify risk factors and warning signs, and what to do about suicidal thinking or behaviors.

**Factors that may increase risk for suicidal thoughts and attempts:**

- Previous suicide attempt(s)
- Current ideation (thinking), intent to harm oneself, plan, and/or access to means (i.e., weapon, pills, etc.)
- Family history of suicide
- Alcohol/Substance Abuse—this is particularly important, as individuals with TBI also may be at greater risk for having problems with alcohol and substance use
- Recent discharge from an inpatient psychiatric unit
- Previous history of psychiatric diagnosis
- Co-occurring health problems (i.e., a newly diagnosed problem or worsening symptoms)
- Impulsivity and poor self control
- Feelings of hopelessness
- Recent losses, including physical, financial, or personal
- History of physical, sexual, or emotional abuse

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**Factors that may decrease risk of suicidal thoughts and behaviors:**

- Life satisfaction
- Spirituality
- Sense of responsibility to family
- Children in the home, establishing a family
- Ability to “test” reality, think “realistically”
- Positive social support
- Positive coping skills
- Positive problem-solving skills
- Positive therapeutic relationship with a therapist, doctor or other healthcare provider
- Positive support from family

**Suicide Warning Signs**

The following suicide warning signs were developed by expert consensus (Rudd, et al., 2006).

Signs that require immediate action and safety measures:

- Threatening to hurt or kill oneself
- Looking for ways to kill oneself: seeking access to pills, weapons, etc.
- Talking or writing about death, dying, or suicide

Signs to consider and that require attention, especially in the presence of any of the above signs or other known risk factors:

- Hopelessness
- Feeling trapped – like there’s no way out
- Increased alcohol or drug use
- Dramatic changes in mood

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- Withdrawing from family, friends, or society
- Anxiety, agitation, unable to sleep, or sleeping all the time
- Rage, anger, seeking revenge
- Acting reckless or engaging in risky activities, seemingly without thinking
- No reason for living; no sense of purpose in life
- Increase in substance and alcohol use

### **Why are those with TBI at Increased Risk for Engaging in Suicidal Thoughts and Behaviors?**

Sustaining a TBI can be stressful:

- Potential loss of a support system
- Loss of a job or income
- Major depression or other psychiatric problems could occur
- Change of role in the family unit
- Decreased ability to function as a parent
- Decreased ability to function as a spouse or significant other

TBIs can contribute to limited problem-solving strategies:

- Difficulties with memory, learning and thinking
- Poor judgment
- Impulsivity
- Poor decision-making ability
- Medical/physical concerns that cause problems with mood

### **What precipitates suicidal thoughts in people with TBI?**

- Loneliness

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- Lack of connection
- Holidays/Anniversaries
- Lack of support
- Social anxiety
- Job/employment issues
- Lack of resources
- Frustration over new tasks
- Bad news about prognosis

**Things that can help people who are suicidal:**

- Psychotherapy
- Medication
- Support groups
- Having accessible providers
- Having a belief system, spirituality, or sense of meaning
- Distractions, such as having something to do, watching TV, taking a walk, or working on the computer
- Having a responsibility such as taking care of a pet or a job
- Having family and friends who care
- Volunteering
- Attending support and therapy groups and activities

**What families and care providers should know or do to help:**

(With thanks to Lisa Brenner, PhD, Beeta Homaifar, PhD, and Jan Kemp, RN, PhD and the Denver VA Medical Center for the following information based on interviews of 13 survivors of TBI and their families)

- Take more time
- Promote independence
- Repeat everything MANY times

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- Recognize that accessing resources can be difficult
- Family and couples counseling is helpful
- Group interactions are helpful
- Provide consistent monitoring and follow-up
- Communicate that suicide is a possibility, and TALK ABOUT IT
- Coordinate care between ALL providers
- Medication can help, but be aware of what it does
- ADVOCACY is necessary; written communication may not be enough!
- Involve family and friends, especially since survivors may forget to give all the information
- Caregivers need help too, to avoid burden and burnout
- Consider respite services from time to time

## **SUICIDE RESOURCES**

National websites:

Suicide Prevention Resource Center:

<http://www.sprc.org>

American Foundation for Suicide

Prevention: <http://www.afsp.org>

American Association of Suicidology:

<http://www.suicidology.org>

National Toll Free Number:

National Suicide Prevention Lifeline: 1-800-273-TALK

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## **MILD TRAUMATIC BRAIN INJURY**

Jody Newman

A mild traumatic brain injury sometimes called mild head injury or post-concussion syndrome, is an injury to the brain, such as a blow to the head (blunt trauma), or whiplash-type injury (acceleration/deceleration) meeting the following criteria:

- ❖ Brief loss of consciousness: less than 30 minutes, or no loss of consciousness
- ❖ Glasgow Coma Scale: 13-15
- ❖ Post-traumatic amnesia: less than 24 hours, or no PTA
- ❖ The person may be briefly confused or dazed, immediately following the injury
- ❖ Results of neuroimaging scans, such as CT and MRI, are normal
  - If there are abnormal findings on CT or MRI scans, and the other criteria listed above are met, the brain injury is considered to be in the “complicated mild” category.

For information on BLAST INJURIES, please refer to the chapter on *The Special Needs of Soldiers and Veterans*.

## **COMMON SYMPTOMS OF A MILD TRAUMATIC BRAIN INJURY**

There is a wide range of symptoms experienced following a mild brain injury. Some symptoms may be present immediately following the injury, while others may become apparent days or weeks later.



- ❑ Headache
- ❑ Dizziness
- ❑ Fatigue
- ❑ Slowed thinking
- ❑ Decreased concentration
- ❑ Decreased memory
- ❑ Irritability, short-tempered
- ❑ Sleep disturbance
- ❑ Sensitivity to light or noise
- ❑ Balance problems
- ❑ Blurred vision
- ❑ Behavioral or mood changes
- ❑ Problems accomplishing tasks
- ❑ Depression and anxiety

Following a mild brain injury, individuals may appear normal and their impairments may not be obvious in a casual conversation. However, these symptoms may be more apparent when the person with a mild traumatic brain injury is fatigued, under stress, or attempts to resume pre-injury responsibilities, such as work. For most people the symptoms associated with a MTBI are temporary and resolve quickly. However, in some cases the symptoms may persist.

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*Symptoms of mild TBI may be more apparent when the person is fatigued or under stress.*

## WHAT CAN I DO TO ENHANCE MY RECOVERY PROCESS?

- ☐ Seek medical treatment from professionals with experience treating people with mild traumatic brain injury
- ☐ Take a family member or friend with you to medical appointments
- ☐ Slow down your pace - even with simple tasks
- ☐ Allow more time to accomplish tasks
- ☐ Take breaks and naps as needed
- ☐ Use a calendar, smart phone, or day- planner to organize your schedule
- ☐ Set up daily routines for accomplishing ongoing chores
- ☐ Carry a notebook, small pad, or smart phone to write down important information and dates
- ☐ Reduce the number of things you try to accomplish in a day
- ☐ Set small realistic goals and break large tasks into smaller steps
- ☐ Do one small task at a time
- ☐ Learn about your brain injury and educate others (family, friends, co-workers)
- ☐ Limit external stimulation (lights, noise, and crowds) when trying to concentrate

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*Set small realistic goals and break large tasks into smaller steps.*

- ☐ Attend support groups and seek out others with mild brain injury
- ☐ Protect your brain from a second injury by wearing a seat belt while in a car and a helmet while bicycling, skiing, skate boarding, rollerblading, snowboarding, etc.

**If you suspect that you or someone you know has a brain injury, you should contact a physician, go to an emergency room, or contact 911 in the case of emergency.**

## **REFERENCES**

Brain Injury Association of America website: [www.biaa.org](http://www.biaa.org)

Mild Traumatic Brain Injury Committee of the Head Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine (1993).

National Institute of Neurological Disorders and Stroke (NINDS) website: [www.ninds.nih.gov](http://www.ninds.nih.gov)

Proceedings of the Mild Head Injury Conference 1991. Copper Mountain, CO.

SAIL: Self Advocacy for Independent Life Edited by Lenore A. Hawley, The Brain Injury Alliance of Colorado, Denver CO, 1995

## **TBI IN MILITARY PERSONNEL AND VETERANS**

Jennifer H. Olson-Madden

## **Introduction**

Military personnel and veterans may face a number of issues related to their services in the military. One of the risks and costs of service could potentially be traumatic brain injury (TBI). Certain military assignments, such as airborne operations or policing in combat areas, often carry more risk of TBI than other military assignments. In fact, TBI is often discussed as a casualty of the war in Iraq (Warden, 2006). There are many reasons for this including the widespread use of explosive devices in combat, the belief that blast injuries may be a growing cause of TBI in combat, and the greater likelihood that mild TBI (mTBI) could be diagnosed among wounded military personnel. Military personnel and veterans may also experience intense stress reactions or Post Traumatic Stress Disorder (PTSD) as a result of their experiences in the military and/or combat. The combination of both PTSD and TBI is complicated because it can be quite difficult to assess, diagnose and treat. However, military personnel, veterans and their families should be aware of these issues and have an understanding of the options available to them through various government, military, and veteran care services.

This chapter will provide military TBI survivors and their families with information about the complexity of assessing and treating various levels of TBI severity and co-occurring disorders (specifically, PTSD), as well as provide

*“The worst part is, with traumatic brain injury, people can’t see it. And they see on the outside that I move around. I do this, and I do that, but they don’t see the struggle inside: the memory loss, the struggles to remember, the struggles to forget.”*

(Military TBI survivor)

information and resources within military and veterans hospitals. Information in this chapter was adapted from several important sources including: The Department of Veterans Affairs (DVA); Defense and Veterans Brain Injury Center (DVBIC); The National Center for Post Traumatic Stress Disorder ([www.ptsd.va.gov](http://www.ptsd.va.gov)); The Veterans Health Administration Handbook on Polytrauma Rehabilitation Program Procedures (2005); Veterans Health Initiative on Post Traumatic Stress Disorder: Implications for Primary Care (2002); and Veterans Health Initiative on Traumatic Brain Injury (2004).

### **Blast Injuries**

The following information was provided by or adapted from the Defense and Veterans Brain Injury Center (DVBIC) website at [www.dvbic.org](http://www.dvbic.org).

For soldiers in theater, it has been suggested that perhaps the most common cause of brain injury is blast. At the time of this publication, the conflicts in the Middle East (Operation Iraqi Freedom and Operation Enduring Freedom; OIF & OEF) created great propensity that America's armed forces might sustain attacks by rocket-propelled grenades, improvised explosive devices, and land mines almost daily in OIF and OEF. Research has suggested that blast injuries could be quite common in civilian disasters and military conflicts. Over 50% of injuries that are sustained in combat were the result of bombs,

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grenades, land mines, missiles, and mortar/artillery shells (Coupland & Meddings, 1999). However, there is still much to be understood about blasts and their potential to cause a TBI. The following information will help to aid in the understanding of blast injuries.

### ***How a Blast Can Cause an Injury***

So how might a blast cause an injury? Well, blast injuries are injuries that result from a complex pressure wave that is generated by an explosion. Technically speaking, the explosion causes an instantaneous rise in pressure over atmospheric pressure, creating a “blast over-pressurization wave.” Injury may occur from the interaction of the over-pressurization wave and the body with differences occurring from one organ system to another. In particular, air filled organs like the ear, lungs, and gastrointestinal tract, or organs surrounded by fluid (like the brain) are susceptible to blast injury. Additionally, brain injuries/damage can occur by other means such as impact from blast-energized debris, from being physically thrown, or from inhalation of gases or vapors.

Even though helmets (i.e., Kevlar) have greatly reduced penetrating head injuries from projectiles, Kevlar give limited protection against non-penetrating forces from impacts, falls, and explosive blasts. Thus, in combat, the head could be quite susceptible to concussive forces. However, the assessment of closed-

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head injuries can be difficult to detect by care providers. Whereas injuries to the body are often accompanied by *obvious* physical signs and symptoms, closed-head injuries rely on objective evaluations of altered consciousness, cognition, behavior, and neuroimaging. You can see, then, that it is not surprising that the diagnosis of TBI is delayed or even missed, resulting in tardy or inadequate treatment for military personnel or veterans.

### ***Why It Is Important To Know About Blast Injuries***

Understanding blast injury as a common mechanism-of-injury for brain injured and polytrauma patients helps guide assessments beyond the most obvious physical problem. Understanding common associated injuries guides a more comprehensive evaluation and care plan process to prevent more disabling conditions from arising in the future. Such a mechanism-of-injury-based approach to evaluation and treatment is more proactive and efficient and, ultimately, cost effective for both patients and providers. You can talk with your health care provider about being assessed for potential blast-associated injuries.

### **Brain Injury (BI) and Polytrauma Rehabilitation Treatment**

Thorough and clear information about TBI and polytrauma among soldiers and veterans can be found on the website for the Defense and Veterans Brain Injury

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Center (DVBIC). It also provides information on various programs available to military personnel and veterans. Go to <http://www.DVBIC.org>.

Military personnel or veterans with TBI or polytrauma are involved in various therapies according to their individual needs. Therapy services are integrated with an interdisciplinary plan of care and established goals. Age appropriate goals, activities, and materials are incorporated into the rehabilitation treatment plan. Family involvement needs to be encouraged in all phases of the rehabilitation process.

Rehabilitation treatment and procedures may include, but are not limited to:

- a) Activities of daily living,
- b) Architectural barriers,
- c) Assistive technology,
- d) Augmentative communication,
- e) Cognitive rehabilitation,
- f) Communication,
- g) Community reintegration,
- h) Driving,
- i) Durable medical equipment,
- j) Gait training,
- k) Instrumental activities of daily living,
- l) Mobility,
- m) Neurobehavioral management,
- n) Neuromuscular balance and coordination,
- o) Oculomotor rehabilitation,
- p) Orthotics,
- q) Physical performance and conditioning,
- r) Prosthetic fitting and training,

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- s) Psychosocial skills,
- t) Sexuality,
- u) Swallowing,
- v) Vestibular rehabilitation,
- w) Visual motor and perceptual skills,  
and
- x) Wheelchair prescription and  
training

### **Post Traumatic Stress Disorder (PTSD)**

While this book primarily addresses issues related to TBI, it is important to provide a *brief* and *general* overview of PTSD and the impact or overlap it may have on TBI. In many combat situations, a variety of stressors are at play at any given time. For instance, some individuals may find that they have to constantly be “prepared” or “on guard” in order to protect themselves and others from harm. In addition, the toll of combat, as well as the after-effects of dealing with battle, is extraordinarily difficult to deal with. Combat soldiers and veterans must face reintegrating into civilian life and work, which can be quite challenging. This can be even more complicated when the individual must also deal with issues related to potential radiological, biological and chemical weapons exposure, or other injuries. Furthermore, soldiers and veterans who have not seen combat still may experience a variety of stressors that will have some kind of effect on their emotional well-being. For example, sexual or gender harassment,

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racial/cultural conflicts, or concerns about life and family disruptions related to deployment are a few issues that may contribute to stress. The following information was provided by or adapted from the Veterans Health Initiative “Post Traumatic Stress Disorder: Implications for Primary Care” (2002), and the National Center for PTSD website ([www.ptsd.va.gov](http://www.ptsd.va.gov)).

### ***What is PTSD?***

PTSD refers to a type of anxiety disorder which occurs after an individual has been exposed to a traumatic event in which the following were present: (1) The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or threat to the physical integrity of self or others, (2) The person’s response involved intense fear, helplessness, or horror, (3) The disturbance causes clinically significant distress and impairment in social, occupational, or other important areas of functioning.

### ***Symptoms of PTSD***

Specific symptoms associated with PTSD include those in which an individual may “re-experience” the trauma. This can occur in the form of a dream, a nightmare, a flashback, or merely in psychological or physical distress at exposure to reminders of the event. In addition, individuals with PTSD may also avoid stimuli associated with

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*“The worst feeling  
is like there’s  
nowhere else to go  
or nothing else to  
try.”*

(Military TBI Survivor)

the trauma including avoiding certain thoughts and feelings, becoming less interested or disinterested in things the person used to enjoy, becoming detached or estranged from relationships that were once important, or simply display a limited or restricted range of emotion. Finally, individuals with PTSD may also have an increased “arousal” response which might take the form of sleep disturbance, angry outbursts, impaired concentration, or hypervigilance/fidgeting.

### ***Potential Overlap of PTSD and TBI Symptoms***

The overlap between PTSD and TBI is difficult to assess, diagnose and, sometimes, treat. There is much to be done in the way of clinical research to further understand the combination of PTSD and TBI. However, it may be helpful for you to know a little about the potential shared symptoms of these conditions.

For example, in both PTSD and TBI:

- Individuals may have difficulty managing emotions, or are “moody”
- Individuals may have attention and concentration difficulties
- Individuals may experience amnesia for the event
- Individuals may be quite irritable and/or display anger
- Individuals may have difficulty with being over stimulated

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- Individuals may isolate themselves from others or have difficulty in social situations

Sustaining any kind of physical injury in theater is known to increase a service member's risk for PTSD (Hoge, 2004) and there may be several symptoms which are found in both PTSD and TBI. For example, individuals with PTSD, TBI, or a combination of PTSD and TBI may exhibit "emotional lability," or mood swings. Anger and irritability are common symptoms for both syndromes. In either case, individuals may also have difficulty with attention and concentration, or they may have difficulty with being "overstimulated." Difficulty sleeping or changes in sleeping patterns are common to both TBI and PTSD. Finally, individuals with either diagnosis may tend to have difficulty in social situations, or may isolate from social settings. However, in the acute evaluation of mTBI, some of the distinguishing symptoms such as **headache, dizziness, balance problems, and nausea/vomiting** may help to differentiate TBI from a stress reaction or PTSD.

It is important to understand that not only is there a potential that soldiers or veterans might develop symptoms of PTSD as a result of their experiences in the military, it is also possible to acquire PTSD after a brain injury. In fact, the combination of these two conditions could result in a chronic

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post-concussive syndrome that has cognitive and mood symptoms that overlap those of PTSD. It is important to explore the potential of co-existing TBI and PTSD with your health care providers.

### ***Treatment Options for PTSD***

Many veterans with PTSD remain unrecognized and may not be receiving the treatment and support they need for this military-related condition. Primary care staff can play a key role in identifying PTSD and getting individuals the help they need. However, other staff like social workers, therapists, vocational rehabilitation specialists, and others may be able to help identify this disorder. There are many ways that a health care provider can differentiate TBI from a stress reaction or PTSD and, fortunately, the acute treatment for both mTBI and a stress reaction are similar. If you would like more information and referral sources about TBI and PTSD, you can contact the veteran's health administration (VHA). PTSD treatment within the VA typically involves participation in individual and group counseling as well as the prescribing of medications designed to treat PTSD (and related problems like difficulty sleeping, anger problems, and depression). Patients also receive careful psychological assessment. Individuals are educated about trauma and are trained in a variety of skills for coping with PTSD or its effects on various areas of their lives. Stress or

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anxiety management skills like relaxation training, deep breathing, or soothing self-talk are commonly taught, as are interpersonal communication skills and anger management/ conflict resolution skills. Training also implements improving family and social relationships and reducing the veteran's isolation.

Use these brief guides to help you or your family member understand and cope with the symptoms and effects of PTSD:

***What strategies can I use or suggest to a family member to better cope with this condition?***

- Seek education about trauma, PTSD and coping
- Participate in PTSD support groups and PTSD treatment
- Seek help in working through related problems like alcohol or drug use, social isolation, anger, and/or avoidance
- Learn to recognize triggers for stress
- Find ways to get support from others, especially others who also suffer from the effects of trauma
- Increase participation in healthy, enjoyable, appropriate activities
- Learn relaxation techniques
- Develop an exercise routine (in moderation and with physician approval!)
- Take classes to learn better coping tools

***What are some common difficulties for military personnel and veterans after TBI and/or the combination of PTSD and TBI?***

There are a number of potential issues to look out for if you or a loved one has experienced a TBI, has PTSD, or a combination of TBI and PTSD. These include:

- Depression
- Substance Abuse
- Obsessive-Compulsive Disorder
- Suicidal Ideation
- Sexual Dysfunction
- Eating Disorders
- Homelessness
- (In PTSD) Re-victimization, or an increased risk of subsequent exposure to trauma
- Sense of helplessness, shame, or stigma
- Feeling different from other human beings
- Isolation or distrust of others
- Loss of meaning in one's life, or despair
- Loss of sustaining faith

Again, for more information specifically about PTSD, an excellent resource can be found at [www.ptsd.va.gov](http://www.ptsd.va.gov)

**Resources and Outreach**

There are many resources available to veterans and their families dealing with

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the impact of TBI. Refer to these programs and services, as they may be a valuable source of assistance to you. All information included below was made available by VA and Veterans Health Administration resources, guidelines, and the employee education system. This information has been adapted for this workbook to include relevant and necessary information for TBI survivors and their family members. The following is a selected list of resources and it is not intended to be an endorsement by the Department of Defense, the Department of Veterans Affairs, or its affiliates and it is not intended to portray lack of recognition of those organizations not included. In general, more information can be obtained through the main VA website at [www.va.gov](http://www.va.gov).

### ***Polytrauma Rehabilitation Centers***

The Department of Veterans Affairs recognized that it must provide specialized care. In addition to medical rehabilitation services, the Polytrauma Rehabilitation Centers (PRCs) offer psychosocial support for both patient and family, and education and training to prepare patients and family members for success upon return from home. The PRCs coordinate the transfer and provision of health care for TBI patients within the VA and Department of Defense (DoD) and ensure timely access to veterans' benefits. VA designated four regional TBI Lead Rehabilitation Centers located in Minneapolis, MN, Palo Alto, CA, Richmond, VA, and Tampa, FL as PRCs. These centers provided unique and highly

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specialized rehabilitation with personalized treatment programs provided by experts in the field. Individuals treated at these facilities may have a serious TBI alone or in combination with amputation, blindness or other visual impairment, complex orthopedic injuries, auditory disorders, and mental health concerns. **Because TBI influences all other areas of rehabilitation, it is critical that individuals receive TBI care prior to, or in conjunction with, rehabilitation for their other injuries.**

Contact information and the referral areas for the Polytrauma Rehabilitation Centers and Traumatic Brain Injury Lead Centers can be found below:

**Minneapolis** 1-866-414-5058 x3235  
[www.polytrauma.va.gov/facilities/Minneapolis.asp](http://www.polytrauma.va.gov/facilities/Minneapolis.asp)

**Palo Alto Health Care System** (650) 493-5000 x66764,  
[www.polytrauma.va.gov/facilities/Palo\\_Alto.asp](http://www.polytrauma.va.gov/facilities/Palo_Alto.asp)

**Richmond** 1-804-675-6548,  
[www.polytrauma.va.gov/facilities/Richmond.asp](http://www.polytrauma.va.gov/facilities/Richmond.asp)

**Tampa** 1-813-979-3671,  
[www.polytrauma.va.gov/facilities/Tampa.asp](http://www.polytrauma.va.gov/facilities/Tampa.asp)

**San Antonio** (219) 617-5300 x18262  
[www.polytrauma.va.gov/facilities/San\\_Antonio.asp](http://www.polytrauma.va.gov/facilities/San_Antonio.asp)

**Physical Medicine & Rehabilitation Services (PM&RS) National  
Program Office Special Programs 1-813-972-7688,or  
www.polytrauma.va.gov**

<b>Polytrauma Rehabilitation Center</b>	<b>Referral Area</b>
McGuire Veterans Affairs Medical Center Physical Medicine and Rehabilitation Services 1201 Broad Rock Blvd. Richmond, Virginia 23249	Maine, Massachusetts, Rhode Island, Connecticut, Vermont, New Hampshire, New York, Pennsylvania, Delaware, Maryland, District of Columbia, Virginia, West Virginia, and North Carolina.
James A. Haley Veterans Affairs Medical Center  Physical Medicine and Rehabilitation Services 13000 Bruce B. Downs Blvd. Tampa, Florida 33612	Tennessee, Kentucky, South Carolina, Georgia, Alabama, Florida, Puerto Rico, Arkansas, Louisiana, Mississippi, and Texas.
Minneapolis Veterans Affairs Medical Center  Physical Medicine and Rehabilitation Services One Veterans Drive Minneapolis, MN 55417	Ohio, Michigan, Indiana, Illinois, Wisconsin, South Dakota, North Dakota, Minnesota, Oklahoma, Iowa, Nebraska, Kansas, and Missouri
Palo Alto HealthCare System Physical Medicine and Rehabilitation Services 3801 Miranda Avenue Palo Alto, California 94304	New Mexico, Arizona, Wyoming, Colorado, Montana, Utah, Nevada, Idaho, Oregon, Washington, Alaska, California, and Hawaii

***Health Care Benefits: Maximizing Resources***

Upon enrollment, veterans are placed in one of the VA's "Enrollment

Priority Groups” (see on the web at [www.va.gov/healthbenefits](http://www.va.gov/healthbenefits)) here are eight groups, with #1 being the highest priority group. Veterans in enrollment group #5 or higher, having sustained a brain injury may qualify for the Priority #4 group through a formal “Catastrophic Disability Evaluation.” **Identifying a veteran as catastrophically disabled may help to maximize VA health care benefits.**

You or your family member can request the evaluation, or your care provider/representative can. To find out more about how to request an evaluation, contact the Enrollment Office at your local VA health care facility. In general, active duty, retired service member, and retired reservists may be eligible for health care under the military health system. Information regarding eligibility and benefits under TRICARE can be found at: <http://www.tricare.mil/>. Veterans covered under other insurance providers may be able to obtain TBI-specific services closer to their home.

## **Veterans Benefits Administration (VBA)**

### Vocational Rehabilitation and Employment Program (VR&E)

Veterans who receive service connection for a disability that was incurred or aggravated in service are potentially eligible for vocational rehabilitation services. VR&E Vocational Rehabilitation Counselors in the VBA regional offices will determine if a veteran is entitled and demonstrates a

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need for vocational rehabilitation services in order to prepare for employment. Information on VBA regional offices is located at [www.vba.va.gov/bln/vre](http://www.vba.va.gov/bln/vre). In addition, a Vocational Rehabilitation application form (VA-1900) is located at [www.vabenefits.vba.va.gov/vonapp/main.asp](http://www.vabenefits.vba.va.gov/vonapp/main.asp).

### Independent Living Program (ILP)

Independent living generally refers to the empowering of individuals to take control of their own lives, live autonomously, and participate fully in society. Independent living services are provided through the Department of Veterans Affairs Vocational Rehabilitation and Employment Program. These services are intended to improve the ability of a veteran to function more independently within his/her family and/or community. Independent living services do not require a program goal of return to work. Additional information is available at <http://www.vba.va.gov/bln/vre/ilp.htm>.

**Service-connected veterans with TBI should apply for Chapter 31 benefits through VR&E for Independent Living Services.**

### ***Other VA Programs***

VA has a number of special needs programs that may be appropriate for persons with brain injuries. These programs are not specifically geared to service individuals who have sustained a TBI; therefore, these services are mostly suited for individuals who are functioning

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at a fairly high level (i.e., independent in activities of daily living, does not need supervision).

## **Family Support**

Patients, their families, and significant others, need to receive appropriate education and training to increase their knowledge of the patients' illnesses or disabilities and treatment needs, and to learn the skills and behaviors that promote recovery and maximize function. The VA and PRCs provide the following assistance and resources to families of military/veteran TBI survivors.

All rehabilitation personnel are responsible for providing education to patients and their families as appropriate to their specific disciplines and documenting the education when provided. Education is provided as a part of ongoing therapy, through patient and family meetings, through written information (handouts and booklets), and through the medical center's ongoing televised Patient Education Series.

Education may include, but is not limited to, instructions in:

- 1) Rehabilitation techniques to facilitate adaptation to and functional independence in the anticipated discharge environment;

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- 2) Accessing available community resources;
- 3) The safe and effective use of prosthetic, orthotic, and durable medical equipment;
- 4) The safe and effective use of medication;
- 5) Polytrauma sequelae and conditions as appropriate to the patient;
- 6) Restrictions and precautions, e.g., driving, alcohol, physical activity level;
- 7) Behavior management techniques; and
- 8) How to handle emergencies.

### ***How Professionals Can Help the Family***

Families of BI and polytrauma patients have unique psychosocial needs due to the etiology of their family member's catastrophic injuries, the severity of the injuries, and the possible long-term impairments. The PRCs are responsible for ensuring that patients and their families receive all necessary support services to minimize stress during the hospital stay.

Each BI and polytrauma patient and family has a designated social work case manager who has the responsibility for ensuring that their psychosocial needs are identified and addressed. These responsibilities include, but are not limited to:

- (1) Ensuring that the patient and family

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have received an orientation to the PRC. This includes providing orientation information; written materials; a tour of the facility, bed unit, and therapy clinics; what to expect; and introductions to members of the IDT.

- (2) Assessing patient and family psychosocial support needs, documenting the assessment and plan in the medical record, and providing psychosocial interventions.
- (3) Establishing a regular schedule for communication that meets the needs of the family, and providing the family with information on how to contact the social work case manager, or the on-call designee, during and after business hours, including a phone or pager number.
- (4) Documenting the content of communications with family in the medical record.
- (5) Facilitating involvement of the family and advocating for the family's needs and interests throughout the rehabilitation process.
- (6) Providing the family with updates on progress and adjustments to the plan of care in a timely fashion.
- (7) Providing the referring MTF and local military health care provider and duty station, as appropriate, with updates on progress.
- (8) Working closely with Voluntary Service and Chaplain Service to ensure availability of resources to meet the immediate needs of the family.

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## ***Community Programs to Assist the Family***

Through the social work case manager, PRCs involve VA and community programs and services to support BI and polytrauma patients and their families. This includes:

- (1) Ensuring that representatives from Chaplain Service and Readjustment Counseling Service are available to patients and families soon after admission and as needed; and
- (2) Collaborating with Voluntary Service and Chaplain Service, who in turn work with local Veterans Service Organizations and community faith-based groups to provide supportive services, including safe and convenient lodging, transportation to and from the medical center, food, personal items, childcare, recreational opportunities, and other services as necessary.

## ***Other Resources for the Family***

A number of books and guides have been produced that may help family members better understand the difficulties soldiers/veterans face upon their return home. These books can be found on the web, or you can ask your healthcare professional in the VA to help you locate them.

- “Warzone-Related Stress Reactions: What Families Need to Know” by Julia M. Whealin, Ph.D.

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- “Returning from the War Zone: A Guide for Families of Military Personnel” (National Center for PTSD); only available online at <http://www.ncptsd.va.gov>
- “Homecoming: Dealing with Changes and Expectations” by Ilona Pivar, Ph.D.
- “Homecoming: Tips for Reunion” by Pamela J. Swales, Ph.D.
- Iraq War Clinician Guide, 2<sup>nd</sup> Edition; only available online at <http://www.ncptsd.va.gov>

## NOTES

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Hoge, M.A., Huey, L.Y., O'Connell, M.J. (2004). Best practices in behavioral health workforce education and training. *Administrative Policy in Mental Health*, 32(2): 107-130.

The National Center for Post Traumatic Stress Disorder (NCPTSD); <http://www.ncptsd.va.gov>

U.S. Department of Veterans Affairs; <http://www.va.gov>

U.S. Department of Veterans Affairs Eastern Colorado Health Care System (VA ECHCS); <http://vaww.denver.med.va.gov/>

Veteran Service Organization Sponsor Program; <http://www.va.gov/vso/index.htm>

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## **MEDICATIONS**

Jane Letsinger, Karen Hildebrand, and Jane Emanuelson

Jane Letsinger, M.B.A., O.T.R., is an Occupational Therapist who has worked in the field of brain injury rehabilitation since 1972.

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Persons who have experienced a traumatic brain injury often have various medications prescribed by their physicians. These may be medications which were unfamiliar to you prior to your injury. It is important to understand as much as possible about each medication in order to know why you need to take it, and to know that you are gaining the maximum benefit from it. Ask questions! What will it do? Why do I need it? How does it work? What are the side effects?

Medications, or drugs, are chemicals which are taken to cause a certain effect in one's body function. However, this desired effect may not be the only result of taking the medication. The medication may also have other effects, called side effects, which cannot be avoided when taking that particular drug. Most side effects are minimal; however, some side effects are very noticeable and may be undesirable. In some cases, the side effects may be severe enough to warrant discontinuation of the medication, since the negative effect outweighs the desired effect.

Side effects can frequently be minimized or eliminated by regulating the dosage, or perhaps even changing to a different drug. **It is very important to be aware of any side effect you notice, and to communicate this to your doctor so he or she can work with you to make these changes.** Since many persons experience some cognitive changes following a brain injury, it is

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*It is important to understand as much as possible about each medication in order to know why you need to take it, and to know that you are gaining the maximum benefit from it.*

especially important for the individual and family to observe any effect a medication may have on one's thinking skills.

It is very common for individuals to have more than one doctor following a traumatic brain injury, and each of these doctors may be prescribing medications. It is very important for you to inform **each** of your physicians of **all** medications you are taking, including the dosage (i.e. the amount and frequency), and including non-prescription medications, such as aspirin, ibuprofen, or decongestants. This is important for several reasons. One physician may unknowingly prescribe a medication similar to one you are already taking. Or, a medication prescribed by one physician may interact adversely with a medication prescribed by another physician.

The Joint Commission, an independent, non-profit organization that evaluates and accredits health care organizations in the United States, requires medication reconciliation from one facility to another. This means when you are an inpatient in a hospital, a list of your current medications must be updated and sent with you if you are transferred to another facility. Also, you should receive a list of your current medications when you are discharged from a hospital setting.

You should always keep a list of your current medications up to date and accessible. It is important that your doctor who sees you for your brain injury

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be aware of all other doctors you are seeing, and the treatments prescribed by those doctors, since it is helpful, not only for you but for your physicians, to keep a record every day of all medications you take, including non-prescription drugs. This will provide a "history" for you of which drugs you take, and when, as well as how long you have been taking those drugs. It also can be informative if you begin to experience some side effects, providing a good start for figuring out what might be causing these effects.

It is important to keep track of non-prescription drugs since, even though you are not required to have a doctor's order to purchase them, they can have dramatic effects on your body. For example, if you are taking a prescription anticoagulant (blood thinner) drug, and your doctor notices that you are taking several aspirin or ibuprofen a day for pain, he or she will probably recommend substituting another medication for pain since those drugs also have an anticoagulant effect. People with brain injuries may also notice unexpected effects when taking a cold medication, since antihistamines and decongestants often cause exaggerated effects for them.

The names of drugs can be very confusing. Any one drug can have several names. The **class name** describes the action of the drug; for example, the class of anticonvulsant drugs would all be expected to prevent

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or treat seizures. Within the class, a drug will have a chemical or generic name, which reflects the chemical makeup of the drug. In addition, most drugs have a **brand name**, which is given to it by the individual manufacturer of the drug. A generic drug will probably be less expensive, but occasionally will not be quite as effective as one of the brand name drugs. Your physician can advise you about this. Ask questions! What will it do? Why will I need it? How does it work? What are the side effects?

## **CLASSES OF MEDICATIONS COMMONLY USED BY PERSONS WITH TRAUMATIC BRAIN INJURY**

**1. ANALGESICS:** These are used to control pain and discomfort. In this category there are narcotic and non-narcotic medications.

**Narcotic:** These drugs require a prescription, and are used for more severe pain; can be habit-forming, and may have an effect on one's thinking abilities and alertness. Some examples are: Tylenol with codeine, Vicodin, Percocet, Dilaudid and Morphine.

**Non-narcotic:** These drugs usually do not require a prescription, and are used for milder pain. They are non-addictive, but do have side effects. Some examples are: Aspirin, Tylenol, Advil (ibuprofen), and Aleve (naprosen). Aspirin, Aleve and Advil are not typically prescribed immediately after a brain

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injury due to the increased risk of blood thinning which can increase the risk of strokes.

**2. ANTICONVULSANTS:** These are used to treat or prevent seizures (convulsions). Some examples are: Dilantin, Phenobarbital, Tegretol, Depakote, and Neurontin.

Various anticonvulsants have different properties which may make one drug preferable for you over the others. Only your physician can make this decision with you. **It is very important to take the proper dosage of an anticonvulsant drug, and not to discontinue it or skip a dosage except under your doctor's specific instructions.** Often your doctor will have you take periodic blood tests to monitor the level of your anticonvulsant medication, and to monitor for side effects. Anticonvulsants can also act as mood stabilizers and may have an indirect effect on a patient's mood as well as reduce aggression and agitation. (Levy, et. al, 2005, page 296).

**3. ANTIHYPERTENSIVES:** These medications are used to treat high blood pressure. There are many antihypertensive drugs available, under both generic and brand names. These need to be closely monitored by your doctor. Beta Blockers, a class of antihypertensive medications can also improve agitation, reduce explosive outbreaks and aggression. The side effect of using a beta blocker for this

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purpose is that the person may experience hypotension (low blood pressure). Careful monitoring of blood pressure is critical. Examples of beta blockers include Inderal, and Clonopine.

**4. ANTICOAGULANTS:** These are used to slow the rate of blood clotting; used to treat or prevent blood clots. Sometimes called "blood thinners." Some examples are: Heparin may be given in the hospital; Coumadin is the brand name of a common drug taken after leaving the hospital. Remember that aspirin and ibuprofen also have an anticoagulant effect. Ask your doctor whether you should avoid these medications, and if so, what you should take for headaches and discomfort. Some vitamins (such as Vitamin E), herbs (such as garlic or ginger), and some foods (such as citrus fruits) may alter the effect of anticoagulant medications. Discuss their use with your doctor. Also take care with risky activities, as you will bruise and bleed easier.

**5. ANTIBIOTICS:** These are used to treat infections. There are many antibiotic or antibacterial drugs available. Your physician will prescribe one based on what type of infection you have. It is important to take all of the antibiotics so that the infection does not return. Symptoms may improve soon after you start taking the antibiotics, but you should continue to take the entire amount prescribed.

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## **6. MEDICATIONS TO HELP MANAGE BOWEL AND BLADDER FUNCTIONS:**

For bowel management, stool softeners, laxatives, or suppositories may be used, although the most desirable way to regulate bowel function is by drinking plenty of water, eating a balanced diet with plenty of fiber, and getting adequate exercise. For management of bladder function, several drugs which affect the muscle tone of the bladder or bladder sphincter may be prescribed to help reduce urinary frequency or retention. Some patients may experience bladder spasms or may have an overactive bladder that causes urinary frequency, urgency, incontinence or increased night-time urination. The physician may prescribe Ditropan to help relax the muscle tone of the bladder. If the bladder does not empty completely, the physician may prescribe a “cholinergic” drug such as Urechoine. Alpha-adrenergic drugs such as Pro-Amatine may be described for incontinence.

**7. ANTISPASMODICS:** These medications can help control spasticity. An example is Lioresal (Baclofen.) The proper dosage needs to be carefully determined by your physician. It is important not to discontinue any of these drugs suddenly. Also, these medications can affect thinking abilities and alertness and these side effects should be discussed with your physician before starting the medication and reassessed periodically while taking the medication.

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In cases of severe spasticity, your physician may recommend an intrathecal baclofen pump. This requires surgery to insert the pump into the abdomen. And very close ongoing medical follow up to manage dosing adjustments.

**8. MEDICATIONS FOR MOOD AND EMOTIONAL CONTROL:** Three classes of drugs may be considered in treating mood, depression, or emotional difficulties after brain injury: antidepressants, tranquilizers, and stimulants. The prescriptions are very individualized, depending on each person's needs, and should be carefully monitored by your physician. Some of these medications can affect thinking abilities and seizure thresholds. Ask questions.

**9. ANTIHISTAMINES, DECONGESTANTS, AND ANTITUSSIVES:** These medications are used to treat symptoms from allergies and upper respiratory infections, and can be purchased over the counter without a doctor's prescription. They can have side effects that are unpleasant or may interfere with functioning and should not be used without the advice or prescription of your doctor.

- **Antihistamines** cause drowsiness and can slow speed of thinking and affect attention. Newer antihistamines, such as Claritin, Allegra and Zyrtec have fewer sedative effects but must be prescribed by your doctor.

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- **Decongestants** such as Sudafed (pseudo ephedrine), can cause restlessness, interfere with sleep, and can contribute to seizures. Cold and allergy medications labeled as "No Drowsiness Formula" usually contain pseudo ephedrine. Nasal decongestant sprays should be used very sparingly, if at all, as they can be absorbed systemically and can cause rebound congestion.
- **Antitussives** or cough syrups obtained over the counter may often contain other medications such as antihistamines or decongestants, and they always, unless labeled otherwise, contain alcohol. **So read the labels carefully** and consult with your physician.

Also, while you are shopping for these medications, if you have trouble understanding the language on the labels, ask the pharmacist. He or she can be very helpful in translating the unfamiliar terms and would be able to help you determine if the medication contains a substance you need to avoid.

Since so many drugs are available today, and each drug has its own set of side effects, requirements for monitoring, and so on, there is not adequate space to discuss this in full detail in this section of the manual. It is often helpful to obtain a reference book written for the non-physician which gives information about specific drugs. These

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are available in most bookstores, and contain many details regarding such things as dosage, precautions, possible interactions and side effects, what to do if you miss a dose, what to do if you accidentally take a double dose, etc. Although it is not expected that you or your family members become pharmacists, educating yourself about the various medications you may be taking will help you discuss questions with your physician more efficiently. Also, keep in mind that different people have different reactions to medications. Please pay attention the way you react to a certain medication and tell your doctor about any unusual side effects.

**A GOOD WEBSITE FOR INFORMATION ON PRESCRIPTION MEDICATIONS** can be found at:  
[www.webmd.com](http://www.webmd.com)

*A note of caution about websites: talk to your doctor if you have questions about information you have read on a website. A website offers information, but does not have the last word on your particular situation and medications.*

**A SPECIAL WORD ABOUT ALCOHOL AND OTHER DRUGS:** Alcohol presents many problems for persons with traumatic brain injury. It can increase the risk of seizures, as well as diminish the effect of anti- seizure medication. In fact, it is dangerous to mix many medications with alcohol. In addition, alcohol has an adverse effect on some of the cognitive functions (such as judgment, reasoning,

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[www.webmd.com](http://www.webmd.com)  
*is a good website  
for information on  
prescription  
medications.*

insight, and problem-solving skills) and some of the physical functions (such as balance, coordination, and visual perception) which may be problematic for you following the injury. You may not be able to tolerate as much alcohol after a brain injury as you were before the injury without experiencing some of these adverse effects. In general, it is recommended that persons with a traumatic brain injury not drink alcohol. In addition, many people find that caffeine and/or nicotine have unpleasant or exaggerated effects after a brain injury that you didn't feel before. You also need to be aware that other substances, such as marijuana or cocaine, may alter or exaggerate the effect of some drugs, or may have an undesirable effect on cognitive or physical functioning. It is a good idea to discuss with your doctor the advisability of using any of these substances.

### **INDEPENDENCE IN MEDICATION**

**MANAGEMENT:** As individuals become more and more independent in their daily living skills after a brain injury, they usually will want to manage their medications independently as well. If you find that there are some factors that keep you from reaching this goal, keep in mind that there are various ways to approach this problem. Be sure to ask for help in the beginning from a family member or other person who is knowledgeable about your medications. There are a number of ways to learn to monitor your own medications. A good system of record keeping or note taking

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will help you keep track of your pills and the correct schedule. Any pharmacy will have a variety of special pill boxes available to help you organize your pills and monitor whether you have taken them or not. Some even have an alarm mechanism which can be set to remind you to take a pill on schedule.

It is very important also to keep track of when you need to get a prescription refilled, so that you don't run out of a medication unexpectedly. Keep in mind that it may take a pharmacist one or two days to prepare a refill for you, and there are many medications that cannot be skipped for that long. A good record keeping system will help you avoid these pitfalls. For example, when you get a prescription filled, you may want to make a note on your calendar to remind yourself to order a refill several days before you run out.

### **MEDIC ALERT BRACELETS:**

These bracelets can be worn so that any medical condition or medications information would be immediately available to others if you should not be able to convey this information yourself. They can be ordered at your local pharmacy.

### **TRAVELING WITH MEDICATIONS:**

With the current trend of increased security, both when traveling and "on the street," individuals carrying medications with them may face the requirement to justify possession of pills. In addition to wearing a Medic Alert bracelet, it may be

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helpful to carry a card in your billfold which briefly describes your injury and identifies the names of your physicians who prescribe medications, as well as the names of all medications and dosages you are carrying. This will be especially important if you are crossing a border (e.g. land travel to Mexico or Canada) or going through a customs inspection. The key is to plan ahead! Many people find it helpful to contact the local embassy of the country to which they are traveling, to obtain advice about carrying prescription medications.

Questions to ask:

- ☐ Can I carry them in a pill case, or should they be in the original bottles from the pharmacy?
- ☐ Do I need a letter from my doctor listing all my medications?
- ☐ Do I need copies of the original prescriptions?

If you are prepared, you should not encounter problems when traveling with your medications.

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## **Preventing Alcohol and Drug Abuse After a Brain Injury**

James Berry and Eileen McLaughlin

James Berry, Ph.D., is a board certified rehabilitation psychologist at Craig Hospital. Eileen McLaughlin, B.A., has worked in brain injury rehabilitation since 1977.

***For many people, the use of alcohol or drugs set the scene for the accident that caused the brain injury.***

***Some of the Statistics:***

- It is estimated that alcohol is present in at least 66% of all moving vehicle accidents and 60% of all assaults
- About 2 in every 5 Americans will be involved in an alcohol related crash at some time in their lives
- Fatally injured drivers with blood alcohol levels of 0.10 g/dl or greater were 6 times as likely to have a prior conviction for driving while intoxicated compared to fatally injured sober drivers
- 50 -66% of patients hospitalized for TBI have a history of alcohol or drug abuse
- 36-51% were intoxicated at time of the brain injury: (Corrigan, 1995)

***Survivors and family members often hope that the accident and injury has “cured” them of alcohol and substance abuse. They often do not realize or want to admit the extent of the problem.***

Often, recreational drug and alcohol use were part of their lives before the accident. A person who has a history of alcohol and drug use before the injury may have health problems associated with it. As a result, the recovery from the brain injury is often longer and more complex.

NOTES



*For many people, the use of alcohol or drugs set the scene for the accident that caused the brain injury.*

***The physical addiction to alcohol or drugs (often called “withdrawal”) is generally over by the time a person with a brain injury is back home; but the causes and influences leading to the original substance abuse are still there.***

The ability to resume a productive life may still be complicated by social, legal and behavioral problems associated with alcohol and substance abuse. It is harder for survivors using alcohol or recreational drugs to find and maintain employment. Depression is a more common complaint in those who admit alcohol and drug use.

If the pre-injury psychological dependency on alcohol is not addressed, we know that the use of alcohol and drugs will likely recur after the person goes home, as the old friendships and old behavioral and recreational patterns are resumed.

***The Problem:***

- Alcohol and drug use are prevalent in our society and a well-established aspect of recreation, college life and social gatherings. Alcohol is legal, cheap, and readily accessible.
- Once home, it can be hard to emotionally deal with the consequences of the injury. People facing losses, boredom and frustration may decide to “self-medicate” with alcohol or drugs,

especially if that was how they coped in the past.

- Often the brain injury makes it even harder to inhibit impulses, and to appreciate the long term consequences of alcohol and substance use.
- Alcohol is an opportunistic neurotoxic agent and will make aspects of a person's residual symptoms after brain injury worse.
- The brain injury survivor may view their drinking buddies as more accepting of their cognitive and physical limitations than society in general.
- Family members may be uncomfortable denying alcohol to an adult or may feel that the person is being denied one more thing that was part of their life before the injury.
- It is hard for the survivor and for the family to ask for help in treating substance abuse while in the middle of rehabilitation for a brain injury. Sometimes it is difficult to find funding or an appropriate program for alcohol and substance abuse rehabilitation.
- People tend to return to pre-injury levels of use by two years post-injury (Corrigan, Rust et al., 1995)

## NOTES

***Intoxication at the time of injury impacts outcome from TBI:***

- Longer periods of agitation
- Longer post traumatic amnesia
- Longer time from admission to rehabilitation
- Greater neurological impairment at time of discharge from rehabilitation
- More likely to require intubation and develop pneumonia & respiratory distress
- Individuals experience a “synergistic effect” (2+2 does not equal 4)
- Alcohol tends to lower an individual’s “seizure threshold” and increases the risk of initiating seizure activity

**Effects of substance abuse on rehabilitation outcomes:**

- higher depression
- non-acceptance of disability
- unemployment
- higher incidences of relapse

***Identifying alcohol and drug use:***

- It may be easier to detect the signs of alcohol than drug use. Tolerance for alcohol is decreased following a brain injury and even small amounts of alcohol further decreases cognitive and physical functioning.
- Significant variations in functional abilities from day to day should be investigated.

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*Structured activities, social supports, relationships, and expanded recreational opportunities benefit people with brain injury in all areas of their lives.*

- Poor memory regarding conversations (reflective of blackouts).
- Changes in tremors or coordination.
- Unexplained absences.
- Inability to account for financial expenditures.
- Legal complications (DUI, assault, etc...)
- Alcohol abuse includes occasional and binge drinking. Binge drinking is considered to be five or more drinks per occasion on more than five or more days in the last month.
- Do not minimize or rationalize a few drinks as an isolated lapse. Alcohol consumption after a brain injury is dangerous.

### **Alcohol use impairs:**

#### Executive Functions:

- Reasoning
- Judgment
- Disinhibition
- Increased Impulsivity

#### Other Systems:

- Effects on the limbic system (mood, emotions)
- Changes in speech & language
- Changes in vestibular system (Balance problems)
- Reduction in “seizure threshold”

### ***Prevention:***

Structured activities, social supports, relationships, and expanded recreational opportunities benefit people with brain injury in all areas of their lives; but they

## NOTES



need it most of all when they are finding new ways to cope with emotional and physical pain.

- Community services such as support groups, 12 step groups, day programs and recreational services can help to reinforce the message of living without the need for alcohol or drugs.
- Formal drug and alcohol rehabilitation programs can be very effective but it is important that the program can be adapted for the person with a brain injury.
  - Tell the leaders of the group of the provider about the brain injury and the medical and cognitive needs; make suggestions on how best to present information to your family member
  - Obtain copies of information that is presented. Repeat and reinforce the information.
  - Family involvement should be an integral part of the inpatient and/or outpatient treatment.
  - Therapeutic approaches that are more likely to be successful in preventing substance abuse require individuals to accept responsibility for their own behavior, give direct, immediate feedback on the issue and address the long term and pre-

## NOTES

existing problems that lead to substance abuse.

- Find ways to eliminate opportunities to engage in alcohol and drug use.
  - Structure and supervision may be necessary.
  - Alcohol may need to be removed from the home.
  - It may be necessary to limit contact or supervise contact with pre-injury friends who are known to abuse alcohol and drugs.
  - Going to the bar with the intention of not drinking does not work. One of the ways to think about this is, “If you are going to sit in the barber shop long enough, you are going to get your hair cut!”
  - Monitoring spending money may be necessary to prevent alcohol/drug purchases.

## NOTES

## **NAVIGATING THE CONTINUUM OF CARE**

Francine Mazone

Franny Mazone, R.N., CCM, CLCP, is a certified nurse case manager and certified life care planner.

The medical care and rehabilitation of brain injury offers a myriad of choices that at first blush are overwhelming and often confusing. Because severity of brain injury and response to treatment is individual, treatment continuums are varied for each person and family.

Following is a conceptual model that presents five (5) Phases of the Continuum of Care for persons with Mild to Severe Brain Injury. Everyone will begin with Phase 0, "The Injury."

Due to individual differences, types of injury, the care involved and payer source requirements, an individual person will require some or all of the various Phases of the continuum of care. They may also take different pathways on the continuum, entering rehabilitation at different points. At times a person may progress forward, and, in some cases, a person will at times reverse direction for various needs. Movement in and out of the phases and places in brain injury treatment may not be sequential and what may appear as regression is not always a setback.

### **Phases of the Continuum of Care in Brain Injury**

Phase 0  
The Injury

Phase I – *Medical needs and early rehabilitation*

Emergency care  
Acute Hospital Care

Phase II – *Rehabilitation with continuing medical needs*

- Acute inpatient rehabilitation
- Sub acute/Long Term Acute Care
- Skilled Nursing Facility

Phase III – *Rehabilitation and community reintegration*

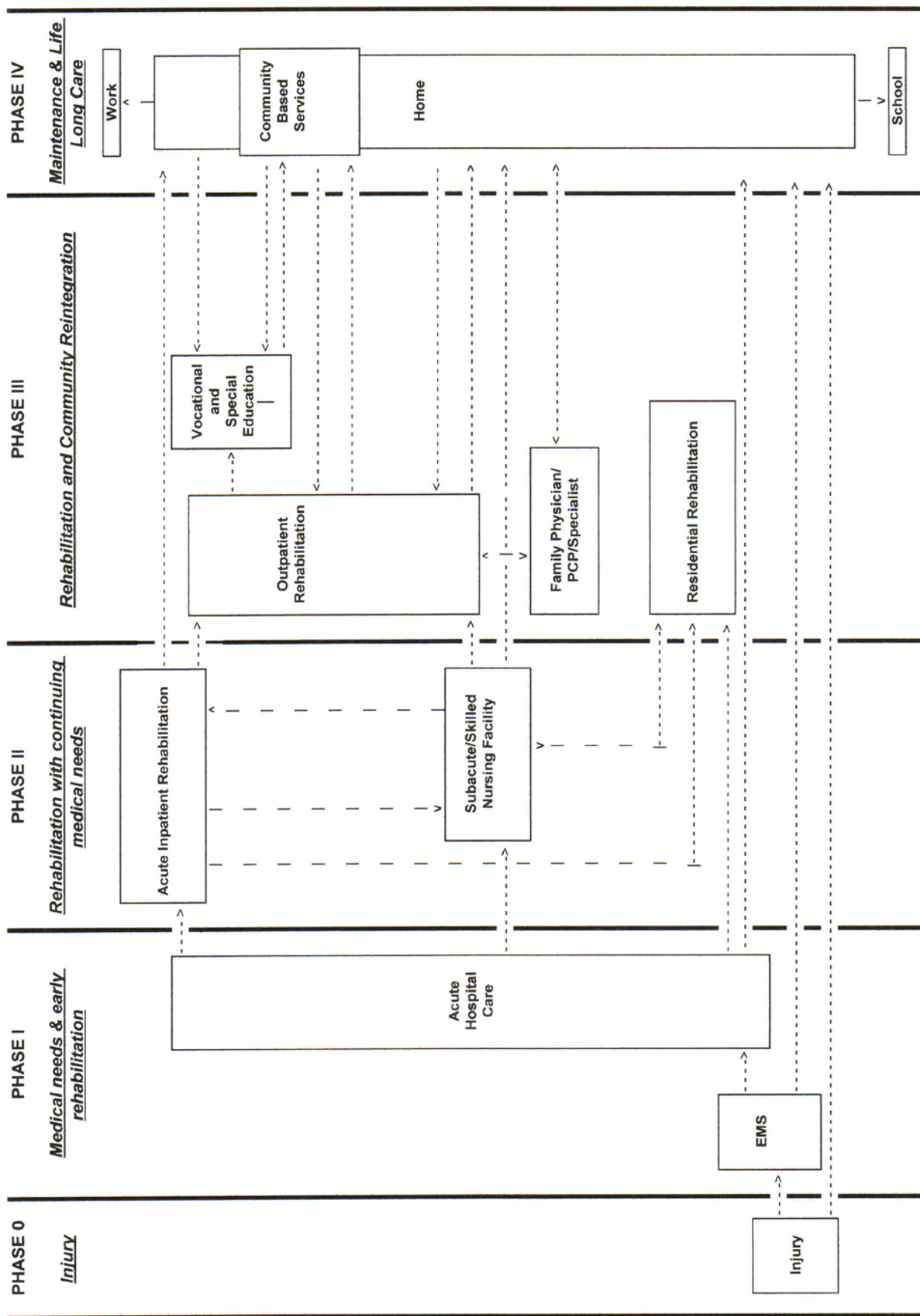
- Outpatient Services and medical specialists
- Residential Rehabilitation
- Vocational & Special Education

Phase IV – *Maintenance and life long care*

- Home
- Community Based Services

NOTES

# BRAIN INJURY CONTINUUM OF CARE



## **PHASE I: Medical Needs & Early Rehabilitation**

### ***Emergency Medical Services***

This phase includes Emergency Personnel (Paramedics, EMTs, Ambulance) and emergency rooms, all dedicated to preserving life and achieving medical stability. If the emergency room evaluation does not indicate a need for hospitalization, the patient will be discharged home with “head injury” instructions.” If this occurs they may move into Phase III upon consultation with their medical provider, (i.e. Family physician, chiropractor, psychologist.); or will move directly to the maintenance phase.

### ***Acute Hospital Care Phase***

Admission to the hospital can occur for any severity of brain injury. A patient may be admitted for a brief observation period or directly to the Intensive Care Unit.

In intensive care the patient may be in coma and medically unstable. Medical equipment may include a ventilator to assist in breathing, an Intracranial Pressure (ICP) monitor to monitor pressure in the brain, intravenous (IV) lines, heart and breathing monitors, bladder and stomach tubes. A rehabilitation assessment and early rehabilitation should begin in the ICU.

People with mild to moderate brain injury who have been admitted to a hospital

## NOTES

may be discharged home if symptoms have resolved and they are medically stable.

The decision to discharge home versus admission to inpatient rehabilitation is largely dependent on the severity of injury and the individual's response to treatment. Other variables such as funding, family location and the wishes of the individual and family will influence the next step or discharge placement. Regardless of location, rehabilitation and education are essential to obtain the highest level of function and in some cases merely the prevention of further complications.

## **PHASE II Rehabilitation with Continuing Medical Needs**

### ***Acute Inpatient Rehabilitation***

After a person is medically stable, patients may be moved to acute rehabilitation. Acute rehabilitation may occur in a variety of settings from a hospital general rehabilitation unit to a freestanding specialized center. There are 16 Traumatic Brain Injury Model Systems (TBIMS) programs in the U.S. These centers conduct various research projects and provide comprehensive, coordinated care for persons with traumatic brain injuries from emergency medical services, to inpatient rehabilitation and long-term follow up. (For the 16 centers see <http://www.tbindsc.org/Centers/centers.asp>)

## NOTES



Central to inpatient rehabilitation is an interdisciplinary team approach to brain injury rehabilitation. The core interdisciplinary team includes a rehabilitation physician, a neuropsychologist, rehabilitation nurse, a social worker, a physical therapist, an occupational therapist and a speech therapist. Additional specialties may also participate and include a behavioral specialist, a psychologist, a neurologist, a recreational therapist, rehabilitation technicians, and a rehabilitation engineer.

When behavior management is necessary it is best delivered in a dedicated brain injury program and should include family education.

Discharge options are determined by the person's functional status, on-going needs and financial resources and any of those further along the care continuum.

### **Sub-acute and Skilled Nursing Facilities**

If the patient remains unconscious or semi-conscious and the recovery is slower or they are not able to participate in full rehabilitation, they may be transferred to a Sub -Acute or Long Term Acute Care Facility (L-TAC), directly from the acute hospital. Specialized neurobehavioral, ventilator weaning, coma arousal programs are often housed in these facilities. Rehabilitation therapies are provided at a lower level of intensity and frequency. Typical length

## NOTES

of stay at this level of care is 30 to 60 days. As appropriate, transfer may be to the acute inpatient rehabilitation setting.

Some insurance plans will not allow acute inpatient rehabilitation if the only needs are cognitive or behavioral, while other may not cover acute inpatient rehabilitation at all. Subsequently sub-acute providers have become the alternative inpatient option for these patients.

Sub-acute rehabilitation programs may also be designed for persons who have made progress in the acute rehabilitation setting and are still progressing, but are not making rapid functional gains.

Transfer from these facilities generally occurs to either acute inpatient or home with outpatient rehabilitation services. Some patients may never discharge from the skilled nursing level of care.

### **PHASE III Rehabilitation and Community Reintegration**

***Residential Rehabilitation*** takes place in small structured settings and concentrates on the long-term needs coupled with recovery from moderate to severe brain injuries. Outpatient therapies are provided individually and in groups aimed at cultivating daily living skills necessary for independent living and return to community. Direct nursing, respiratory and physician care are either not provided or are very part time. Therapists and lay staff provide support

and follow through with the rehabilitation and transitional living goals.

**Outpatient Services** and therapies range from a single individual therapy to group and structured day programming. A person with a brain injury that was not severe enough to require inpatient hospitalization may attend outpatient therapies to address functional impairments. Those discharging from acute inpatient rehabilitation or living in a residential setting may also benefit from outpatient therapies including physical, occupational, speech, neuropsychology, psychology and cognitive treatment. A primary care physician and other medical specialists address ongoing medical issues and medication management.

Insurance plans limit the amount of therapy a person is eligible to receive and often consider brain injury rehabilitation to fall under behavioral services. Be sure to review the chapter on Financial Resources to look at sources of funding in this phase. A lack of funding for outpatient services can be a major barrier in this phase. This is a phase where you may need to be an active advocate, looking at all possible resources in the community, including support groups, case managers, vocational rehabilitation services, and BIAC.

As one progresses in outpatient therapies, the focus is on Community Reintegration, whether it be return to work, school, volunteer activities or

## NOTES

recreational pursuits.

### ***Family Physician/Primary Care Physician/Specialist***

Frequently, this is the first contact for a person with a mild brain injury. Emergency medical care was not required and after a short period of days to months, the person experiences (and/or their significant others observe) changes in personality, memory and/or physical well-being. When medical care is sought, the continuum of care begins. The point of entry is initiated by the family physician, or another provider such as a pain specialist, osteopath, chiropractor, or massage therapist.

### **Vocational & Special Education**

The Rehabilitation Act provides vocational rehabilitation services in every state. To be eligible for state vocational rehabilitation services, an individual must have a disability that hampers employment. Eligibility is also determined by the anticipated result of services, specifically re-entry into the work force. Assistive technology, the use of assistive, adaptive, and rehabilitative devices are often used in the workplace to assist individuals with disabilities.

The Individuals with Disability Education Act of 1990 provides for rehabilitative services and education for children with traumatic brain injury. An individualized education plan (IEP) is developed to plan and evaluate services and assist in the

## NOTES

transition from each Phase in the care continuum.

#### **PHASE IV: Maintenance and Life Long Care** ***Community Based Services***

Supported living services are necessary for those who are unable to live independently or alone. State Medicaid waiver programs provide these supported living services in the community. Support groups and other social and recreation groups provide settings to participate fully in the community.

#### ***Home***

When one can return to home either independently or with family and caregiver supports, home modifications, equipment and accessible transportation are often required. Assistive technology is also used in the home to promote independence.

#### ***Maintenance and Life Long Care***

Ongoing medication management, physician supervision and mental health support, are among the life-long services required by many brain injury survivors and their families. Brain Injury Association membership and support groups offer peer and family support and assistance in self-advocacy.

#### NOTES

## **Advocating for a Child**

## **PEDIATRIC BRAIN INJURY**

Karen McAvoy

Karen McAvoy, Psy.D, is the Director of the Center for Concussion with Rocky Mountain Hospital for Children. She is a former member of the Board of Directors of BIAC.

If you are the parent of a child with a brain injury, you will find that you will quickly become your child's best advocate. The first step to advocating for your child is to truly understand TBI and how the TBI has affected your child specifically. In addition, the more you know about resources for your child, the better able you are to advocate for them. As you travel the winding road of your child's recovery, doctors, therapists and teachers will come and go. You are the one constant factor in your child's life. It is best for you to understand some of the most common factors associated with TBI. The descriptions are brief and not exhaustive. No TBI is exactly the same. However, there are some features that are more common than others. This chapter covers the following:

- 1) Characteristics of TBI in children
- 2) Child development and TBI
- 3) School resources/programs
- 4) Taking care of yourself.

This chapter is intended to provide a broad overview and to get you started on your path to learning. A list of resources is provided at the end of this chapter if you would like to learn more about pediatric TBI in detail.

## **CHARACTERISTICS OF TBI**

### **PHYSICAL CHANGES**

Before beginning this section it is important to discuss terminology. As a parent of a child with TBI you will likely

## **NOTES**

*As you travel the winding road of your child's recovery, doctors, therapists and teachers will come and go. You are the one constant factor in your child's life.*





have heard the terms mild, moderate, and severe TBI. It is likely that one of these descriptors of brain injury severity have been prescribed to your child. What is important to understand is that these are medical terms. And as such, they are helpful for the medical management of your child. However, these terms can be misleading when looking at long term outcomes of your child's injury. A child with a medically mild brain injury can still experience serious educational consequences related to this brain injury.

As your child recovers from a TBI, he/she may have visible signs of injury – weakness on one side of the body, speech difficulties, etc. Your child may use a wheelchair or your child may not show any sign of injury at all. The physical, “visible” effects of the TBI may be addressed by physical therapy, occupational therapy, speech therapy, and/or vision therapy. The “invisible” effects of the injury are often harder for professionals (teachers, therapists), friends and family to understand and to make allowances for.

Whether a severe TBI or a mild TBI (a concussion), one of the most common effects is **mental fatigue** – a feeling of extreme tiredness or exhaustion over the smallest physical or mental exertion. Mental fatigue can be caused by visual and auditory stimulation, learning a new skill or just simply attending to class room instruction. Mental fatigue will often cause a child with TBI to “melt down” behaviorally, emotionally, academically,

## NOTES

*The “invisible” effects of the injury are often harder for professionals (teachers, therapists), friends and family to understand and to make allowances for.*

and/or physically due to pure exhaustion. When a child “melts down” the adult can attempt to console them and regulate them, however, it is best to avoid mental fatigue by reducing physical and mental exertion and building in more frequent rest periods. Rest periods need to include cognitive rest, not just physical rest. For example, many teachers will allow a student with TBI to “miss recess” as a way to build in a rest break. It is actually preferable to build in a 15 minute “mental rest” (one in the morning and one in the afternoon) where the student can cease academic work or sit quietly with eyes closed or in the nurse’s office. **Pacing** the cognitive as well as physical demands during the child’s recovery from a TBI is actually the most effective and sensible way to deal with mental fatigue. If you can manage your child’s fatigue you have won half the battle.

Strategies for addressing mental fatigue:

- Build in rest breaks (lunch time and recess are not restful for a student with TBI)
- Avoid introducing new learning when the student is fatigued
- The child’s school day may need to be shortened initially, increasing time in school as your child recovers
- Understand that medication can affect fatigue
- Adjust child’s schedule (when possible) to have most challenging classes when fatigue is less likely

## NOTES

*If you can manage your child’s fatigue you have won half the battle.*

## COGNITIVE CHANGES

Cognitive changes are the effects of the TBI on your child's ability to think and to learn. Again, there can be more visible effects – some students with more serious deficits may need to learn how to talk, to count, or to write again. These students will most likely need special instruction and modified curriculum. The majority of students with a severe TBI's require an IEP (Individualized Education Plan) in order to meet their educational needs (see Brain Injury and School section below). However, whether on an IEP or not, a TBI will most commonly affect **processing speed** and **new learning/working memory**.

**Processing speed** is how quickly the child can analyze, synthesize, and think through a problem to come up with an answer. Secondly, it is the ability of the child to act physically and motorically on that answer. *Slowed processing speed is the most common cognitive problem resulting from TBI.* It may take a child longer to think through a question or to follow a directive. While the child may ultimately understand the request, he/she may take noticeably longer to reflect that he/she understands and begin to act. These children need more time with class work and homework and more patience from teachers and parents to work them through this process. Processing speed may always be slower for the child with TBI, even as they grow into adulthood, or it may noticeably resolve with time. Helping the child relearn and rehearse common situations,

## NOTES

*A child with TBI often struggles with the ability to make NEW memories.*

questions, demands, and chores may help to increase processing speed slightly; however, slower processing speed may still be a problem when faced with a novel situation to solve.

Difficulty with **new learning/memory** is also a common characteristic of TBI. A child with TBI often struggles with the ability to make new memories. Long-term memory (memories from before the injury) often remains intact. But the ability to make new learning “stick in the brain” as a new memory may be problematic. New learning in school is ALL about having information convert into memory and be lodged in a logical spot in the brain. If the child with TBI has impairments in the ability to hook new learning/new memory to a place in the brain where it is retained, catalogued, and can be easily accessed at will, then everyday learning in school may be extremely challenging. On a good day (and children with TBI will have noticeably better days than others), a student may retain a newly learned math lesson. Yet, a day or two later, or on a “bad” day, no learning may occur. This “inconsistency” is a consistent characteristic of TBI. However, if a child can learn on one day but not the next, he/she often gets labeled as “lazy,” “resistant,” or “unmotivated”. To reiterate, a student with mild TBI may look completely healed on the outside and many adults in their lives will not know about making, or how to make, allowances for internal, “invisible” brain dysfunction. It may be your job as a

## NOTES

*Executive functions are the brain's ability to organize, plan and regulate itself.*

parent to help educate the teachers in your child's school so that they can not only understand the above effects of TBI but also help devise ways to compensate for these difficulties.

#### Strategies for Addressing Cognitive Changes:

- Give the individual instructions one at a time, make them clear and concise
- When giving instructions, check for comprehension. Have the individual verbalize the instruction as well as demonstrate that he/she understands
- Regularly summarize information with the individual as it is being given, especially critical in regards to new learning
- Give instructions in written, verbal and visual format when possible

### ORGANIZATIONAL CHANGES/EXECUTIVE FUNCTIONING

The frontal lobe of the brain (just behind the forehead) is known primarily as the keeper of “**executive functions.**”

Executive functions are the brain's ability to organize, plan and regulate itself. One metaphor appropriate to this discussion is to think of the frontal lobe as the “Commander” in an army. It is the part of the brain that organizes, plans, and coordinates the rest of the army. It studies the situation. It pays close attention to minute details and can multi-task directions coming from multiple sources. It weighs the pros and cons, and when all systems are go, it makes the good judgment to move

#### NOTES

forward in a structured, organized fashion. If a miscalculation has occurred, it keeps calm, re-engages thoughtful problem-solving, and directs the army to safety. You can imagine that if the commander is impaired in any way, the end result could be chaos.

Some of the most common executive functions are listed below:

- Attention
- Memory
- Planning
- Judgment
- Organization
- Problem-solving
- Emotional lability
- Social Skills

If your child's TBI has affected the executive functions, you may feel as though your child has a markedly different personality. More pronounced in the acute phases of the recovery, your child may show limited abilities in the following: attention and concentration, impulse control, emotion regulation, judgment, and/or problem-solving. For a period of time, your child's behavior may be quite demanding and challenging. He or she may want and need immediate gratification and attention, or they may become inconsolable over the smallest of limits placed upon them. As your child heals physically from the TBI, often these issues with executive functioning heal as well. However, executive dysfunction is still one of the most common lingering effects of a TBI, at times lasting long after the outward physical effects of the TBI are no longer

## NOTES

visible.

**Problems with attention** – A child with TBI-related attention problems may present as extremely inattentive and impulsive. Their prior ability to delay gratification may be compromised. While before the accident a child may have understood not to run out into traffic, a child recovering from a TBI may no longer have the ability to pay attention to the context of the situation. He/she does not notice oncoming traffic (inattentive) or he/she has an unstoppable desire to get to the other side of the street (impulsive); either scenario can be quite problematic. A note of caution: impulsivity and attention problems following TBI are not technically a diagnosis of Attention Deficit Hyperactivity Disorder. While the behaviors may look extremely similar to ADHD, having a medical doctor diagnose and prescribe medications for ADHD for a child with TBI is too simplistic. Medications may be ineffective in the least or they may be dangerous in the worst case scenario. Impulsivity and/or attention problems in the child with TBI are secondary to a larger issue of executive dysfunction. Some medical doctors may choose a trial of ADHD-type medications; however, this should only be attempted by an MD with a good understanding of TBI. However, the strategies most useful with teaching ADHD children to learn to pay attention and to delay impulsivity, such as cognitive-behavior skill-building, and group and parent training, can be equally

## NOTES

*Break tasks down into manageable steps...*

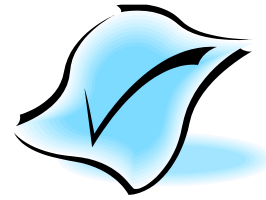
as helpful to children with TBI-related attention problems.

Strategies for attention:

- Provide the individual with an uncluttered environment
- Eliminate as many auditory and visual distractions as possible
- Eliminate as many interruptions as possible
- Break task down into manageable steps based on the individual's attention span
- Provide the individual with clear expectations for what he/she is supposed to accomplish during the activity time

**Problems with planning and organization** – As we move from childhood to adulthood, there are invariably more and more demands placed upon us to multi-task, plan, organize and to keep multiple balls in the air at any given moment. So, depending upon the age of your child when the TBI occurs, you may notice more or less problems related to these executive functions. For a younger child, even without TBI, parents generally provide a structured schedule. In elementary school, teachers structure their day. For the young child with a TBI, parents and teachers gladly take on, and need to take on the role of Commander, with the expectation that the child learn skills to become their own Commander by the later elementary grades. However when an *older* child with TBI continues to struggle with planning and organization

## NOTES



*Develop checklists with the student that he/she can use to help remember daily routines.*



problems, the daily demands of school are painful. How to plan, organize, and write a five paragraph essay may be foreign to a child with TBI. In addition, social interactions and social skills can be extremely challenging for a child with TBI regardless of their age whether it be dealing with the complicated and subtle dance of social interactions – ( i.e. turn-taking with younger children; dating rituals for adolescents) can prove to be mind-boggling!

Strategies for planning and organization:

- Help student develop and organize a “Homework Only” folder and check it with him/her at the beginning of each class
- Check student’s planner at the end of the day (elementary) or each class (secondary) to ensure that they have written their homework assignments completely and accurately. Have the teacher initial the page so the parents know the planner is correct.
- Develop checklists with the student that he/she can use to help remember daily schedule, routines etc.
- Help student organize notebooks by using dividers, colored folders, portfolio containers etc.
- Do not assume that the individual has the ability to take responsibility for the organizational aspects of his/her education, especially early in the recovery; however, teaching compensatory skills for organization

## NOTES

is crucial to helping your child be successful in his/her adult life

- Understand that it will take an individual with a brain injury longer to learn routines and to understand what is expected of them
- Routines are critical to minimize the need to initiate tasks
- Individual may need support to see a task through to completion until the task is routine

### **Problems with emotional lability –**

Emotional lability is the process by which normal emotional responses to situations are exaggerated and exacerbated. The TBI “disinhibits,” or removes the filter by which a person might otherwise use to hold in anger, sadness, or frustration. With the gatekeeper out, a reaction to a small situation may cause extreme outbursts of crying or anger, and stressful “melt-downs” in even the most benign situations. Once these emotions get released, they may be difficult to bring back under control again, especially without external support and structure from an understanding adult. The goal of the parent and teacher in relation to emotional lability early in the recovery is to help anticipate, predict and avoid emotional outbursts. Later in recovery, the goal is that the child with TBI can, for themselves, begin to anticipate a potential “melt-down”, advocate early for his/her needs and find ways to avoid the reaction, and then finally, to use internal coping skills to self-soothe and bring emotions under control.

### **Difficulties with problem-solving and**

#### **NOTES**

*Provide the student with direct and clear feedback.*

**judgment** – Being impulsive, inattentive, disorganized and emotionally dis-regulated can make a child with TBI feel socially uncomfortable. Our society tends to be more understanding and forgiving of social/behavioral problems related to TBI in young children. However, older children and adolescents with TBI are painfully held accountable for social, behavioral, and emotional changes that are often beyond their control. There is frequently awareness by older children with TBI that they are now “different” and that many of those differences are permanent. There is no “disability” more devastating to a late elementary, middle, or high school student than to be “different” from the others. This sudden lack of social aptitude, often accompanied by an abrupt drop in social status, leads to vulnerability. Coupled with poor problem-solving skills and judgment, many children with TBI succumb to negative peer pressure. In their mind, it is better to belong to a group that gets in trouble or defies authority than to not belong to a group at all.

Strategies for problem-solving and judgment:

- Provide a framework for structure in social situations (e.g., invite a friend over for a specific period of time to do a specific activity)
- Small group settings are usually better for a student with a brain injury
- Use peer buddies as mentors when developmentally appropriate
- Help the student identify what activities they may enjoy following a brain injury

## NOTES

- Provide the student with direct and clear feedback

The point of understanding the physical, cognitive and emotional effects of pediatric TBI are to help the child negotiate the often long and sometimes painful path of recovery. In the acute phases of recovery, the parent and the teachers need to be the Commanders in Chief and put into place accommodations and modifications that will decrease the negative effects of TBI. The brain can only recover as quickly as it can recover and no one can predict which issues, how long and how intense these issues may be. So preservation of energy, self-confidence and social relationships are managed with assistance from parents and teachers. However, at some point in the recovery, there comes a time when some of the lingering effects of the TBI may be less pronounced but still present. Sadly, some symptoms may simply become life-long effects of the TBI. This is where the work of the parent and teacher transforms to help the child with TBI transition from a world of “accommodating the disability” to “learning to compensate for the disability”.

In order to make children with TBI successful adults, the child must eventually come to:

- Understand his/her own TBI
- Learn to advocate for him/herself
- Ask for a “fair playing field” not an “advantage” due to the disability

## NOTES

*Learn to  
compensate for  
areas of  
weakness by  
building on areas  
of strength*

- Learn to compensate for areas of weakness by building on areas of strength
- Accept who they are with a disability, not be defined or crippled by the disability

### **CHILD DEVELOPMENT AND TBI:**

The age at which your child sustains a TBI may determine unique and specific reactions to the injury. Severe TBI's at any age - early elementary school, late elementary school, middle school, high school, or college - carry significant physical, cognitive, and behavioral ramifications. However, mild to moderate TBI's may also manifest quite dramatically depending upon how the TBI disrupts the emerging developmental task.

Young elementary age: The developmental task at this age (K-4<sup>th</sup> grade) is to cautiously explore, learn to master certain concrete tasks, and define oneself within the context of parents and the family. Children at this age are still very much dependent upon family. A TBI at this point of development allows the family to appropriately take over some of the executive function demands and fold the child into the structure and support of the family.

Late elementary school/middle school: The developmental task at this age (5<sup>th</sup> grade-8<sup>th</sup> grade) is to more bravely explore the world, begin to incorporate abstract, multi-task demands and to define oneself in the context of a still limited, but larger, social

### NOTES

structure of friends and family. There is an emerging move toward independence. A TBI at this point of development may meet with some amount of resistance as families attempt to pull the child in close for support, structure and protection. Problems with executive functioning, which is not well developed in typical children of this age, may be heightened for the child with TBI.

High school/college: The developmental task at this age (i.e., 9<sup>th</sup>- 16<sup>th</sup> grades) is to boldly (and sometimes, recklessly) explore the world; to fine tune and master highly complicated tasks of abstract thought, forward thinking, planning, and problem-solving; and to define oneself in the context of non-family social groups (friends, professional organizations and ultimately romantic relationships). This is the stage of ultimate independence. It is not uncommon to see pronounced resistance, even denial of the realities of a TBI if it happens to fall in this period of development. Exactly at the time when the executive functions all come together to make a young adult equipped for the world, a TBI can set a young adult backwards on the continuum of dependence - independence. When all of his/her friends are getting ready to launch into the real world, a young adult with TBI may be back at, or still at, home needing the structure of parents for basic day-to-day living skills.

The key to understanding the developmental tasks and the effects of TBI on development is to remember that the role of adult is to push the child as far

## NOTES

toward self- sufficiency as possible. While caring for your child's most basic needs, you must always make every attempt to keep them on the appropriate developmental track. For a period of time, especially in the acute phases of recovery, the child with TBI will need to revert back to the needs and behaviors of a younger child. However, when the child's injury allows him/her to move forward on the road to independence, all adults should be on-board with this forward movement. There may be times in your child's recovery that a teacher or therapist will make a suggestion to push the student one more step beyond his/her comfort zone. Your natural instinct as a parent may be to protect your child who has suffered so much, and you may have an urge to reject the suggestion. A word of caution: no recovery is easy. No physical recovery comes without sweat and some pain. Most parents understand and accept that the "medicine" of physical therapy is necessary for their child to maximize muscle development. Cognitive and emotional recovery is no different. And likewise, it requires some amount of work and discomfort. A teacher may recommend that it is time to place a student with TBI in a regular education classroom. A therapist may suggest that it is time to allow a student with TBI to be home alone for 15 minutes or to learn to cook a simple dinner. Parents must understand that taking these risks is necessary in order to achieve forward motion toward independence.

## **SCHOOL RESOURCES/PROGRAMS:**

It is a common myth that there are separate pediatric rehabilitation facilities for children with post-acute TBI. In the acute phases of recovery, most children stay in a medical hospital until medical stabilization. Some children then are moved to a rehabilitation hospital to maximize rehabilitation progress.

However, the majority of children with TBI are sent home to receive some sort of combination of outpatient therapies and therapy at school. *Schools meet the majority of the physical, cognitive, emotional and behavioral rehabilitation needs of students with TBI.* There are some important school-related terms that you will need to know and understand in order to advocate for your child with TBI:

**Individual Education Plan, also known as an IEP**, is a federal protection given to children with disabilities through the Individuals with Disabilities Education Act (IDEA, the newest revision of 2004). If a child is determined to have a disability (Learning Disability, Speech/Language Disability, Social Emotional Disability, Cognitive Disability, Vision Disability, Hearing Disability, Physical Disability, Autism or School-Identified Attention Deficit Disorder Disability), the child may receive special programming, instruction and modification of curriculum. In 2013, Colorado added a special education category labeled Traumatic Brain Injury. Now, a student with a TBI can potentially qualify for specialized educational services

## NOTES

*For a student with TBI, meetings may have to occur more frequently than once a year especially during the beginning phases of recovery as goals may be quickly reached and therefore become outdated.*



due to the TBI. . The IEP Team at the school (parents are considered part of the IEP team) must meet to determine eligibility requirements and need for services. If the IEP Team agrees that there is sufficient medical documentation of a TBI and/or significant history of TBI and 2) the TBI significantly impacts learning, the IEP Team can recommend that the student be staffed into Special Education. Under Special Education, the team of educators creates an Individualized Education Plan (IEP) to address the specific needs of the student. If appropriate, it can allow placement in specific programs at school, access to modified curriculum and specialized instruction. Upon being staffed into Special Education, your child will receive a “case manager”. This is usually a teacher who will oversee your child’s programming needs at school. It will likely be a Learning Disability or Life Skills teacher or a Speech/Language therapist. There are no specific teachers for TBI case management. Case managers for TBI students are invariably teachers or therapists for other disabilities. It will be important for you to educate the case manager on TBI if they are not experienced in this area. Many school personnel receive limited to no training on TBI. On the IEP, goals and services will be outlined. The IEP Team must meet annually to review the goals (this meeting is called an Annual Review). For a student with TBI this review may have to occur more frequently than once a year especially during the beginning

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Chapter Seven includes information about Players on Your Team, which begins on page 88.

*Schools meet the majority of the physical, cognitive, emotional and behavioral rehabilitation needs of students with TBI.*

phases of recovery as goals may be quickly reached and therefore become outdated. You can request an additional meeting during the year to modify or change the student's goals to reflect the progress they have made. A re-evaluation of services (which may or may not include standardized testing) must occur every three years; this meeting is called a Re-Evaluation or Triennial Evaluation. Work closely with your child's IEP team (see Players on Your Team section of this manual) to create a fluid, working plan to meet his/her specific learning needs. Conflict between you and your child's medical team or school team will only slow down progress. There may be times that you disagree with the school's recommendation. Ask for or seek out a neutral mediator to help ease the impasse. Remember that your child has a right to be educated in the **Least Restrictive Environment (LRE)**. That means that the school team will make every attempt to educate your child in a typical regular education classroom. If your child can academically and behaviorally handle being with typical peers, that is where he/she should be. However, if your child's academic needs or behavioral needs call for a more specialized and structured setting (such as a self-contained classroom or a pull-out program), then the school will talk with you about such a setting. During periods of your child's recovery, he/she may need more or less academic intervention. These decisions must be based upon the behaviors of your child at the time. However, know that the goal of the school, as it is your goal, is always to

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get your child to be functioning as close to age-appropriate in a typical classroom as soon and as much as possible.

The second way to secure protection for your child is through a **504 Plan**. The 504 Plan comes out of the Americans with Disability Act of 1991. This act (primarily coming from the world of work) presumes that the person with a disability can perform as well as any able-bodied person if just given an accommodation for the disability. For example, a person who uses a wheelchair may be able to perform a desk job if simply given the opportunity to get their wheelchair in the building and to a desk. The accommodation for this disability (to “even the playing field”) may be an elevator. In school, a student with a disability may be able to learn at the same rate as typical peers if just given the accommodation of large print books. To qualify for a 504 Plan, the parents must submit to the school 1) documentation of the disability and 2) sufficient proof that the disability substantially impacts the ability to learn. There is not a case manager that accompanies a 504 Plan. It is a plan written up for the teachers so that they may provide specific accommodations for a student with a disability. Knowing what we know about slower processing speed as a common deficit of TBI, a 504 Plan may allow a TBI student to take extra time on a test. Note, the TBI student takes the same test as his/her peers but may have extra time to complete the test. The difference between a 504 Plan and an IEP is that the 504 Plan allows for **accommodation of instruction**; an IEP allows for **modification of instruction**. For example, a 4<sup>th</sup> grade

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You can find a copy of the Traumatic Brain Injury Eligibility Definition by copying the following link and pasting it in your browser:

[http://www.cde.state.co.us/sites/default/files/documents/healthandwellness/download/brain%20injury/bi\\_manual\\_hi-res\\_final\\_web.pdf](http://www.cde.state.co.us/sites/default/files/documents/healthandwellness/download/brain%20injury/bi_manual_hi-res_final_web.pdf)

(Look on page 63 in the document)

student with a TBI may still be able to read 4<sup>th</sup> grade material but may need audio books to supplement learning. That is an accommodation. In contrast, a 4<sup>th</sup> grade student with a TBI may no longer be able to read at a 4<sup>th</sup> grade level and may need instruction at a 2<sup>nd</sup> grade level. That is a modification.

Each year, your child will transition from grade to grade, teacher to teacher. At some point, your child will transition from elementary school to middle school, middle school to high school, high school to the world of college or work. Transition meetings are the best way for school teams to communicate. Depending upon your child's school, a transition meeting may happen in the spring or it may happen in the fall. Transition meetings for students on IEP's are commonplace. Transition meetings for 504 Plans are not common and a parent will need to request one if they so desire. Some school districts have Brain Injury teams – a team available to your child's teacher to consult and educate the teacher on the effects of TBI. However, many schools districts do not have Brain Injury teams. In those cases, you, and perhaps your child's past teacher, are the most knowledgeable people on the subject of TBI and your goal is to educate your child's next teacher. Your child's school team may consist of many players (special education teacher, aide, elective teachers, regular education teachers, vocational teachers or coaches, security, etc.). Between your child's case manager and you, make sure that all players

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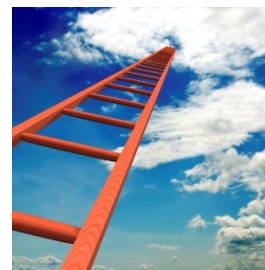
understand your child's goals and are working toward the same outcome.

On an IEP, your child has the right to stay in an educational setting (usually not **at** the high school) until the age of 21 years. Most school districts have a "Transition Program" – some type of programming for disabled students to help them explore post-secondary options (job or college). No later than your child's first semester of senior year, discuss the Transition options with your child's IEP Team.

### **TAKING CARE OF YOURSELF:**

When you brought your baby home from the hospital, you did not expect the twist of fate that would lead you to this TBI. You must allow yourself time to grieve the loss of the hopes and dreams you once had for this beautiful child. As your child's primary care taker(s), your first responsibility is to take care of yourself so that you can take care of your child. Until your child learns to fly again, he/she will rely on you. While there are no set people or programs ready to scoop you up and pave the way for your child's recovery, there are many wonderful people out there on the shared path. You will not find them waiting for you at a "TBI Center." You will not initially find them as "TBI Experts." But most teachers, neighbors, friends, relatives, babysitters, swim coaches, Girl Scout leaders, piano teachers, fellow baseball teammates, pastors, etc. will take their cues from you. As you become the TBI expert, you will teach them. They will stretch from here to the highest level of your child's recovery with you.

### NOTES



Information is powerful. This is just a start to your path of learning. To gain more in-depth knowledge about TBI and about resources available to you and your child, the following are provided:

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## **PEDIATRIC RESOURCES**

Educational Dimensions of Acquired Brain Injury, (1994), Savage & Wolcott (Eds.), Austin, TX: PRO-ED, Inc.

BrainSTARS Manual, (2002), Calvery & Dise-Lewis, Children's Hospital, Denver, CO (available through Lash & Associates Publishing)

Brain Injury Association of Colorado (BIAC)  
[www.biacolorado.org](http://www.biacolorado.org) 1-800-955-2443 or 303-355-9969

Colorado Department of Education:

1.) Brain Injury: A Manual for Educators  
<http://www.cde.state.co.us/cdesped/sd-tbi>

2.) CDE Concussion Guidelines  
<http://www.cde.state.co.us/healthandwellness/braininjury>

Colorado Website:  
[www.cokidswithbraininjury.com](http://www.cokidswithbraininjury.com)

Colorado Brain Injury Program  
[www.tbicolorado.org](http://www.tbicolorado.org) 1-888-331-3311  
Look into the Youth Brain Injury Connection (YBIC), funded by the Colorado Brain Injury Program, accessed through BIAC.

Health Care Program for Children with Special Needs (HCP)  
<http://www.cdphe.state.co.us/ps/hcp/>

Division of Vocational Rehabilitation <http://www.cdhs.state.co.us/dvr/>

Elvin: The Elephant Who Forgets by Heather Snyder

Lash and Associates Publishing, [www.lapublishing.com](http://www.lapublishing.com)

## **ADVOCACY FOR YOUR CHILD**

Jim and Alice Brouhard

Jim and Alice Brouhard's daughter, Kara, sustained a traumatic brain injury in 1986 at age 5 when she was struck by an out of control skier. This chapter was published in the first edition of the SAIL Workbook. It is now followed by a second chapter, providing an update on Kara's life, and her parents continued advocacy efforts.



As parents of a child with a traumatic brain injury, we can look back and see how the past years have shaped us. We have learned skills from other parents, from the school system and from healthcare providers. We didn't learn how to advocate overnight, just as initially, we didn't learn how to parent overnight. It took time, effort, some good experiences, and some bad.

We learned that as Kara was healing from her injury, we needed to heal from the terrible hurt and pain we felt. Initially, we were very dependent on the professionals working with us to guide us in making decisions. As we began to heal, we grew, we learned, and we gained confidence in being parents of a child with a TBI. We became more independent in making choices for her and for us.

Parenting a child with a TBI differs from advocating for an adult who has had TBI. Parents have hopes and dreams and visions of a better life for their child as part of normal parental expectations. Emotional ties of a parent-child differ from that of a spouse-spouse. We realize and accept that at some point in time, our spouse may become ill or injured, but we see this as in the future and something we can cope with when the time comes. We also see this as a natural progression of life.

When a child is injured, everything we hold to be true and fair about life is shattered. We have to give up our role of being parents and are asked to be nurses, therapists, teachers and major decision-makers before we totally know what has

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happened to us or to our child. We are dealing with tremendous pain, perhaps guilt, and an overwhelming sense of our life being out of our control. There is a feeling of *terrible* loss as the perfect child of our hopes and dreams is gone - and these things don't happen to kids.

In learning how to parent Kara after her injury, we found that what was most beneficial for us was to hear that we had entered into a cycle of loss and grief. Life would get better for us, but the sorrow over the dreams lost would never completely go away. We heard parents of children with a wide array of disabilities explain this grief process in their own lives, and it hit home for us that our life, for a while, was to be lived in a series of steps and stages.

The grief cycle that made the most sense to us was described by Dr. Gil Foley, psychologist and author of "The Grief Reaction." He has worked extensively with families whose children have disabilities. His work with families has shown that parents and survivors can be triggered to "re-cycle" through the grief and loss process as we reach certain milestones like a birthday, anniversary of the accident, or a transitional period, or even sometimes for unknown reasons. This may sound discouraging to those of us who want to get on with life, to get over this pain, hurt, and anger, but each time going through the cycle is faster and we emerge stronger and more capable to deal with that which comes our way. Plus, it helps us to realize we are not crazy when we experience the wide range of feelings that accompany this

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process. We encourage parents, and anyone working with families, to learn more about this process. Recognizing these feelings in ourselves and others can lead to improved understanding and communication.

Kara was injured in December and was hospitalized until mid-March. After Kara came home from the hospital and we had arranged to provide the extensive physical rehab she needed, we asked ourselves, "What about school?" We knew we had to get her reconnected into school to have her be with friends and work on socialization again.

In early April, we made arrangements with school for Kara to go to her kindergarten class 2-3 times a week for art and music. The principal told us we could get extra help from school with additional occupational therapy, so by mid-April, four months after her injury, we had settled into a pattern of rehab, some school, and more rehab. We had a staffing in May with fourteen people in attendance. Most of the emphasis was on the things wrong with Kara. She was labeled "multiple handicapped," an IEP was formulated, and Jim and I hadn't a clue as to what this whole process was about. We had another staffing in September, shortly after Kara started first grade. This time, a group of twelve discussed her weaknesses and told us what we needed to do. We agreed without knowing what an IEP was, why it was written, and how it was going to impact us over the next few years.

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In retrospect, we learned that the most important step in learning how to advocate for your child was to learn about the *federal and state laws* governing the rights of children with disabilities, in order to receive free and appropriate public education in the least restrictive environment. For many of us, the school system is where our children are going to receive the majority of the rehab services they need in terms of speech, OT, and sometimes, PT. These services often will need to be provided over a period of years and often until age twenty-one. If families are fortunate to be insured, they may find that their insurance company has *limits* on the amount of private therapy they will pay for. Many families without insurance are not eligible for Medicaid and certainly aren't able to pay for private physical therapists, etc.

So, it is vital for parents to learn about the laws and the formulation of an Individualized Educational Plan (IEP) so that their child receives a "free and appropriate education" for as long as they are entitled to it, possibly to age twenty-one. Learning about and understanding the laws can take a great deal of time. Fortunately, there are many great resources available to help parents. The following are some resources you may find helpful.

**The Brain Injury Association of America (BIAA)** has an extensive list of publications available for a nominal cost. You can receive a bibliography from them to order the materials of interest to you.

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**PEAK** (Parent Education and Assistance for Kids) based in Colorado Springs, offers free mini-workshops and trainings throughout the state. They also have written materials detailing the laws and regarding the IEP staffing process.

**PEP** (Parents Encouraging Parents) sponsored by the Colorado Department of Education is an organization which holds conferences three times a year at different locations in Colorado. These two and a half day conferences are free (including lodging and meals!) and cover everything parents need to know about the education of children with disabilities. We highly recommend attending a PEP meeting. This is also where we first learned about the grief process.

We found it much more beneficial to listen to discussions at workshops on the laws and about how an IEP is written than to simply read about it. It also gave us an opportunity to interact with parents of children with all kinds of disabilities. Many of these parents had been working with the educational system for years and gave us excellent suggestions. We all shared the same frustrations, fears, hopes, and dreams for our children regardless of the disability our child may have. It gave us hope to see other families surviving and thriving. We had to hear about the process several times before we had a good understanding of it, but it has been absolutely essential for us to have this knowledge so that we could confidently advocate and ask for what Kara needed and was entitled to under the provisions of

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the laws.

We went through some rough times over the next two years with first and second grade. The hardest was placement of Kara, eighteen months after her injury, into a school program designed to serve students with severe developmental delays. This program was within our school district twenty-five miles from our home. We felt tremendous pain, then sorrow, as we watched her regress socially and emotionally. As we learned more about the laws and her right to be in the least restrictive environment (LRE), we were enraged about this inappropriate placement. Certainly, a great deal of grief was brought to the surface during this time. Fortunately, during this period, we had begun to have a good working knowledge of the laws, and most importantly, how we could communicate effectively with the educational team. We learned that we had to know who were involved on the educational team, including the regular education teachers, the special- education teachers, the therapists, the school principal, the director of special education, and finally, the school district administrator. We had to establish communication with all of these people.

We had to take an active role in helping them learn about the needs of students with traumatic brain injuries - this included sharing articles we had received from BIAA and giving them the resource list from BIAA so they could order information that would be helpful to them in terms of specific teaching strategies. We helped them to see

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that a student with a brain injury can change rapidly in a year's time hopefully to improve - and it was absolutely essential not to underestimate a child's recovery capabilities.

We found that some educational team members were more willing to listen and learn than others, and we had to be the experts for a while. This, too, was a skill we had learned from other parents who had gone through this process. There are so many children with special needs in the school system that teachers cannot possibly know about all of these disabilities. Parents have to be able to help the teachers gain an understanding of these disabilities and aid them in determining the child's best learning style.

With lots of time, work, effort, and sharing our hopes for Kara with the staff, she was moved back into a regular education classroom for most of her school day with supports of a teaching assistant and a highly modified curriculum - and she thrived by being with her peers again! She finally was able to return to her neighborhood school after completing third grade in the school twenty-five miles from her home.

We saw ourselves as part of the educational team and as an equal partner in the efforts at supporting Kara. We became committed to the idea of forming partnerships with this team. We knew that we did not have the technical expertise and experience they have, but we brought to them our perception of who she was and

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our vision of what we saw for her in the future. We have had to open up our most personal parts of our lives for testing, evaluations, and analysis and we deserved to be heard.

We did go through a period of feeling that it was "us against them," especially in terms of Kara's mistaken placement. We felt we had to fight for her rights, but we found that the angrier we became, the more counterproductive we were. We used a variety of techniques suggested to us by parents of children with other types of disabilities. The techniques that worked best for us included increasing our knowledge of the special education process, learning how to communicate our needs, and also being able to look at both sides of an issue. We also learned to value the tasks the teachers face every day with all of their students. Most teachers are very dedicated and caring and want to learn how to best meet each student's needs.

The most effective tool we found in establishing the team concept, partnership idea, was to provide a flip chart during Kara's staffings. This allowed us to share our feelings about Kara and her feelings about herself - sometimes things she could not verbalize freely to others. This was not an elaborate project. We bought an 18 x 24 newsprint pad, a package of wide tipped magic markers, and wrote down these thoughts. Doing this also gave us a feeling of power and shared responsibility; as all of the therapists, psychologists, and teachers shuffle their papers and reports, we have our papers to keep in order and

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ideas to contribute. The flip chart also gave us a chance to share our vision with the whole team, kept the staffings focused toward her strengths, and explained what supports she needed to continue to succeed. Jim and I do not know a lot of teaching strategies, but we know Kara. For an example of the flip chart, see the end of this chapter.

Undoubtedly, there are a lot of negative issues discussed during staffings (i.e., test scores, evaluations, and observations). We have found it helps to live with the philosophy that "there is no measure of the human spirit." Certainly, with our TBI survivors we know that these scores can be meaningless in telling us what our child can truly accomplish. In our encounters with families of children with other kinds of disabilities, they share the same frustration with testing and evaluations. Critics may say in viewing statements on her flip chart that we were "in denial" of her deficits, but we were fully aware of her weaknesses as we lived with them twenty-four hours a day. Still, we chose to focus on her strengths and ways to maximize them. Educational and healthcare systems are often designed to focus on what's wrong rather than what's right.

As time progressed, we learned that friendship-building and maintaining relationships was and is a key element in Kara's progress. For a long time, because of her intensive physical rehab program, she had many more adults than children as supports in her life. We would pick her up after a busy school day and rush off to

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another PT or OT or speech session. We started feeling the need to try to find natural everyday ways to incorporate these therapies so we could learn how to be a family again. Kara did have a nice group of friends at school; some of it initially was contrived in terms of assigning students to be her peer supports. This evolved into the students getting to know her and liking her. What we were frustrated with was how to have some carry-over in terms of friendship away from school.

We found that as Kara entered a new school year, it worked very well to send in a photo album we put together showing pictures from the first year of her recovery. We used non-threatening pictures and the kids really benefited from it. They could see pictures of her shaved head (makes a big hit), of her progressing through with pictures of PT sessions, and of her learning to sit up and walk again, but mostly the pictures of Kara doing "kid" things were the most impacting – Kara fishing, going to the zoo, participating in family gatherings, dressed up for Halloween and being part of her kindergarten and first grade classroom. As Kara would tell them, "I'm just a kid who got hurt in a ski accident." This really increased her classmates' sensitivity towards her physical disabilities. She did have a few friends who would stop by on weekends to play, but we knew she needed more than that. We wanted her to learn how to build on other friendships started in school.

We started by enrolling Kara in our library's summer reading program and a few of our

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town's summer recreational programs. We chose safe classes she could succeed in, like a swimming trip, a picnic, or an easy hike. Initially, we felt we had to explain in detail to the adult leaders any potential problems they might encounter; seizures, impulsivity, a very short attention span, and memory deficits. This would really make the leaders apprehensive and nervous, but they would still include Kara in the activities. What we found in all these activities is that there would be at least one neighborhood friend or classmate who already knew Kara and accepted her. Oftentimes, the other children were the ones redirecting behavior if she would get too wild and Kara would listen to them. The children's acceptance of her and the ease in which they interacted made the adults much less apprehensive. We then learned to use words when describing her to new program leaders that focused on her strengths – that she has a great sense of humor, she loves to tell jokes, she laughs a lot, she likes to keep active. This helped them to look beyond her physical disabilities and focus on her being a kid first. The leaders knew that we were open to them calling us with any questions or concerns.

The fact that there are schoolmates and neighborhood children in these programs affirms our belief that children with disabilities have to be included and integrated into their neighborhood schools if they are to lead as normal a life as possible. It's a natural extension of life that kids from neighborhood schools go to the same grocery stores, library, neighborhood

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McDonald's, movie theaters, local swimming pool, and summer recreational programs. Each time Kara made connections with kids in these situations, it reinforced to them that she belongs, that she's okay, and that she's just a kid first doing the same things they are doing.

All of this work enabled us to arrange for sleep-overs, swim parties, trips to the movies, and sometimes just having friends come over and "hang-out." She joined Girl Scouts and actively participated in their summer camp. All of this has allowed her to make tremendous strides in increasing her socialization skills. Yet, there is a strong tendency for families with a TBI child to isolate and withdraw. Families of children with other types of disabilities report the same feelings. Sometimes it is necessary for us to keep up this isolation as we progress through the grief cycle. It's hard to be "out there," in the supermarket, movie theater, park, or McDonald's with a kid who's showing some bizarre behavior or who is obviously physically disabled and drawing stares. It is also very painful to watch friends and neighborhood children the same age growing, changing and progressing as our children are left behind. Friends can turn away out of fear and out of embarrassment of saying the wrong thing. We have to face so many of our own emotional fears, scars, and pain to allow ourselves to continue to be part of society and to let our child be part of society. Some families are never able to progress beyond some of this isolation and move through the grieving process. Professionals need to acknowledge this but not give up

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on them or their child.

For those of us who are able to pass through this phase, it is invaluable to know the stages of the grief process, to realize that these are normal feelings and that the hurtful, lonely times will pass. A good way to help these times pass more quickly is to stay involved and stay connected with other families, through support groups. These groups probably will not be strictly for TBI survivors. By getting connected with other parent support groups, you will find that we all share the same emotions regardless of the disability plus these parents and groups can really give us some great coping strategies to see us through these down times.

Most important, during the hard times and also during the great times, try not to forget to give yourself, your family, and your child credit for how far you've all come. Many of you have already survived days, weeks, months, and perhaps years of intensive care, hospitalizations, painful rehab and watching your child endure things that no one should have to experience. You are stronger than you ever thought you could be and you have already learned some tremendous coping skills that you can share with others. You have learned to change some of your dreams but you can still dream, so look at your survival skills and be proud of where you are.

Jim and I may not be on the same path we had planned for our lives, but it hasn't been the worst road we could have taken. We've learned, we've grown, we've changed, and

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we've altered our perception of what is of value and importance to us in life. We've found that spending time with family and friends is what enriches our lives. We've done many things we never knew we had in us - like contributing to this manual!

We've never given up on Kara. We continue to hope and dream for her and with her. We hope this sharing enables you to do the same in your family.

## NOTES

# KARA:

## Good things about Me:

I'm Smart, Nice	I have lots to say
Funny, Kind	I have tons of friends
Pretty, Generous	

## My favorite things about Me:

My laugh, my yell

## What I like to do:

Swim, Dance, Horseback Ride, Hike, hang out with kids (Girl Scouts, Ecology class)

## What I like about my friends:

They are funny  
kind  
nice  
generous

## What my friends like about me:

I'm nice to them	
generous	I'm nice to them, generous
and careful	

## What Kara is to us:

- a joy
- a giggler
- brave, independent, stubborn
- "the wind beneath my wings"
- a crooked smile
- a terrific listener
- a swimmer, a hiker, a camper
- a horseback rider, a cross-country skier
- a great singer!



## **THE NEXT CHAPTER...GROWING UP WITH A BRAIN INJURY**

Alice Brouhard

In the 16 years since we wrote our original chapter for the SAIL Workbook, it is staggering to think about the changes in our lives and the lives of so many others. The Head Injury Foundation is now the Brain Injury Association. The new name is much more appropriate as a head injury does not sound nearly as complex as a brain injury.

We have continued to stay connected with BIAC and other cross-disability groups as we speak up and ask for more funding, more resources, and more support as our loved ones with a disability grow older. We know there is strength in numbers and in our voices if we maintain those ties.

Using strategies such as those described in our original chapter (see the previous chapter on Kara in this book); Kara successfully graduated from Glenwood Springs High School. She had friendships and supports through school groups and church groups. We continued to push for full inclusion for Kara in these school years, and met with a positive outcome. Jim and I continued to develop partnerships with those in the schools providing support to her. We felt supported and valued as we worked with the Colorado Department of Education in helping to develop some of the initial position papers on TBI and the set-up of some of the early TBI support teams within the school districts. So to those of you reading this, speak up, and make your needs known and heard.

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Because Kara is legally blind due to a significant visual field loss from her BI, we chose to have her complete a transition program from age 19 -21 at the Colorado School for the Deaf and Blind in Colorado Springs. This brought a whole new dimension to all of our lives, as she was living in a dorm far away from us. This was generally a positive experience as she continued to grow independently and began to advocate for herself.

Jim and I had been very comfortable with the school system and in advocating for Kara. Once she reached adulthood, we were faced with the question, "What next?" The adult services area is a challenge to say the least. We continued to have hopes and dreams with and for Kara. She had achieved some of her dreams in high school such as "traveling and seeing the world," as she was able to go on a school and a church trip to Greece and Italy. Her next dream was "to live in [her] own house." So, we started asking many questions about long- term services and supports. We signed Kara up for Social Security and Medicaid, and gained guardianship of her. Because of the age at which her injury occurred and the many cognitive challenges she has, we were advised to classify her as "developmentally delayed" in order to receive services through that system. This was particularly complicated as there was a 10-year waiting list for a comprehensive placement. We kept saying "But she had a brain injury!" It just didn't feel as if this was the road we

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needed to go down. I persisted in attending conferences, asking questions, and speaking up, until we received the Medicaid Brain Injury waiver for Kara. After she finished the transition program in Colorado Springs, she moved into a group home there with other brain injury survivors.

Unfortunately, during this time period, Jim had developed a benign brain tumor and required surgery. He had many complications, and after two months of hospitalization in Denver and Grand Junction, he was able to return home to Glenwood Springs. I found myself right back at it with arranging PT, OT, speech therapy, etc. I will say that the coping skills I learned early on because of Kara's injury helped me through this dark time. I developed partnerships with the therapists, surrounded myself with positively minded people, and tried to maintain a positive attitude for myself as much as possible. I started setting up three-ring binders as I filed and tracked the insurance, Social Security, bills, etc. for the both of them. Jim had been in charge of all of this prior to his tumor. I reserved an hour for myself each day to take a power walk, and eventually, we got through it.

The years from 2002 to 2005 were very painful for us as we tried to help Jim gain the best outcome from his tumor and as we searched to find the best long-term "placement" for Kara. We were very well aware that Kara would always need long

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term care and services. However, we could not see it happening in a group home miles away from where we lived and where she wanted to live. After spending time in brain injury programs in Colorado Springs and Grand Junction, she came back to Glenwood Springs to live with us. She was 23 and desperate to “have my own life.” She is on the Medicaid BI waiver and we tried to piece together an “independent program” for her. She received independent life skills training under the BI waiver for a few hours a week. I also sought out community connections and involvement for her. Our family has always had the belief that we had to be contributors in the community, so Jim and Kara both started trying out different volunteer options. Kara found her niche as a support person for our local police and fire stations. She continues to bake cookies once a week and takes them to the stations. Because of this involvement, she has made some great friends and she has been able to request things like going on a fire truck ride for her birthday. In fact, for one of her birthdays, the firemen closed down the station for an hour and had a surprise birthday party for her.

As we continued to try to help Kara realize her dream of living on her own, I discovered the power of the computer along with some gifted programmers who have developed software to allow people with disabilities to live as independently as possible with technology. By the grace of God, we found a little house about six

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blocks from ours and started moving forward on helping her to live independently. With support from Kara's case manager at Garfield County Social Services, we enrolled her in a Medicaid pilot program for the Consumer Directed Attendant support program (CDASS.). This allowed us to hire, train, and utilize people who could help us and offer Kara support in leading a self-sufficient life. In April of 2007 Kara moved into her own home. She has a computer "mother" who guides her through her day with timed voice prompts and picture prompts, a room-mate who provides another set of eyes and ears in case of a problem, two wonderful attendants who assist her with her day-to-day activities under the CDASS program, and her own dog.

Jim and I still provide a lot of support and checking in, but our family dynamic has grown and changed. We are extremely proud of Kara. We continue to move through loss and grief cycles with her at milestone events, which now include the weddings of friends and the birth of their children. But we have also maintain a sense of extreme satisfaction in knowing that we dared to have hopes for the best life possible for Kara and for our family.

So, as your children grow up with a brain injury, hang on to your hopes and dreams. Look at the strengths, gifts, and talents you all have. Stay connected to BI support groups and whatever other groups you can find that share that belief in the *abilities* of

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your survivor, not the disabilities.

By the way, Kara's next dream is to have a husband and two children.....

## **RETURNING TO SCHOOL AFTER TBI**

Mary O. Layman

Mary and her husband, Bob, are the parents of Katie and Bobby. Bobby sustained a Traumatic Brain Injury at age 16.



The story that changed our lives began December 23, 2003, a Christmas to remember. Our youngest child, Bobby age 16, was in a ski crash in Snowmass, CO. He sustained a massive closed head injury resulting in traumatic brain injury. He was wearing a helmet, and I believe it saved his life.

A flight for life helicopter delivered him from the initial hospital to a trauma hospital. He had been resuscitated twice. When we arrived, we were given little hope for his survival. A Catholic Priest was summoned to administer last rights. We made arrangements for his organs to be donated, as we knew was Bobby's wish, in the event of his death.

He was then raced to surgery to place an intracranial shunt in his brain because the pressure had risen so dangerously high. We were told his chances of surviving the surgery were 5%. He made it through the night but we were given very little hope. That continued for the entire month in ICU. The next month we were told that if he did in fact survive he would be in a vegetative state for the remainder of his life.

A jet ambulance transported him across the state to the third hospital. The fourth hospital move was accomplished in a regular ambulance. After four hospitals, eight ambulance rides, and uncountable hours of physical therapy, occupational therapy and all other types of therapy under our belts, we left the hospitals six months later.

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Against all odds our son lived. He survived seizures, fevers, eight tracheotomies, MRSA, pneumonia, staph infection, pulmonary contusion, bruised lung, phenol injections, casts for spasticity in his arm, an injection in his vocal chords, pharmaceutical dispensing mistakes, allergic drug reactions and a weight loss of over 40 lbs.

During the 6 months in hospitals he relearned how to breathe, swallow, feed himself, smile, laugh, roll over, regain bowel/bladder control, stand, walk, talk, and feed himself. Most importantly he learned how to learn again in a whole new way. We began his school studies while he was still hospitalized in a rehab facility.

Our roles as parents were also changed overnight. We felt very overwhelmed that we now had to learn all these other jobs (in a hurry) in order to advocate, and make more independent choices for our son. We became part of the medical team and tried to understand the jobs of the doctors, surgeons, nurses, respiratory therapist, nutritionist, X-Ray and CT techs, bed side assistants, occupational therapist, speech therapist, physical therapist, recreational therapist, lab techs and hundreds more including the business department staff. I never knew there were so many acronyms for medical terms.

Many times we were accused of being in denial of our son's long term outcome for recovery. Our family felt we were in acceptance of God's will for Bobby and prayed for the strength to endure the

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journey.

The parental role takes on a new twist when you leave the hospital and begin transition into school again with your child. I am not a teacher and home schooling was out of the question for Bobby and me. I wanted to see my taxpayer dollars at work. My jobs now included: special education teacher, school principal, director of special education, school psychologist, counselor, bus driver, coach, social director and evacuation specialist. You need to become part of the educational team, communicating effectively as an advocate, with a firm pulse on the heartbeat of the system. We learned the law for disabled students. We learned our son was entitled to an education in the least restrictive environment. We learned what an Individualized Education Plan (IEP) is, how it affects everything for a child, and how to write one. Anyone involved with the Laymans were aware that we “knew the law” and intended to see how well it worked. We learned that evaluations and test scores following a TBI mean absolutely nothing. Thanks to families in similar situations, we got the “dirt” from them and were able to slide through a few major barriers, including inappropriate placement and an IEP that was not completed in Bobby’s best interest. These folks had already traveled the road with their children.

I requested that the Superintendent send three school employees to the Brain Injury Alliance of Colorado conference in Vail.

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Most teachers are extremely dedicated to every child that comes through their door. They are expected to become experts on many different types of disabilities their students have. My son was one of the first severe TBI students to return to this high school, in our rural area; so, there was a need to bring in as much information as possible on how to teach Bobby effectively. Armed with my “Brain Stars Manual” and his “Neuropsychological Assessment,” I visited each of his 8 teachers and counselors, requesting that they read the highlighted assessment items and two of the 10 chapters. It took a few weeks to get through all the teachers. Some were not as eager to do my assignment; others were hungry for more information when they completed the task. I had no time or resources to go out of town to conferences. I had to rely on the internet. I constantly was finding education techniques I thought might help my son. I would make 8 copies and deliver one to each teacher, (highlighted, of course!) the following morning.

Bobby would not hear of having a teacher’s assistant follow him around to every class to help him. He said “why can’t we use my friends?” So, we developed a system, with the help of the counselor, where we found 8 students to match him up with in each class to be his personal aides. It worked, but it took a lot of effort. I trained them in seizure support, evacuation, what to watch for in Bobby’s mood swings, triggers (loud noises & bright lights), and how to scribe and take notes for Bobby. Whatever homework was

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assigned had to be completed during the class time. By the time Bobby returned home he was too fatigued to do homework and it was impossible to accomplish without his aid. We found students who had a free period in their schedule and were willing to help Bobby. It took us nearly the whole semester to get the wrinkles ironed out and guess what? When semester changes, it means new classes, new aids, and new teachers ...so, back to the schedule shuffle and training of teachers and aids. During his senior year we were able to take a team of teachers, counselors and therapist to a Brain Star training about 80 miles from their school. That proved invaluable to them getting on board as a team to support Bobby. We then had teleconference planning with Brain Stars to make sure we were all on the same page, and an appropriate IEP was in place.

In his senior year, we were getting pretty good at finding the gals to help him. We determined the prior year that girls seemed more helpful teaching Bobby organizational skills. We looked for the AP students; we passed the word that if any of them were pursuing a teaching degree or a medical degree, working with a TBI survivor might be interesting for them in their careers. They were honored at the Senior banquet as "Bobby's Girls" with the song being played in the background as they were called up to the stage. Thanks to "Bobby's Girls" and the staff's unending patience, dedication, and determination Bobby graduated with his class. There may even have been some celebrating because I

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would no longer be at the school.

Every day after school there were therapy appointments, doctor's appointments, sports, and recreational therapy to go to with Bobby. There were very long, exhausting days for us all.

Following High school graduation we enrolled Bobby in Colorado Mountain College (CMC), a local community college. He began summer semester pre-college classes as an introduction to college level courses. The first hurdle was college reading and pre-math. He worked with private teachers to accomplish those classes. In the fall, he began classes with one tutor who worked with him in all three courses. They would go to class together, then come home and tutor at home for the afternoon.

I have found college easier to help Bobby navigate through than high school. Because he takes fewer classes per semester and he has one tutor to communicate with it helps simplify things. Hopefully over the last four years we have learned more about the education system, and Bobby has been busy healing since his junior year of high school.

He is now living on the CMC Spring Valley campus (at the time I am writing this). His tutor meets him at campus and goes to class with him, and then they have study sessions/tutor in the afternoon. He has made the Phi Theta Kappa honor society with a 3.65 GPA. He says that what used to take him an hour to learn/study now

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takes him five hours. Bobby's rate of mental processing speed was greatly reduced after the injury; he is now a visual learner and his working memory, which affects his new learning capability, is decreased. He now uses his non-dominant left hand exclusively for fine motor activities, such as writing.

Finding and keeping a tutor has not been proven to be easy. I had to figure a way to get more money allotted for a tutor. I have his tutor funded through three agencies to equal an adequate wage, comparable to the county averages, to inspire a person to take on this daunting task of helping Bobby learn. She has to wear different hats for each role she plays. Sometimes she is the "Tutor," sometimes the "Note Taker/Scribe." Often, she is a friend who is helping Bobby manage his mood swings, fatigue, nutrition, and social life. She is young and full of energy, both of which I am lacking at the moment. She, too, is enrolled as a student. During the summer I also have her funded through another agency for "Life Training Skills".

I imagine it will take Bobby 3 ½ years to complete his associate degree. He plans to go for his Bachelor degree at a larger University. We felt it was necessary to transition to living in the dorm 32 miles from our home before he would move 200 miles away. We have already found some bumps in the road and are working hard with Bobby to smooth those out. I see one obstacle as Bobby has been protected from peer pressure for the four years since his crash by living at home with his family.

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Now, with the new freedom, he has needed some reminding of how to make smart choices, how to think first.

The ski crash in 2003 was not his last scary moment for us. Bobby had a major bicycle wreck in 2006 breaking his helmet and the steel frame of his bike, resulting in road rash (and, another ambulance ride). Last winter, 2007, he had a “brush with a tree branch” while skiing, resulting in ten stitches in his face. The percentages are very high for repeat brain injuries because TBI survivors are often off balance and their judgment is not as good following their first injury. I REALLY don’t want to do this again!

Bobby is a healthy, happy 20 year-old young man, busy changing his disabilities into abilities. He is flourishing in his role as a TBI survivor. He is very involved in school, exercising, and sports. His passions are soccer, recumbent bicycling and skiing every weekend with Challenge Aspen, an adaptive ski program in Snowmass. He has become a self-made motivational and injury prevention speaker to share his story with others. He is an inspiration to all who hear him speak, but his motives are purely selfless as he just wants to help others realize their abilities. He says, “Whatever your passion is, DO IT, but take it down a notch. Do it like there is a tomorrow, think first!”

I have always thought of this journey as a job. I instantly had numerous employees. Becoming a manager of hundreds of people overnight was not easy especially

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since I was learning new businesses all at once. Some will remain friends for life, some not, and some were thrilled to see me go through the exit door. These people were paid for their services by my insurance, my property taxes, my income taxes, my money and donations from friends. This is why I see them working for me. They were trained in all walks of life including the medical profession, educational system, rehabilitation system, business/ legal profession, federal and state agencies. We met some of the most brilliant people in their fields, dedicated in every way to saving the life of my child and educating him to be as productive, and self-sufficient as is possible for him post injury. They educated our family to better serve the needs of our son. Our goal is to help Bobby return to a full life where he can support himself, fulfilling many of his long term goals including sports and raising a family. We admire their brilliance. To all those we have met and successfully worked with us along this journey, thank you, look at our son Bobby, it must make all of you very proud as it does us.

That being said, I do have to tell you we had our fair share of incompetent people “employed” during this time. We found them in the medical, educational, federal, state and private sectors. These folks should never have been doing the jobs they were. My child would not be left in their care, not alone at least. Being in business myself I was amazed at the wasted time, time being money, throughout all of the agencies. Employees who are not doing a good job need to be trained or

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Additional information about strategies for college can be found in chapter 22 which begins on page 337.

dismissed for our children's sake. As the employer, the amount of paper work I face for Bobby is amazingly redundant and time consuming. Everybody sure likes paperwork in TBI.

Our faith in God and His will is what gives our family the strength to bear the insurmountable pain, the overwhelming loss and survive the grief. Finding it nearly impossible to survive without our sense of humor also helped our family ease the pain. We celebrate the young man Bobby has grown to be, and count His blessings on us.

Bobby has many challenges he will face his entire life. His determination remains an inspiration to all of us who share his journey. He truly is an amazing young man.

These pages are written to help people as they begin a journey of brain injury with their child by sharing our story. My wish for you is hope. Never let anyone take away your hope.

*Note: Options and strategies for college are also addressed in the chapter on Productive Activity.*

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## **ORGANIZATIONAL TOOLS**

Elizabeth Meschievitz

Elizabeth completed her Master's in Occupational Therapy in 2004, and has worked with youth and adults with acquired brain injury.

This chapter is meant to provide you with strategies for ORGANIZATION – from putting your personal things in order like mail, those stacks of medical records, files, your closet, your refrigerator, (*your whole house?!), to organizing verbal information coming at you during phone calls or meetings. The information and suggestions provided in this chapter are included to help you, one small step at a time, streamline your life and in turn, be able to advocate for yourself in a composed and collected manner. These strategies could be for anyone, but side notes will suggest things to keep in mind as you tackle “getting organized” following brain injury.*

Organization can be a complex process and it certainly requires complex thinking and planning. Executive functions are key components to creating and maintaining organizational systems. These executive functions occur in the frontal lobe of the brain and include:

- Initiation
- Sequencing
- Problem solving
- Follow through
- Self-monitoring

Unfortunately, this area is often affected after brain injury. To compensate for difficulties with executive functions, consider the following strategies:

### **INITIATION**

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*These strategies could be for anyone, but side notes will suggest things to keep in mind as you tackle “getting organized” following brain injury.*

Schedule some time to allow for organizing. Once you get started, you are the best judge of how OFTEN you will need to schedule times for organization. Once a week may be enough to give you time to settle into the changes you are making to your environment and prevent you from giving up before you are done. Or, maybe you will prefer a small amount of time devoted to organization every day to keep your momentum going. YOU DECIDE, but it is important that you set aside *specific* times in your schedule dedicated to organizing.

## **SEQUENCING**

Make a list of areas or items that you think may need to be organized. Then, break each area into manageable, smaller pieces. Create a checklist starting with the areas that you use most frequently and have the most frustration with, and move down the list as those areas are completed.

## **PROBLEM SOLVING**

Come up with specific questions that will help you to help make decisions. For example (Hix, 2007):

- “When was the last time I used this?”
- “Do I have more than one of the same things?”
- “Does it work? Is it worth fixing?”

### ***NOTE! Set limits.***

*Use time or physical boundaries and start small. Set a timer for 15-30 minutes at first to work on the task at hand and that's it! When the timer goes off, take a break. Another essential piece of limit setting is to break areas down into small spaces – organize ONE cabinet or drawer instead of thinking about organizing “the whole office” or “the entire apartment.”*

- “Could someone else use this (could I donate it somewhere?) or should it be thrown away?”
- “If I’m keeping this – does it belong here?”

Another idea: As you sort, have boxes labeled as:

- Donate/ Give away
- Garage sale/ Consignment
- Goes somewhere else
- Trash
- Undecided

As soon as you are done for the day, put the donation box in the car (in the front seat so it is in plain view, NOT the trunk so it is forgotten!) or at the door to make sure it is taken care of soon.

Clutter can create stress and frustration, as it builds up into a seemingly uncontrollable mess. To keep clutter in control, remember these rules:

- ✓ *Put things in their place* – Have a consistent, appropriate home for everything. Use labels if you need to until you establish a routine as to where things go. When you are done using something, **put it back where it goes right away** instead of setting it down somewhere “just for now.” (Gracia 2007).
- ✓ *Something in, something out.* If you buy something new, whether it

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is clothing or a piece of furniture, make a point of getting rid of something you are not using.

## **FOLLOW THROUGH**

You may want to find someone who will help you during scheduled organization times, and it helps to have someone along with you to keep you going. It is important that you are able to communicate openly with this person about your limits, your plan, and your ultimate goal.

## **SELF-MONITORING**

Organizing is going to be *EXHAUSTING*. Take frequent breaks and note what part(s) of organizing is hard for you. The following components are most likely to contribute to exhaustion:

- *Physical* (fatigue, headaches, pain, visually overwhelming)
- *Cognitive* (a lot of information to process, decisions about what to get rid of and what to keep, how to start and how to finish)
- *Emotional* (constant challenges, feeling like “I’m sick of this!,” or, “I want the ‘old me’ back,” or, “this shouldn’t be that hard”)

These can all pile up onto each other and create a “snowball effect” if they are not kept in check. For example, being

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overwhelmed about making a lot of decisions and doing so much planning can make you tired. Then your emotions are hard to manage because you are tired. In turn, your fatigue makes it more difficult to think straight and make decisions and the cycle just keeps going.

So, remember: **Take frequent breaks.** Leave the area or thing you are working on and allow yourself to rest cognitively, physically, and emotionally. Listen to your body and give it what it needs.

## **ORGANIZING INFORMATION**

### THE RIGHT PLANNER FOR YOU

Walking into the “planner” aisle of an office supply store can be an overwhelming experience. The choices seem endless. Knowing what you’re looking for ahead of time can save you time and energy. Ask yourself these questions to focus your preferences as much as possible before you shop:

- Do you prefer to see the big picture (such as a full month at a time)?
- Or do you prefer to focus on one week at a time?
- Is it helpful for you to have times already listed or do you like to write in your own times?
- Will you carry it with you? If so, what size will work best?

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- Do you usually have other papers that end up in your planner? (If so, consider a cover that zips closed)

Below are some examples of planners you might consider.



**Full month view** – Either in planner or wall calendar form. Where you keep your planner is key – if you have a habit of writing things down, but forgetting to *look* at your calendar, put it somewhere you will see it absolutely every day . Is it by the bathroom mirror? On the back of your “exit” door? On the refrigerator door?



**Expanded Weekly view** – This option usually comes with time increments listed and plenty of space to write or add Post-It notes with details of appointments.

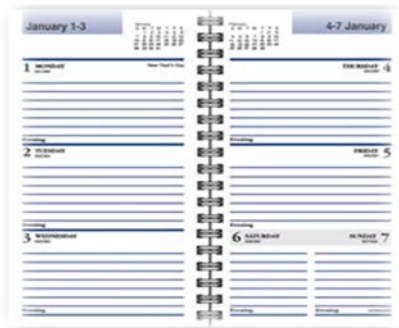
**\*\* IMPORTANT \*\***

*Pick ONE system!  
Avoid having multiple calendars that you have to transfer appointments to or duplicate your scheduling. If you don't know what works for you, try one and give it some time (at least a couple months) before you decide to try something else.*

Colorado Assistive Technology Partners is an excellent resource for assistive technology products.

Visit their website at

<http://www.uchsc.edu/atp/index.html>



**Weekly view (condensed)** – This is usually the style inside smaller planners, which would fit in your purse or be easy to carry with you.

## Electronic calendars

There are several electronic calendar options:

- Outlook
- Google
- Different versions of PDAs (Personal Digital Assistant) such as the *Palm Pilot* or *Blackberry* series, etc.

Electronic tools offer alarm options that are very helpful for some people. Alarms can be set for daily, weekly, or specific appointments/reminders, providing an auditory alert for you to look at your device and read or hear voice output of what you had programmed in. Note that technology is a great tool for some, but not all. Often it takes additional training and time to get used to a more complex electronic system

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if you are not already technologically savvy. Again, know your limits and “keep it simple” if that is the best option for you.

## **LOGS**

Logs can be an important tool for organizing information coming at you during phone calls, medical appointments, in meetings, or from your own head! Create a folder or notebook for your log – designated and labeled for one category only (keep medical appointment notes separate from a personal journal/log).

**\*\* Positive outcomes from keeping logs include:**

- ✓ Logs build confidence and reinforce strategies
- ✓ Logs increase a person’s sense of control
- ✓ Logs help a person with TBI by showing needs and letting them be part of solutions
- ✓ Logs help the survivor realize what they do has an impact
- ✓ Logs help a person with TBI to identify reasons for failures and make changes

(\*\*from “Get Organized to Simplify Your Life” by Nancy Freeman and Mary Anne Lessley, BIAC Conf. 2007)

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The following forms may be helpful to organize your notes or could be replicated in your own notebook. Modify and personalize them if you find you need different categories or more space for different sections.

It may also be helpful to tape record conversations you have with medical providers, lawyers, family members, and anyone who is giving you lots of information at once. You can then go back to listen again and review what you heard.

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## **PHONE CALL JOURNAL**

**Date:**

**Time:**

**Person on the phone:**

☐ I called them      ☐ S/he called me

**What we talked about:**

**I need to:**

☐ Done!

## **MEETING/APPOINTMENT NOTES**

**Date:**

**Time:**

**Reason for meeting:**

**People in attendance:**

**Place:**

**Important notes:**

☐ Review/clarify notes

**Questions:**

**I need to:**

☐ Done!

## **FILING SYSTEMS**

A filing system is an excellent place to start getting organized. Often bills, other mail, and piles of paperwork can be a source of disorganization that seeps to every corner and flat surface of your home. The tips below will help you get a system going.

- Gather all supplies you can predict before you begin. A basic supply list to create a filing system includes:
  - File cabinet or file box (depending if it will be helpful to carry it to different locations) – keep it simple
  - Hanging files
  - File folders
  - Labels
- Gather your “to be filed” papers in a comfortable workspace (\*\*Remember to set a limit for your work session – pull out a pile to get through in one sitting or set a timer).
- As you begin sorting, create file folders for specific categories (Examples may include: *Excel, Comcast, phone bills, utility bills, Medicare, Medicaid, SSDI, SSI, letters/ cards to keep*, etc.)
- Once you have papers sorted into file folders, decide on categories for your hanging files. The table below gives examples of hanging file categories (listed along the top row) with file folder



***\*\* In this age of technology, filing systems also include documents, digital pictures, emails, and other files you store on your computer. Treat them the same as paper files – create folders, categorized in a way that makes sense to you to keep your electronic files organized.***

categories listed below them that may be included.

<b>MONTHLY BILLS</b>	<b>CAR</b>	<b>MEDICAL</b>	<b>SOCIAL SECURITY</b>
• <i>Utilities</i>	• <i>Insurance</i>	• <i>Bills</i>	• <i>SSDI statements</i>
• <i>Phone</i>	• <i>Payment</i>	• <i>Prescriptions</i>	• <i>Medicare</i>
• <i>Internet</i>	• <i>Repair</i>	• <i>Neurologist</i>	
• <i>Trash</i>			



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### Other Filing Tips (Hix, 2007):

- If one hanging file gets to be bigger than one inch thick, it needs to be further divided or sorted through for items that could be thrown away.
- Put hanging file tabs on the front of the file. When they are on the back, it is easy for contents to be slipped between folders and lost forever!
- Avoid using “Miscellaneous” as a category. If something is important enough to file, it is worth giving it a label.

Keep “to do” items  
*visible* until you  
have DONE what  
you need to do with  
them.

### Visual Storage

Visual storage is an important piece to keep in mind as you are organizing. As you decide on a system for filing your bills especially, create a place out in the open where you keep unpaid bills or paperwork needing attention. An in/out box or visible mail slots on top of your file cabinet work well to create a “NEEDS ATTENTION” spot. Once you have paid your bill, THEN it can be filed. Until then though, keep it visible so it is not forgotten.

In summary, be encouraged that you can achieve the daunting task of organization. Start small, set specific and realistic goals, and know that it is an ongoing process. When you find what works for you, stick with it and use similar strategies in other areas of your life. *You can do it!!!*

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## **HOUSING OPTIONS AND RESOURCES**

Jan Nice

Jan Nice, LCSW, has been a social worker in the field of brain injury rehabilitation for over 20 years.

This chapter will talk about housing and possible options you may access. With the differences amongst communities, it is not possible to identify all the resources in your community. It is hoped that this will generate ideas of where to start and how to develop a plan that is best for you.

This chapter will discuss six areas of considerations in choosing a home:

- Cost
- Type
- Location
- Accessibility
- Supervision/assistance required
- Support services

The worksheets at the end of the chapter are divided into the same six areas. They are available as a guide in making decisions about the home that is best for you.

## **CONSIDERATIONS IN CHOOSING A HOME**

### **COST**

- Each person has to decide how much money can be spent on rent or payments. Housing options vary considerably in availability and cost. For some, the only way to find affordable, clean housing is to apply for a housing subsidy. Subsidies are available for eligible applicants through the Department of Housing and Urban Development (HUD). An eligible applicant would pay **30%** of

### **NOTES**

*Use the worksheets at the end of this chapter to guide you in making decisions about the home that is best for you.*

their adjusted monthly income for rent.

- Applicants are determined eligible for HUD subsidies based on household income. The two categories are: low income (**24,200** or less annually for one person) **or** very low income (15,100 or less annually for one person). Total income for the entire household from all sources must be reported. This is income of your household, not an unrelated person sharing your current home.
- Applications are made through housing authority offices both at the county and city level(s). Subsidies are also available at private sector properties. In this case, you can usually apply directly at the manager's office. In both cases, they will determine your eligibility. **The nearest housing authority office should be listed under city government offices in the telephone book.** Private sector properties may be listed through housing agencies. Potential resources to contact are listed later in the chapter. Eligible applicants may apply for subsidized properties or Section **8** existing programs. There are a variety of options. The Housing Authority offices have available properties which they manage and operate. Some may focus on senior residents and the handicapped or disabled. Other properties are specifically for family housing.

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*Your nearest housing authority office should be listed under city government offices in the telephone book.*

## NOTES

- The other category of programs available is in the Section 8 Existing Programs. The programs provide housing subsidies to eligible persons to rent a home through the private rental market. Types of housing include single-family homes, duplexes, townhouses, apartments, mobile home and pad spaces. Under Section 8 existing programs, applicants may apply for a Certificate or a Voucher. Many find this preferable as it "belongs" to you, not to the property. In other words, it is portable and can be used as you move, as long as you continue to be financially eligible. The Section 8 Certificate is portable within your state of residence. The Section 8 Voucher is portable anywhere within the United States that administers the program.
- In July of 1988, the Federal Preference rule was implemented. During your application process you may find that you fall within one of these categories and will be certified accordingly. This can help you to be placed higher on the waiting list based on your Federal Preference. The preferences are:
  1. Involuntary displacement or a victim of domestic violence.
  2. Substandard housing ("homeless family" applicants fall in this category).

3. Percent of income is paid for rent. You may request a "Definition and Verification Sheet" from the Housing Authority office. This will provide you with the information required to verify if you have a Federal Preference.

Each Housing Authority office can inform you of the order persons are selected from the waiting list (example: a local resident with a Federal Preference may go to the top of the waiting list once application and verification is made).

**Considerations:**

- Once in a subsidized property, it may be difficult to move to another as your Federal Preference may not be applicable anymore (example: no longer are paying 50% of income for rent). Choose wisely and ask what will happen if you refuse the opening(s) offered to you.
- Call Housing Authority offices regularly to see if applications are being taken for the program you are interested in. You will not be notified of openings unless your application has been processed and you are on the waiting list.
- Respond timely to any notices sent regarding your desire to stay on the waiting list.
- Provide all the information requested as quickly as possible so your application can be processed.
- Private Sector subsidized properties may be harder to find, but may be quicker and easier to obtain.

NOTES



- Ask if support services are attached to the property (example: case management services are being offered in some HUD subsidized properties).
- Call if any changes occur (example: if you have a new phone number to reach you, or you now have a possible Federal Preference). It is also not necessary to be a resident of a particular city or county to apply for subsidized housing. Call and ask if there is a residency requirement.

**HUD may also be a resource for:**

- low interest loans for purchasing a home
- low interest home improvement loans
- home mortgage assistance
- housing tenants rights
- referral to other appropriate agencies

Advocacy and resource agencies have sprung up to assist persons in locating clean, affordable homes. These agencies can also assist with tenant's legal rights, moving assistance, home modifications, etc.

**Housing Advocacy and Resource Persons/Agencies:**

- State Brain Injury Association(s) or Alliances
- Independent Living Centers
- Independent Living Research Utilization  
(713) 520-0232
- Hospital Discharge Planners

**NOTES**

Visit the HUD website to learn more about its programs and HUD contact information:

<http://portal.hud.gov/hudportal/HUD?src=/states/colorado/offices>

- United Way: Information and Referral
- Governor's Task Force for the Disabled
- City and County Community Development Offices
- Commissions for the Disabled
- Church Social Services Agencies
- County Social Service Offices
- Other Disability Advocacy Groups:
  - Mental Health Associations
  - Epilepsy Foundation
  - Multiple Sclerosis
  - Stroke Association
  - Cerebral Palsy Association
  - Easter Seals
- Home Health Agencies:
  - Case Managers/Social Workers

## TYPE

The type of place you would like to live is an important consideration. Although it is not always possible to get exactly what you want, it may be preferable for you to wait for the place which most matches your needs. This will cut down on costly moves.

Flexibility is required and may be possible in some aspects of your consideration. Be clear as to what you will want and will require before looking at actual property. This will help you to select what feels right for you. For example, moving to a place which is not large enough for your belongings may require costly storage space or a move in the near future.

## LOCATION

### NOTES

*Accessibility should be an integrated part of community planning for housing.*

Another important item to consider before looking for available properties is the location you would like to live. Determine for yourself what exactly is easy traveling distance for you: Five blocks? One mile? etc. Also, determine what has to be easy for you to get to without assistance. Being close to a recreation center or your volunteer work place that you use on a daily basis may be more important for you than a grocer/pharmacy you use once a week. Again, what works for you is the key.

## **ACCESSIBILITY**

With the implementation of the Americans with Disabilities Act, accessibility should be an integrated part of community planning for housing. Resources for modifications are available through various groups. A good place to start is the closest independent living center which will often have a housing coordinator on staff. This person can direct you to resources which will assist with modifying a property for your needs.

Do not minimize your needs in this area. If you are not certain, ask for guidance from a physical and/or occupational therapist with experience in this area. Call local hospital rehabilitation programs for community based resources. Do not put yourself in an at-risk situation (example: in an apartment that you could not get out of in case of fire).

## **SUPERVISION AND/OR ASSISTANCE**

### **NOTES**

## REQUIRED

Carefully thought out planning is needed if you require assistance at periods throughout your day. Some help may have always been available if you have been living at home. Moving out on your own will require decisions about type of supervision and care to make the most successful transition. Start out by thinking about all of the supervision and assistance you would like to have in your daily/weekly routine. If this amount is not a realistic possibility based on financial and community resources, write down what assistance you have to have to safely live on your own. Also consider the possibility of sharing resources with a roommate and/or other residents in a building. This may make the assistance financially feasible for you as well as the caregiver to have a number of persons needing assistance.

## SUPPORT/RESIDENTIAL SERVICES

This may be the most challenging area for some individuals. Each person has specific needs which require planning. Some states and communities have approached the provision of services in a very flexible and comprehensive way. Others are completely lacking which leaves the person with only the options of living without needed services or in a nursing home. Fortunately, through the determination and advocacy efforts of many, needed services are often being offered outside of an institutional setting. If this is not possible in your community, a

## NOTES

facility or program with the needed services offered may be the best choice at the current time.

This section refers to care provided outside of your own home or apartment. This type of care is typically licensed by your state to provide services along with a place to live. This varies considerably from state to state and even from community to community. As it is difficult to know where to begin, it may be helpful to call: local hospital discharge planners, home health agencies, your state brain injury association, state and/or county health departments, county social services offices, and state Medicaid offices (State Medicaid numbers are listed at the end of this chapter).

**In selecting an alternate care/ residential facility, you might want to consider the following:**

- Do I have opportunities to decide my daily routine and activities?
- Am I involved in any, or all of the treatment planning surrounding my stay?
- What activities/services are offered and how frequently are they offered? (use checklist in the chapter)
- Are activities/services included or must they be purchased?
- Are there persons of my age group and with same interests?
- Tour the facility; talk with other residents and staff.
- Is this the least restrictive facility or

**NOTES**

- program available for me?
- What support/resources are there to help me move to the next step?

Each state varies but potential residents usually have to go through a screening process to determine eligibility for state financial assistance and level of care or assistance needed which would determine appropriate resources. If you are unsure, contact your state Medicaid office and ask for the long term care division as a place to start. Staff in this department will direct you to your local county offices and resources.

## NOTES

## WORKSHEET

Things to consider in choosing a home:  
(consider ranking 1-6 how important each area is to you)

### Cost

HUD subsidized; 30% of adjusted monthly income

- can pay \$200 to \$250 a month
- can pay \$250 to \$300 a month
- can pay \$300 to \$400 a month
- Can pay \$400 or more a month

### Type

(Estimate amount of square footage you might need for your belongings/furniture to fit)

- one bedroom apartment
- two bedroom apartment
- one bedroom house/duplex
- two bedroom house/duplex
- will take pets

### Location

- suburb, neighborhood, downtown
- walking distance to bus stop; can access bus line
- easy traveling distance to family/friends
- easy traveling distance to job and/or volunteer activities
- easy traveling to grocery store, post office, laundry, etc.
- easy traveling to recreation and social activities

## NOTES

## Accessibility

### Support Services Desired:

- wheelchair accessible unit
- bathroom has grab bars; space to use personal
- equipment as needed
- has elevator
- need bottom floor unit
- landlord/manager will work with you to get necessary modifications completed in a reasonable time frame
- have curb cuts
- would like to share with a friend or have a roommate match
- other residents of own age
- resident manager available 24 hours a day
- sidewalks around the area a call system
- one-to-one assistance available
- one-to-one skilled assistance available as needed
- assistance can be contracted as needed at residence
- case management
- social/recreational activities organized for the residents
- meals provided
- laundry and house cleaning
- personal self-care assistance
- transportation or assistance to coordinate
- weekly check-in
- daily check-in
- on-site clubhouse and pool

## NOTES



## **PLANNING WORKSHEET**

What I want in a home:

What I need in a home:

For me, the best combination of these would be:

**NEED TO DO:**

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

**QUESTIONS:**

**OBSTACLES:**

## Maintaining Housing

Housing resources are becoming less available in many communities. Therefore, there is a strong push to support people and provide resources which will assist them in staying where they are currently.

## Financial Issues

For some individuals, financial problems may threaten an eviction. Seek help from a case manager or housing agency to develop a realistic budget and look for areas to help reduce monthly expenses. Suggestion: explore budget utility billing, consumer credit counseling to reduce monthly bills, state property tax rebate, bill paying assistance on a monthly basis. Contact agencies which could help get your rent caught up if needed. Contact tenants association to become informed of your rights related to eviction. Evaluate if you need to apply for HUD subsidized housing to reduce your rent payment. Keep your apartment manager informed of your efforts to pay your rent. Ask what flexibility is available to assist you.

## Disputes with Other Residents

Attempt to talk the problem over with a fellow resident when both of you are calm. Talking during a conflict may confuse the issues more. If you cannot resolve an issue, ask the manager what resources are available to you to resolve conflicts. The manager may direct you to

## NOTES

*Explore budget utility billing, consumer credit counseling, state property tax rebate, bill paying assistance...*

a mediator, offer to help you himself, or direct you to a resident council. Develop a written plan agreed upon by both parties. Disputes with Building Manager: Keep the communication open with the property manager. Write down what you have understood to be the agreement. In HUD subsidized properties, you can call the Housing Authority office if you cannot resolve the problem through the in-house channels (example: resident council). Housing agencies often have mediators available if problems arise and cannot be resolved.

## NOTES

## **ADVOCATING FOR FINANCIAL RESOURCES**

Bob Felker  
Bonnie Sims  
Linda Bourret-Rodriguez

Bob Felker has an M.A. in Rehabilitation Counseling and worked at Craig Hospital for over 20 years as a Family Service Counselor. He previously worked at Spalding Hospital and St. Anthony's Hospital Neurotrauma Unit.

Bonnie Sims has an M.A. in Rehabilitation Counseling. She served as the Director of Family Services at Craig Hospital and is active in many related community organizations.

Linda Bourret-Rodriguez has an M.A. in Psychology, Counseling and Guidance. She has worked at Craig Hospital since 1980 as a Family Service Counselor, including several years at Swedish Medical Center Neurotrauma Unit.

Melissa Abate, LMSW, came to Craig in 2005 on the inpatient TBI team. Melissa earned her MSW at Yeshiva University in New York City. She has been active in post graduate studies in family systems. Melissa is a member of NASW and the CO Brain Injury Collaborative, ACRM.

Becca Bixler, LCSW, came to Craig in 2012 on the outpatient TBI team. Becca earned her MSW at the University of Denver in Denver, Colorado. She has a certificate in Trauma Studies and is a member of the Ethics Committee at The Denver Hospice.

## **THE FUNDING PUZZLE: PUTTING THE FINANCIAL PIECES TOGETHER**

When an individual sustains a catastrophic injury, succeeding events can be overwhelming. In addition to the emotional trauma, there can be a significant financial burden. Determining medical coverage and financial resources as early as possible provides an opportunity for you to make more definitive plans as your family member progresses in his or her recovery. This chapter addresses benefits you should research to determine coverage for medical and rehabilitation insurance, income services and financial assistance for long-term planning. While this list is in no way comprehensive, contacts are included for you to obtain more information.

### **MEDICAL/REHABILITATION BENEFITS**

#### **HEALTH AND ACCIDENT POLICIES:**

Health and accident insurance can be either group or individual. The scope of coverage can vary greatly. Be aware of deductibles, co-insurance, life-time maximums, exclusions, and non-covered items. You should research benefits needed for catastrophic needs such as durable medical equipment, home health care, outpatient services and long-term care services. Also prior to an admission a pre-certification review may be needed with continued re-certification

#### **NOTES**

during the hospital stay. A Case Manager or cost containment specialist may also be assigned to your case.

Within recent years there have been specific plans relevant to health and accident insurance coverage, called PPO's or Preferred Provider Organizations, and HMO's, or Health Maintenance Organizations. These plans were developed to contain costs by allowing insurance companies to work with a select group of providers including specific physicians and hospitals.

#### MAINTAINING COVERAGE: **COBRA**

"The Combined Omnibus Budget Reconciliation Act" (COBRA), requires most employers with a health benefits program to allow their employees to continue health coverage when they terminate employment. The employee must now pay the premium but coverage can last from 18 to 36 months, depending on circumstances. Employers are required to notify employees of COBRA benefits upon termination of employment. There may be an option to convert from a group to an individual plan when coverage is due to expire under COBRA. It is important to maintain your coverage since it is unlikely you will obtain new coverage with a pre-existing condition, unless you return to work and are eligible for group coverage.

To obtain assistance in interpreting your insurance, speak to your employer's benefits advisor, attorney, social worker,

#### NOTES

or State Insurance Commissioner.

## **WORKERS COMPENSATION:**

Workers Compensation covers injuries and diseases that are work related. The full cost of this insurance is paid by the employers. This insurance provides prompt, partial wage replacement and medical benefits to workers injured on the job. Each state does require Workers Compensation Insurance, and each has its own laws. An agency such as the Division of Labor in your state may be an appropriate resource for questions and information. Workers Compensation covers medical expenses. They will pay all reasonable and authorized expenses, including medical, surgical, dental, nursing and hospital treatment, extended rehabilitation as well as reasonable and necessary supplies, prescriptions and travel as a result of your injury. The insurance company will look to your primary physician to help them manage your claim. It is imperative to develop a relationship with your physician and to know that he or she is communicating with the insurance company.

During the time that your claim is open, you will also qualify for a percentage of your lost wage until you go back to work, or are released to return to work, or when the physician feels you have reached maximum medical improvement. Your benefits will be 2/3 of your average weekly wage, up to the maximum

## **NOTES**

amount in effect on your date of injury. Workers Compensation benefits are not taxable. Benefits may be reduced for a variety of reasons, such as failure to use a safety device or obey any reasonable safety rule or if your injury results from intoxication. If you get Social Security Disability benefits, your Workers Compensation benefits may be reduced depending on the policy in your state. Employer pensions or disability payments that you receive may also reduce your Workers Compensation benefits. Your employer or insurance company has the right to request that you apply for Social Security Disability benefits. It is important to understand that *the law does not guarantee you a job after an injury* and the employer is not required to hold a job open or create one for you.

Some states also provide Vocational Rehabilitation benefits as part of the medical and wage loss components to Workers Compensation laws. In your state, the offer of rehabilitation benefits may be voluntary on the part of the employer or insurance carrier.

At some point you may wonder about the ability to settle your Worker's Compensation claim. Due to the complex nature of claims, you might want to seek advice from persons experienced in Workers Compensation laws in your state.

### **AUTOMOBILE INSURANCE:**

All states have laws requiring liability

## NOTES



insurance, or proof of financial responsibility for accidents, to vehicles and/or drivers licensed in the state. States require vehicle owners carry liability insurance in specified minimum amounts. Liability is a traditional type of insurance. It protects the owner and/or operator of a vehicle against claims by a person(s) injured in the accident. Liability Insurance requires a determination of fault or responsibility for the accident. A major problem with this traditional insurance system is that it offers no insurance coverage for the driver or the person found to be at fault in the accident.

Uninsured/Underinsured motorist coverage is designed to protect people injured by a driver who is not insured or whose insurance coverage is not sufficient. Uninsured motorist insurance provides coverage when there is a failure to comply with compulsory insurance laws by the other driver. If you are hit by an uninsured driver, your own insurance company is responsible for paying you what you would normally receive from the uninsured driver. The coverage is independent of any other benefits provided by your insurance carrier.

Underinsurance applies when you are struck by a driver who is not carrying enough insurance to cover your injuries. For example, you receive serious injuries that should be compensated in the amount of \$100,000.00; however the driver that struck you only has \$25,000.00 in insurance coverage. That

## NOTES

driver is underinsured to fully compensate you. The balance of \$75,000.00 will be covered by your own insurance. In most cases you can file a claim with your carrier and negotiate directly with them. However, should you be unclear as to the full package of benefits available in your state in automobile insurance, it is important to consult someone such as your Insurance Commissioner's office for specific details.

### MEDICARE:

Medicare is a Federal Insurance Program for Americans 65 years of age or older and certain disabled Americans. You pay for it with your Social Security contributions and premiums. But as many people discover after a major illness, Medicare does not pay for all your medical expenses. Medicare and most private insurance that supplement Medicare do not begin to cover the costs of long-term care.

The Medicare Program has two parts. Part A, which is hospital insurance that helps pay part of the costs of inpatient hospital care, related care received in a Medicare certified skilled nursing facility, home health care and hospice care. You pay no premium for Part A coverage, but you are responsible for paying a deductible and co-insurance.

The second part of Medicare is Part B, or medical insurance, which is designed to cover physician services, outpatient hospital care and lab services. There is

## NOTES

a monthly premium for Part B coverage, which is either billed quarterly or deducted from your Social Security check. In addition to the monthly premium you must pay an annual deductible and 20% of the amount that Medicare approves for each of your medical bills. If your doctor or other health care providers does not accept Medicare assignment (the amount Medicare approves as a reasonable charge for that service), you are responsible for paying the 20% co-insurance charge, plus the difference between the Medicare approved amount and your provider's actual bill.

You are eligible for Medicare at age 65. If you are under 65 and disabled, you will have Part A hospital insurance protection automatically when you have been entitled to Social Security Disability benefits for 24 months. Part B medical insurance, however, is optional.

The newest addition to Medicare is Part D. Part D is also optional and is handled through private insurers. Part D provides Medicare beneficiaries coverage for prescription medications which were previously excluded from Medicare. Part D coverage is handled through a variety of insurance carriers and the medications that are covered and the cost of premiums vary greatly. For more information you can go to [www.medicare.gov](http://www.medicare.gov)

For a description of all of the Medicare services, it is best to contact your local

## NOTES

Social Security office and obtain the Department of Health and Human Services official publication "Your Medicare Handbook", which is updated annually to reflect the increased deductibles and premiums.

It is also important for those individuals of low income to know that they may be eligible for other subsidies. Please contact Medicare or your county Medicaid office for more information. If your income falls below a certain level, it is feasible that your state Medicaid program will pay the deductibles and coinsurance amounts owed under Medicare.

### **MEDICAID (MEDICAL ASSISTANCE-TITLE 19):**

Medicaid is a jointly funded Federal/State program designed to provide medical assistance to persons with low income. There is great variability in the scope of services that states may offer. For example, some Medicaid programs offer personal attendant services, prescription drugs, supplies, medical transportation, while some states have eliminated these and other services.

The benefits under the state operated Medicaid program are in many ways more comprehensive than Medicare. But since Medicaid is a needs program, financial eligibility is determined by a person's income and assets. Some states use Supplemental Security Income (SSI) eligibility as a qualification

### **NOTES**

for Medicaid, while others have more restrictive requirements, such as stricter income or asset limitations. It is also important to learn if your state allows spending down income in order to be eligible for Medicaid. In a spend-down state (2099), persons can spend excess income on their medical care. In addition to spend down programs, if over resourced for Medicaid it is important to consult an elder law attorney. To find an elder law in your community visit <http://www.nala.org>.

All states require that other insurance, including Medicare, be used before Medicaid is made the final payer. Medicaid will seek reimbursement from any other pay source that is found liable. This includes the right to subrogate or recoup monies from any lawsuits (see section on Legal Issues.) The structure of what the state pays the provider varies from state to state. These fees may determine if a private provider, such as a nursing home or a rehabilitation center will be willing to accept a person on Medicaid.

Some states can set a higher income level on Medicaid eligibility for people requiring special services. This level can go as high as three times the current SSI benefit (sometimes called the 300% program). This allows people to receive income, such as Social Security Disability, and still qualify for Medicaid. However the facility or Medicaid agency is authorized to claim some payment from the individual if they are

## NOTES

institutionalized.

In some states, Medicaid has allowed waiver programs which allow clients who meet certain clinical criteria to be eligible for extra services when they live at home and/or in the community. The services for waiver eligible clients are designed to assist their ability to live outside of an institution and to increase their level of independence. The waivers that are available and the eligibility criteria for them may vary state to state. Also, if the client meets the clinical criteria for a waiver, he/she has a higher income cap (up to three times the Federal SSI benefit for the year) without losing Medicaid benefits. You will need to contact your local Social/Human services for more information.

If you are married, you may qualify for Medicaid under Spousal Protection. This program can apply with either the disabled spouse residing in the home or in an institution. This program allows excess income to be deemed to the non-disabled spouse. The couple is also allowed excess assets. To apply, you need to contact your county Social/Human Services office and work closely with them.

Once eligibility is established, you will receive a monthly Medicaid card. Most providers will want to see the card and take the number for billing purposes. There may be a required co-payment on medical services. Applications for Medicaid should be made at your county

## NOTES

Welfare or Public Assistance office.

### **VETERANS BENEFITS:**

The Department of Veterans Affairs provides a full range of benefits for eligible veterans and dependents. The scope of benefits available is dependent upon when you were in the service, and whether your disability is service-, or non-service-connected. The latter determines the priority of services as well as the scope. Income benefits include compensation if you were injured while in the service or even a pension if you served during periods of war time and if you meet the income requirements. However, most important for either situation is the eligibility for medical services from a VA facility. In some situations you can receive services in a civilian institution if these services are unavailable in a **VA** hospital. There are also nursing home care benefits, but again, this is based on a priority system. One benefit of special importance is the aide and attendant benefit for personal care. See the chapter specifically for military personnel and veterans for further resource information regarding veteran's benefits.

### **INCOME**

Sources of income following brain injury can be one of the most difficult issues for families. Many of these sources come from County, State, and Federal programs. When inadequate or inaccurate information is obtained, you

### **NOTES**

*More information on Veteran Benefits can be found in the chapter titled "TBI in Military Personnel & Veterans" on page 133 of this manual.*

run the serious risk of obtaining income for your family member only to be penalized financially regarding another seemingly unrelated benefit. An example of this would be if your family member has a private disability insurance policy, which would pay him a small monthly wage while he/she is disabled. This could exclude him/her from Medicaid benefits, which may be his/her only source of medical coverage. For these reasons it is important to obtain as much information from as many sources as you can before submitting any applications.

The following is a brief general list of possible benefits available in most states. For additional benefit information contact your County or State Social Services Department, or other individuals as listed regarding specific benefits.

## **SOCIAL SECURITY DISABILITY INSURANCE:**

Social Security is a Federal Insurance Program designed to provide basic protection against the loss of personal or family income due to disability. Our Social Security taxes are used to finance the program. The definition of disability is related to work. A person is considered disabled when they have a severe physical or mental impairment that prevents or is expected to prevent employment for at least 12 months or

## **NOTES**



end in death. The work does not necessarily need to be work done pre-injury. There may be periodic reviews to assure that you are still disabled and you cannot perform gainful employment.

To qualify for Social Security Disability Insurance (SSDI), you must have worked long enough and recently enough to be insured. Once eligibility has been established, monthly benefits for a disabled worker start after 6 full months of disability. You are paid out after a 6 month waiting period, with the first check arriving on the 7<sup>th</sup> month. Certain family members may qualify for disability benefits on your work record.

Since SSDI is not based on need, you can have assets and unearned income. You cannot receive full benefits from both SSDI and Workers Compensation and your primary source of income will be determined by state law.

To begin the application process, call the Social Security at 1-800-772-1213. The representative will set you up with an appointment by phone with the office closest to you. You will be directed to complete some paperwork prior to the interview. The application can also be done on-line at [www.socialsecurity.gov](http://www.socialsecurity.gov). It is important to have information about your employment from the past 15 years, tax information, including a **W-2** form from the past year, proof of your age, medical information and the names and address of doctors and hospitals where you have been treated. If you are found eligible and receive benefits

## NOTES

for **24** months, you will be eligible for Medicare. Remember there is a gap between Social Security eligibility and eligibility for Medicare, and so you may have no insurance for at least **24** months.

There are work incentives built into the Social Security system. Work incentive programs are complex and it is important to contact the Social Security office to obtain information prior to making a decision about returning to work.

### **SUPPLEMENTAL SECURITY INCOME:**

Supplemental Security Income (SSI) is a monthly payment available to the aged, blind and disabled who have unearned income of less than \$637.00. This is the SSI amount for 2008 and this amount increases slightly each January 1<sup>st</sup> due to the cost of living and resources less than \$2,000.00 **at** the time of application (the amounts are higher for a couple). SSI is a Federal program administered by the Social Security Administration; therefore, benefits are the same nationally. However, individual states may add to the monthly payment. Your living situation can affect the payment amount as well.

Since this is a needs program, your eligibility is not based on your work record. Some children may be eligible although parental income is considered for children under age **18** if they are not institutionalized. Upon

## NOTES

reaching age 18 children become eligible based on their own financial picture whether they are living at home or on their own. If you live in another household and do not pay your fair share of living expenses you do get a reduced benefit payment, usually by one-third. If you **are** in an institution and the state Medicaid program is paying more than half the bill your payment will **be** reduced.

Although your work record does not determine eligibility, there is a requirement that you have a physical or mental impairment which prevents you from doing any substantial work and which is expected to last 12 months or result in death. You must also be a citizen residing in the United States, or a lawfully admitted immigrant or alien. You must claim all other entitlement benefits including Social Security Disability benefits. SSI is income of last resort but if you're eligible for even a small payment this may mean entitlement to your state Medicaid program.

Application is made at the local Social Security Administration office and benefits start (if you are eligible) the first calendar month after application filing date. The application process is the same as outlined in the section for Social Security Disability Insurance. However, processing your application may take some time. It is important to have supporting documentation available such as: birth certificate, bank statements, auto registration, proof of earnings, as well as the names

## NOTES

and addresses of physicians and hospitals where you have received treatment for your disability. It is important to remember that any money made available to you is considered income even if it is paid out immediately. Your house and car are usually exempted as assets, especially if you plan to return to your home and if your vehicle is used for medical transportation.

There are work incentives that allow you to remain eligible for SSI and Medicaid, but it is important that you know the limits of these incentives.

### **WORKERS COMPENSATION:**

As detailed in the previous section on Medical/Rehabilitation benefits, you may also be eligible for wage loss benefits if you have a Workers Compensation claim. You will receive your wage loss until you return to work or are released to return to work by an authorized treating physician, or until the physician feels you have reached maximum medical improvement. Your benefits will be two-thirds **of** your average weekly wage up to the maximum amount in effect on the date of your injury. Your average weekly wage includes your gross earnings, plus overtime and your benefits such as life insurance and anything furnished by your employers in addition to salary such as meals, uniforms, housing and tips. Workers Compensation benefits are not taxable.

### **NO-FAULT LOSS WAGE BENEFITS:**

## NOTES

You may be entitled to receive a lost wage benefit if you were injured in an automobile accident and your automobile coverage is a No-Fault policy. Wage Loss Benefits are usually calculated on a percentage of the injured person's wage before the accident and are often subject to a weekly or monthly cap. They are also usually time limited or subject to caps on the overall benefits. Very few states continue to have No-Fault auto coverage, however.

### **DISABILITY INCOME:**

Disability income is designed to replace a percentage of lost income due to an injury or illness. Disability usually pays a specified amount per month while the policy holder is unable to work. Some employers may have short-term disability benefits and/or long-term disability benefits. Generally short-term disability benefits begin immediately after injury or illness and can last as long as 26 weeks. Long-term disability benefits usually begin after 26 weeks, or 6 months of injury or illness. The length of time you can stay on long-term disability may vary from policy to policy, so it is important to check the specifics of your coverage. It is also important to check if your policy covers total, partial or residual disability. In other words, do you have to be totally disabled and unable to perform any work in order to receive benefits? With Disability Insurance, it may require a physician to fill out monthly statements indicating that you remain disabled or ill.

### NOTES

## **TEMPORARY ASSISTANCE FOR NEEDY FAMILIES: (TANF)**

TANF replaced the National Welfare program known as Aid Families with Dependent Children (AFDC). In Colorado it is known as Colorado Works. Colorado Works is a state-supervised and county-administered program that emphasizes “work first” and places time limits on basic cash assistance. Colorado Works imposes a 60-month cumulative lifetime limit on the receipt of basic cash assistance and requires most adult recipients to be in a work activity within 24 months of being deemed job-ready. While the state sets minimum benefit levels and eligibility criteria for the programs, counties have considerable flexibility in identifying allowable work activities and determining the level of benefits and support services provided to needy families. TANF funds may be used to provide support services designed to keep families from requiring monthly cash payments. You need to contact the Department of Social/Human Services in your county to determine your eligibility for TANF and whether you are additionally eligible for Medicaid.

## **AID TO THE NEEDY DISABLED: (AND)**

In some states there are two categories of AND. The first, AND/SSI, provides financial and medical assistance for disabled SSI recipients. States may

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choose to supplement the Federal SSI amount. The second category is AND - (Aid to the Needy Disabled only) - which provides financial assistance to disabled persons. However there is no automatic entitlement to Medicaid. Due to more flexible disability requirements it is often easier to qualify for the AND money payment but it does not give you medical coverage.

### **OLD AGE PENSION: (OAP)**

Old Age Pension provides a monthly income payment to individuals who are over age 60, and who have limited income and resources. It is not dependent on a work history, and it does include automatic eligibility for Medicaid. In addition to financial and age requirements, you must be a resident of the state, a U.S. citizen or lawfully admitted alien. If you are a disabled person, you must first apply for SSI from the Social Security Administration. With written verification showing that you have applied for SSI you can then go to the County Department of Social Services and apply for OAP, which may give you additional income. There may be other benefits that you can apply for at the same time such as food stamps. With this program you are allowed to "spend down" accountable resources in order to be eligible.

To apply for TANF, AND and/or OAP, contact your County Social/Human Services office.

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## **HOME OWNERS INSURANCE:**

Home Owners Insurance is designed as protection against law suits for accidental injuries which occur on your property. You cannot collect on your home owner's policy, but you can collect if your accident occurs on someone else's property. Sometimes coverage applies even when accidents occur off the policy holders' property if it was caused by them, their family members, or their pets. In order to collect any liability payments you may have to retain an attorney if direct appeals do not produce results. The medical benefit under a home owner's policy is usually limited but it may pay your health insurance deductibles or co-insurance.

## **VICTIMS ASSISTANCE:**

Many municipalities have incorporated a crime victim's compensation act which compensates victims of a crime for some losses. If your family member has sustained injury due to someone's unlawful act, Victims Compensation should be investigated. Losses that can be compensated can be hospital and medical expenses, medically necessary devices and various other services relevant **to** the person's care and rehabilitation. It should be noted that monies are usually limited. To obtain **more** information, contact your County District Attorney's office or Office of Legal Services.

## **UTILITY ASSISTANCE:**

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Your state may have an assistance program which helps low income households pay some of their winter heating costs. Often households which are receiving Social Services/Welfare benefits fit the income guidelines for this program. To obtain more information regarding this program contact your Public Utility Company or Department of Social/Human Services.

### **PROPERTY TAX/RENT AND HEAT CREDIT REBATE:**

Some states provide a tax rebate for certain low-income individuals to return property tax, rent payment or heat costs. This usually applies to senior citizens or individuals who are totally disabled regardless of age. The rebates can be significant and to obtain more information you should contact your State Department of Revenue, **or** Social/Human Services Department.

### **TRAUMATIC BRAIN TRUST FUND:**

The TBI Trust is a program specific to Colorado. It provides a benefit to a client with a TBI if he/she is a Colorado resident and sustained a trauma related injury. To apply, contact the Brain Injury Alliance of Colorado. For more specific information on the Trust, please see page 363.

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*The Colorado TBI Trust Fund is described in more detail in the chapter beginning on page 427 of this manual*

## LONG-TERM SERVICES

Brain injury is **a** long-term disability and so are the financial concerns resulting from it. These concerns continue a long time after leaving the acute rehabilitation setting. For that reason it is beneficial to begin exploring these long-term services early on so that you can submit applications and be placed **on** waiting lists for services should they be needed in the future. The following is a list of some general services and agencies that may **be** able **to** provide this long-term financial help.

### WAIVER PROGRAMS:

If you are applying for or are eligible for Medicaid benefits through your County Social Services office, it is important to ask about the possibility **of** Waiver Programs that may be available in your **state**. Waiver programs are generally pilot programs set up to meet a specific need that might ordinarily not be covered under the standard Medicaid package.

All waivers come under the acronym HCBS which stands for Home and Community Based Services. The waivers are handled by the long term care department of the county Social services office. HCBS provide ongoing Medicaid benefits as well as other specialized services to qualifying individuals who would otherwise have to be institutionalized. HCBS can include specialized services of case management, adult day care and day treatment,

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personal care, non-medical transportation, environmental modifications, assistive technology, independent living skills training, counseling, behavior management, respite care, and transitional living.

The waivers available will vary state to state. You need to contact Social/Human services to determine which waivers you may be eligible for and how to apply for them.

### **SUBSIDIZED HOUSING:**

The Federal Department of Housing and Urban Development operates a subsidized housing program intended to provide affordable rent to low-income individuals. The individual pays a portion of his gross income and the subsidy program pays the balance of the rent payment. There are two main categories: Public Housing - which is usually administered by a city or county public housing authority, and Privately Owned Housing - usually operated by church groups, fraternal organizations and other types of non-profit organizations. If you qualify for subsidized housing, you must meet low-income guidelines for Social Service agencies. It should be noted that in many larger metropolitan areas there may be significant waiting lists to obtain subsidized housing, and applications should be filed as soon as possible. To obtain additional information or to apply for benefits, you should contact your local Public Housing Authority. This is described in more detail in the chapter on Housing.

### **EDUCATIONAL BENEFITS:**

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Housing Options are discussed in chapter 15, beginning on page 217.

If you are injured before age 21 and do not have a high school diploma, it is important to explore Special Education Services in your school district. These services are mandated by Public Law 94-142, and amended by Public Law 99-457. This is a federal law which basically guarantees a free appropriate public education for children who have handicaps. This program mandates the school system to provide an individualized education program developed by you and your children's school teachers and administrators. Services may include therapy, transportation, tutoring, etc. To obtain information regarding the Special Education Services you should contact the Principal of your child's school or the Director of Special Education in your state.

### **DIVISION OF VOCATIONAL REHABILITATION:**

Although this agency is discussed in more detail in a separate section of this guide, it is important to include a brief overview as well. This agency can provide vocational evaluation, counseling and training as well as services allowing you to pursue your vocational or education goals. There may also be services available to provide for independent living or to assist the person in becoming a functional homemaker. To apply or to obtain information, contact your State Department of Rehabilitation.

### **NOTES**

## **REFERENCES**

"Legal Considerations of Insurance Issues - Friend or Foe" John Breit, Esq. January, 1991 "Knowing Your Rights", AARP, 1989

"How to Provide for Their Future", Association for Retarded Citizens of the United States, 1989 "Benefits for Seniors", Senior Answers and Services, January, 1991

"Financial Planning for Long-Term Care - A Guide for Lawyers, Caregivers and Consumers", Ira S. Schneider, J.D. and Ezra Huber, J.D.

## LEGAL INFORMATION

RUTH C. MALMAN

Ruth C. Malman, Attorney at Law, has been a practicing Attorney in Colorado since 1978. She has served as a member of the Brain Injury Alliance of Colorado Advisory Board and Board of Directors, and was the coauthor of the Head Injury Guide to Legal and Financial Resources. This chapter was originally published in the CHIF Regional Guide to Traumatic Brain Injury.

After a brain injury occurs, the person with traumatic brain injury and his family will often be confronted with a variety of important legal issues. Those issues include payment of medical bills, costs of long term care, the need for a guardianship or conservatorship and whether any type of lawsuit should be pursued. The following is an attempt to address these issues and provide a broad overview. An attorney should be consulted for specific concerns. Case workers at the hospitals or rehabilitation centers are also good resources.

### **MAKING DECISIONS FOR THE TRAUMATICALLY BRAIN INJURED PERSON**

Decisions for the severely injured person's welfare are often necessary immediately following a brain injury. Family members will be asked to sign forms for hospital admission and patient care. Generally, if married, the spouse can take the legal responsibility for these decisions. If there is no spouse or the spouse is unavailable, parents and other interested persons may be able to enter into decisions with the hospital particularly if a life threatening situation exists. Parents or legal guardians are responsible for their injured children.

Depending on the severity of the injury, a person with a traumatic brain injury may experience a period of time where he/she is not able to make any decisions. If there are urgent matters to attend to, or if it appears that the effects of the brain

#### **NOTES**

*After TBI, legal issues you and your family may be confronted with could include payment of medical bills, costs of long term care, the need for guardianship or conservatorship and whether any type of lawsuit should be pursued.*

injury will persist for an extended period of time, it may be necessary for the family to investigate various legal alternatives in order to deal with the person and his property.

One initial step would be to find out whether or not the person with the traumatic brain injury has provided for the event of his disability through a durable power of attorney, a trust, or a will. These documents may provide a designated person to take care of financial and other personal matters. If no such document exists, then it may be necessary to look at either a guardianship or a conservatorship.

## **GUARDIANSHIP**

The main focus of a guardianship is to provide for the physical well-being and safety of the person. The guardian will be appointed by the court if the court finds that the person with the traumatic brain injury lacks sufficient understanding to make or communicate responsible decisions. Under the Uniform Probate Code, the priority for the appointment of the guardian is the spouse, a person nominated by the injured or disabled person in writing prior to his incompetence, an adult child of the person, the parent, an adult with whom the person has resided for more than six months prior to the filing of the petition and lastly, a person nominated by a caretaker or somebody who has paid benefits to the injured person. If the injured person is a child, the parent is the legal guardian

## **NOTES**



unless and until the court would appoint somebody different, if there is a problem with the parent-child relationship.

The guardian is given the authority by the court to give consent for medical care, to establish a place to live for the injured person and general custody of the person. The person who wishes to act as guardian for the injured person files a petition with the court in the county in which the person with traumatic brain injury resides. The docket fee, if any, must be paid at the time the documents are filed. A letter is necessary from a doctor indicating the injured person is unable to communicate and make decisions. The court may appoint a visitor to help verify the need for guardianship.

## **CONSERVATORSHIP**

The conservatorship is used to protect and manage the estate and financial affairs of the person. The conservator will be called upon to provide inventories, interim accounting and a bond to the court to be sure that the financial affairs of the person are being properly administrated. The priorities for appointing a conservator are similar to those of a guardian except that before the spouse of the protected person comes (1) the trust company or bank, (2) the choice of the protected person, if able to make that choice, or (3) a person that had been previously nominated through a writing such as a

### **NOTES**

*A conservatorship is used to protect and manage the estate and financial affairs of the person.*

power of attorney executed prior to the need for a conservator.

## **OTHER PROBATE MATTERS**

Dependent on the severity of the traumatic brain injury, the provisions made in any will should be looked at with a probate attorney. Specifically, there may a need to make changes regarding both distribution of property and custody of children.

Additionally, it may be advisable to set up some type of trust either for existing assets or for potential assets which may be recovered in any type of personal injury claim. All of these matters should be discussed with a probate attorney.

## **PURSUING AN ON-THE-JOB INJURY CLAIM**

Workers' Compensation provides very comprehensive insurance coverage. If the person with traumatic brain injury has been hurt while performing job duties, he may be eligible for Workers' Compensation benefits. The injured worker or his representative must notify the employer immediately of the on-the-job injury. The employer may admit or deny that the injury occurred while the injured person was employed. If the employer admits liability, the insurance company would then determine the rate of the employee's disability benefits. The disability benefits are weekly benefits which are dependent on the employee's rate of pay up to a

### **NOTES**

*It is important to know your legal rights and how various needs might be met.*

maximum amount.

Disability benefits are generally payable until the injured person returns to some type of gainful employment, reaches maximum medical improvement, or is determined to be permanently and totally disabled. If a person is deemed to be permanently and totally disabled, disability benefits may be payable for the insured person's lifetime.

In most cases, the injured worker has the first right to choose the medical care provider from a list provided by the employer. Of course, in an emergency situation, the injured worker can be taken to a facility able to render the needed care. All reasonable and necessary medical care is paid by the employer, generally through its Workers' Compensation insurance policy. The employee is also entitled to reimbursement for travel costs associated with medical care.

If the employer denies liability, the worker is entitled to a hearing on his or her eligibility for benefits. It is suggested that the worker seek a qualified Workers' Compensation attorney for representation at such hearing. Even if the case is admitted, it is advisable to consult a Workers' Compensation attorney to be sure that the injured worker receives all benefits allowable by law.

## **PURSUING A PERSONAL INJURY CLAIM**

If the person with traumatic brain injury

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was injured due to somebody else's negligence, misconduct, or a defective product, there may be a claim to compensate the traumatic brain injured individual for his injuries and losses. An attorney who has experience in these areas of the law should be consulted as to whether or not a personal injury claim should be pursued. It is important to consult an attorney early on to avoid destruction or loss of necessary evidence. Most attorneys who specialize in personal injury cases do not charge a fee for initial consultation. In addition, most will take the case on what is called a contingency basis. That is, if there is a recovery, a portion of the recovery would go to the attorney as attorney's fees. If there is no recovery, then the only out-of-pocket expenses would be for the costs of pursuing the claim but not for attorney's fees. An attorney can also inform you about how to cover the medical expenses pending the outcome of the case as well as inform you about your own insurance policies that may come into play depending on the circumstances of your claim.

## **HOW TO FIND A QUALIFIED ATTORNEY**

Most attorneys have special areas of practice. It is important to find an attorney who has the expertise necessary to handle your case. In the Workers' Compensation field, the Department of Labor and Employment has a list of qualified attorneys. (See [www.coworkforce.com](http://www.coworkforce.com)) In the personal

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injury area, the local brain injury association or the case workers from the hospitals know attorneys who handle personal injury claims and have a particular interest in traumatically brain injured persons. In general, good resources include hospital caseworkers, your local chapter of the Brain Injury Alliance, your personal attorney or physician who may know attorneys in the particular specialty that you need, and friends and relatives who might have had experience with attorneys. If all else fails, attorneys can and do advertise their specialties and those can be found through the local bar associations as well as in the Yellow Pages. Remember that you are not obligated to hire the first attorney that you meet and you should feel free to interview several attorneys until you feel you have the one who is both competent and is interested in your particular case.

## CONCLUSION

The short and long term effects on the person with a traumatic brain injury and his/her family can be confusing and unsettling. From immediate needs of a guardianship or conservatorship to long term estate planning, it is important to know your legal rights and how various needs might be met. An attorney will often present a solution to a problem that had not been thought about previously by family members. Do not be afraid to talk to attorneys. You will find that you can generally interview an attorney at no cost for the initial consultation. There is

## NOTES

*It is important to know your legal rights and how various needs might be met.*

no need to be intimidated and there should be no hesitation to ask an attorney about his or her particular experience in the areas of concern to you.

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## **QUESTIONS TO ASK WHEN SEEKING LEGAL COUNSEL FOR HEAD INJURY**

1. What is your experience with brain injured clients? How many such clients have you represented? Have you gone to trial in any of these cases?
2. When/how did you become involved with brain injured clients?
3. What seminars have you attended concerning brain injuries?
4. Are you involved with the Brain Injury Alliance?
5. Can I see you for an initial free consultation with no obligation?
6. Do you charge on a contingency fee (percent of the amount received) basis? What is the percentage?

## **EMPLOYMENT AFTER TBI**

Joe Lewis, Karen Ferrington, and Wilma Fisher

Joe Lewis, B.A., is an Organizational Consultant for Creative Training/Accelerating Talent (CTAT). Joe has worked with people with TBI for more than 25 years and was involved in the original SAIL program. Karen Ferrington, M.S., CRC, is a Human Resources Development Specialist for the Colorado Division of Vocational Rehabilitation. Wilma Fisher, M.S., is a Rehabilitation Counselor with the Colorado Division of Vocational Rehabilitation.



Many individuals with TBI will utilize employment services at some point in their recovery for the purposes of assessing their skills, exploring career alternatives, developing new skills, determining accommodation needs, and securing and maintaining employment. In general, such services fall into the category of Vocational Rehabilitation, or “VR.” The following provides an overview of both the private and public Vocational Rehabilitation systems.

## **PRIVATE VR SERVICES**

Private vocational services in states that still provide Personal Injury Coverage, along with Worker's Compensation Insurance, are able to offer an individual a wide array of services. Private vocational counselors assess if an individual is in need of return to work site modifications and accommodations. After an injury, they may assist individuals with researching a new career direction. Sometimes, private vocational counselors are asked to make determinations, based on medical and vocational information, of the economic wage loss of an individual and the severity of the injury after an accident. This type of case may involve court or a settlement conference.

Individuals in need of private vocational services in states that still have the PIP coverage are referred to a professional or group of professionals in vocational rehabilitation by an attorney, a psychologist, a physician, and/or an

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*Employment services offer support in assessing skills, exploring career alternatives, developing new skills, determining accommodation needs, and securing and maintaining employment.*

insurance adjuster. The private vocational counselor provides referred individuals with an intake meeting and sets goals for case direction. During this time frame, the vocational counselor determines if the individual's medical and psychological information is clear enough, with set work restrictions, so that the counselor is able to ethically proceed with a career direction or work assessment. When vocational coverage is in place, private vocational counselors may be able to assist individuals with work site assessments (such as a situational assessment in a volunteer setting), guided job interviews, and direct job placement.

The State of Colorado no longer provides its citizens with Personal Injury Coverage, as the legislature voted for "no fault" coverage. This means that much of the medical coverage in an individual's auto insurance will be covered up to a set amount and then may be split, after much debate, with their private health insurance coverage. Sometimes individuals discover they have too little medical coverage and have to pay out of pocket for additional medical and psychological services.

In the early 1990's, Colorado's State Legislature made significant changes to the Worker's Compensation Law limiting the involvement of the private rehabilitation counselor. At present, most of the work performed by private vocational service providers is limited to writing reports outlining future

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recommendations for the automobile accident survivor and economic wage loss reports for worker's compensation cases. Private rehabilitation firms are listed in the phone book as Rehabilitation Professionals.

Community-based organizations that provide services to individuals with disabilities are another private resource for TBI survivors. These are typically non-profit agencies that receive funding through a variety of third-party sources, including Medicaid, state Vocational Rehabilitation, state and federal grants, and donations. The range of employment services provided by these agencies varies based on their mission and funding source(s), but they are often in position to link survivors and their families to other employment service providers. Community-based Independent Living Centers (ILC's) or state Vocational Rehabilitation agencies can direct TBI survivors to the programs in their communities that provide employment services for individuals with disabilities.

## **STATE VOCATIONAL REHABILITATION PROGRAMS**

Through a partnership with the federal government, all states have an agency that assists individuals with disabilities, including survivors of TBI, to achieve their highest level of independence. In Colorado, for example, the Colorado Division of Vocational Rehabilitation (DVR) is the state and federally-funded

### **NOTES**

*In Colorado, the Division of Vocational Rehabilitation (DVR) is the state and federally-funded program that exists to assist eligible individuals with disabilities to become productive members of the workforce and to live independently.*

program that exists to assist eligible individuals with disabilities to become productive members of the Colorado workforce and to live independently. While the vocational rehabilitation process identified here reflects the Colorado service delivery system, the same fundamental principles will be found in all state VR services.

DVR has more than 40 offices located throughout Colorado serving individuals with physical and mental disabilities. Each field office has a supervisor who, in addition to providing leadership and guidance to the staff, takes the lead in developing partnerships with area employers, workforce centers, schools, and other public and private service agencies within the community.

### The Role of the Rehabilitation Counselor

Colorado employs approximately 120 extensively trained rehabilitation counselors who work individually with consumers to help them identify goals and implement plans that meet their specific VR needs. Rehabilitation counselors are required to meet stringent standards put forth by the Commission on Rehabilitation Counselor Certification. This requires a master's level degree, typically in the highly specialized field of rehabilitation counseling. The Division's rehabilitation counselors coordinate, purchase and/or directly provide necessary services to eligible individuals with an identified and agreed-upon vocational goal.

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### *DVR Process:*

- *Application/Intake*
- *Assessment*
- *Eligibility*
- *Employment Planning & Service Provision*
- *Employment obtained*
- *Follow-up*

## **Rehabilitation Process**

**Application/Intake** – the rehabilitation process begins when an individual applies for services from DVR. An application form is completed and an intake interview is held to explore the individual's medical, social, financial, educational, and vocational experiences. This is an opportunity to explore the applicant's skills, abilities, and interests, and to understand his/her specific vocational rehabilitation needs.

**Assessment** – Further assessment of the individual's employment barriers is conducted when necessary to establish eligibility for services.

**Eligibility** – A determination of eligibility is made by the VR counselor based on the existence of an impairment documented by a qualified practitioner (e.g., physician, psychologist, etc.) and substantial barriers to employment due to the impairment.

**Employment Planning and Service Provision** – Once eligibility is established, the participant and his/her vocational rehabilitation counselor work together to select a suitable and appropriate employment goal. Next, an Individualized Plan for Employment (IPE) will be developed outlining the steps and the services

that will be needed so that the individual can reach his/her employment goal. Each participant's program is individually tailored to assure that the services necessary to achieve his/her goals are provided. There are a variety of VR services that may be included on an individual's IPE when necessary to reach the employment goal. An overview is provided:

**Evaluation and diagnostic services** provided to determine eligibility and the services needed for the individual to become employed;

**Vocational rehabilitation guidance and counseling** provided directly by the VR counselor during the individual's plan of services;

**Physical and mental restoration services** which may be provided to correct or substantially modify an individual's physical or mental condition;

**Training services** when necessary to become employed, including vocational training, academic training, personal and vocational adjustment training, job coaching, on-the-job training, job-seeking skills training, and books, tools, and other training materials;

**Specialized services for individuals who are blind, deaf,**

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**and deaf-blind**, including interpreter services, note-taking services, and reader services;

**Rehabilitation technology services**, including assistive technology devices, assistive technology services, and rehabilitation engineering services to address barriers encountered by an individual in attaining or retaining employment;

**Placement services** provided to assist an individual with a disability to find adequate and suitable employment in his/her chosen career;

**Supportive services**, such as maintenance, transportation, personal assistance services and services to family members may also be provided if necessary for the individual to utilize the services identified above.

Appeal processes are in place and provided, in writing, throughout the DVR process giving individuals dissatisfied with services or decisions avenues for resolution.

**Employment Obtained** – The anticipated outcome of the individual's vocational program is suitable employment in a career of the individual's choice. Depending on the services needed, the program can last anywhere from a few months to

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several years.

**Follow-up** – Follow-up services are provided by the VR counselor to assure that the individual's employment is stable and satisfactory. After an employment period of at least 90 days, the VR counselor will close the individual's file after stability has been achieved. However, post-employment services may be provided to previously rehabilitated individuals when needed to maintain or regain suitable employment.

### Common Terminology

#### **Americans with Disabilities Act (ADA)**

The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications.

#### **Applicant**

An individual who submits an application for vocational rehabilitation services in accordance with the Division's policy.

#### **Assistive Technology Device (Adaptive Aid)**

Any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve

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functional capabilities of an individual with a disability.

### **Auxiliary Aids (and services)**

A wide range of services and devices that promote effective communication. Examples may include, for individuals with hearing impairments: qualified interpreters, transcription services, closed caption decoders and videotext displays; for individuals with visual impairments: qualified readers, taped texts, materials in Braille and audio recordings; for individuals with speech impairments: TDDs, speech synthesizers and communication boards.

### **Cognitive Disabilities Training**

Training in the development of cognitive skills to improve attention, memory and problem solving.

### **Homemaker**

An employment outcome in which the individual is performing the majority of homemaking activities necessary to maintain a suitable living environment, either for himself, herself or for family members. Homemaking activities do not typically include self-care activities which directly relate to physical needs such as hygiene, dressing, eating, mobility, etc.

### **Job Coaching**

Training provided by an individual to an eligible individual after he/she has been placed in a paid employment situation. Job coaching services include job skill training at the work site, work site

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orientation, monitoring of the individual at the job site to assess employment stability and coordination or provision of specific services at or away from the work site to maintain employment stability.

### **Job Seeking Skills Training**

Training to teach eligible individuals how to conduct job searches, how to prepare resumes and complete applications, and how to interview effectively.

### **On-The-Job Training (OJT)**

Job skill training provided at the work site by the employer after placement in a paid employment situation has been secured with the clear expectation that employment in the same or a similar job for the employer will continue for the individual with a disability if training is successful.

### **Personal Adjustment Training**

Training provided to help eligible individuals develop compensatory skills and/or to adjust behavior in the areas of independent living, communications, homemaking, personal mobility and ability to travel in the community, and personal functioning. It includes rehabilitation teaching services and mobility training for individuals who are visually impaired, blind or deaf-blind.

### **Personal Assistance Services**

A range of services provided by one or more persons designed to assist an individual with a disability to perform daily living activities on or off the job that the individual would typically perform without assistance if the individual did not have a

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disability. The services must be designed to increase the individual's control in life and ability to perform everyday activities on or off the job. The services must be necessary to the achievement of an employment outcome and may be provided only while the individual is receiving other vocational rehabilitation services. The services may include training in managing, supervising and directing personal assistance services.

### **Post-Employment Services**

One or more vocational rehabilitation services that are provided subsequent to the achievement of an employment outcome and that are necessary for an individual to maintain, regain or advance in employment, consistent with the individual's strengths, resources, priorities, concerns, abilities, capabilities, interests and informed choice.

### **Provider**

The individual and/or organization which will render a necessary good or service.

### **Rehabilitation Technology**

The systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, individuals with disabilities in areas that include education, rehabilitation, employment, transportation, independent living and recreation. The term includes rehabilitation engineering, assistive technology devices and assistive technology services.

## NOTES

**Self-Employment**

An employment outcome where the individual or the entity owned by the individual is responsible for paying for the employer and employee portion of his/her own social security taxes, income taxes, insurance, licenses and other employee benefits. Self-employment ranges from sole proprietorships and independent contractors to multi-employee companies and independent franchise operations.

**Situational Assessment**

A type of vocational evaluation conducted to assess work behaviors, interpersonal skills and job-related skill levels for purposes of establishing eligibility or developing an Individualized Plan for Employment. Situational assessments may take place in community-based settings, including real life work settings, or in facility-based settings, such as community rehabilitation program facilities.

**Supported Employment**

Competitive employment in an integrated setting, or employment in an integrated setting in which individuals are working toward competitive employment, consistent with the individuals' strengths, resources, priorities, concerns, abilities, capabilities, interests and informed choice with ongoing support services for individuals with the most severe disability.

**Supported Employment Services**

Ongoing support services and other appropriate services needed to support and maintain an individual with a most significant disability in supported employment that are provided by DVR for a period of time not to exceed 18 months, unless under special circumstances the eligible individual and the rehabilitation counselor jointly agree to extend the time to achieve the employment outcome identified in the Individualized Plan for Employment.

### **Transportation**

Travel and related expenses that are necessary to enable an applicant or eligible individual to participate in a vocational rehabilitation service, including expenses for training in the use of public transportation vehicles and systems.

### **Vocational Evaluation**

An individualized and systematic process in which an applicant or eligible individual, in partnership with an evaluator, learns to identify his or her strengths, resources, abilities, capabilities, interests and viable vocational options in order to develop employment goals and objectives. A variety of testing and assessment strategies may be used, including a standardized vocational assessment using work samples, situational assessments, community-based job tryouts, job shadowing, etc.

### **Work Adjustment Training**

Training provided to help individuals with disabilities adjust behavior and/or

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develop compensatory skills in vocational areas, such as peer work relationships, supervisory work relationships, general work behaviors and expectations and work habits. Work adjustment training may take place in facility settings or in community-based settings, and it includes training to improve an eligible individual's interpersonal skills to the degree necessary to engage in employment. (Also known as vocational adjustment training).

### **Work Opportunity Tax Credit (WOTC)**

A federal tax credit that can reduce employer's federal tax liability when they hire job seekers who have traditionally faced significant barriers to employment. The employer can reduce their taxes up to \$2,400 or \$4,800 during the first year of employment or up to \$9,000 over two years, depending on the qualified applicant.

To locate DVR services throughout Colorado, individuals can:

- Visit the website at:  
<http://www.cdhs.state.co.us/dvr/>
- Call our Administrative Office Toll Free at 866-870-4595 or, in the Denver metro area, call 303-866-4150.
- Check a phone directory under "Government" listing

### **The Effect of Earned Income on Disability Benefits**

#### **NOTES**

The whole process of working for pay after receiving disability benefits requires an understanding of your benefits; *but it should not keep you from working.*

The whole process of working for pay after receiving disability benefits requires an understanding of your benefits; but it should not keep you from working. The best policy is to maintain close contact with your Social Security Office or your disability carrier, keeping them informed of what you are doing and requesting that any advice you receive be in writing. No matter how little your paycheck, you are required by law to keep your Social Security Office informed.

Social Security Disability Benefits allow for a 9 month **trial work period** for you to test your capacity to work. This program is designed as an incentive for you to determine if you can earn a competitive wage without risking your benefits in the attempt.

Social Security will also do periodic evaluations to determine if you are still disabled. There are two possible scenarios that can cause your Social Security Disability or Supplemental Security income to stop. The first is if medical evidence indicates that you are no longer disabled from working. The second is if, after the trial work months, your income is considered “substantial gainful activity” (SGA). Your Social Security office can provide you with the amounts that are considered SGA.

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**ADVOCATING FOR PRODUCTIVE ACTIVITIES:  
ALTERNATIVES TO FULL TIME PAID WORK**

EILEEN MCLAUGHLIN

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## INTRODUCTION

Loss of a job can be an unwelcome transition in this society where self-expression is often manifested through work. We are taught that independence is achieved in financial self-support. How then can we use our motivation to work and to be productive when job options are lost because of an injury? What conclusions are drawn when a person is assumed to be unable to work? What do we answer when people ask, "What do you do?"

This is to view work and productivity by its narrowest definition: a paycheck. Many individuals consider a return to full time competitive work as the only truly successful outcome after an injury because they do not consider other possibilities. Attempts to return to work full time are filled with financial and emotional uncertainty and risk, as well as potential reward. This is complicated by an assumption that people who demonstrate work abilities no longer need disability support. Individuals receiving disability pensions or social security income are often advised to avoid risking their benefits in tenuous job attempts. Rarely are they presented with an alternative that will adequately fill the void left by the job loss.

We know that **work, paid or unpaid**, can restore an individual's sense of identify and self sufficiency, will provide the routines that define daily life and can re-establish social ties.

## NOTES

*We know that **work, paid or unpaid**, can restore an individual's sense of identify and self sufficiency, will provide the routines that define daily life and can re-establish social ties.*

Looking for increased opportunities does not mean more minimum wage openings in fast-food jobs or custodial work. We are talking about a range of opportunities including education, arts and cultural involvement, skilled labor options, professional consulting, direct service and community work, environmental concerns and more. This must start with the recognition that individuals who have sustained traumatic brain injury differ from one another in abilities, skills and potential contribution and should never be lumped together as a vocational group. Individual definitions of success can be expressed through a variety of activities, paid employment being only one such option.

### **THE ISSUE OF “UNFINISHED BUSINESS” AND OTHER REFLECTIONS ON THE LABOR MARKET**

It is one thing to quit a job because you have decided to try something else; it is your choice and you make the decision for yourself. It is something completely different to lose a job or drop out of school for reasons beyond your control. It feels like you **have** to get back because you weren't finished. The sense of having an unfinished part of life can be very compelling and will drive many people to believe that return to what they were doing before is the only acceptable outcome.

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For many people, return to work represents “recovery” and a “return to normal”. It is how they prove to themselves and others that they have overcome the injury. So it can be hard to separate these very compelling emotional reasons for working from the practical concerns of finding an adequate job match.

Additionally, the labor market has its ups and downs. We know that when there are layoffs or other adjustments to the economy, job placement becomes more difficult. Employers who are feeling a squeeze financially will question every risk and will be looking closely at the needs of the company as a whole and less at how to accommodate individual workers.

This chapter is devoted to exploring the many alternatives to traditional full time work. The good news is, there really are a lot of alternatives and they generally don’t fluctuate with the economy.

### **VOLUNTEERISM:**

**Volunteer work is an option with a lot of flexibility.**

The volunteers choose the group, or the cause, or the activity according to their own ideals. It may be a religious or political organization, a self-help, service or support group, an activity with kids, work with a library or a museum, or an outdoor interest.

- They decide on the time commitment.
- They decide whether they will work on a specific project or will be there

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on an ongoing basis.

- Volunteers consistently report that they feel a renewed sense of control and accomplishment when they find the right option.

**Volunteer work can teach new skills or explore a new direction.**

- Talents that didn't have relevance to a previous job can be tested, at the same time rebuilding endurance and work skills.
- Volunteer work belongs on resumes and on the "Work Experience" section of applications. It establishes productive activity for future employers.
- Volunteer work helps to forge new ways to relate to others and reduce self consciousness about a disability. Volunteers often report that expanded relationships with friends and family result.

**Volunteer work is useful to help deal with a difficult emotional time.**

- It can be a way to confront the injury and its aftermath. Some people who work in support groups express that they want to "give back" to others in response to the assistance given to them at the time of the injury.
- Others who feel anger that the injury or subsequent suffering could have been prevented will use volunteer groups like Mothers

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*Many people value volunteer work because it leads to a sense of community.*

against Drunk Driving or political action groups to try to change things.

- Volunteer work can break the cycle of self doubt that often plagues people after an injury. Concerns about post-injury capabilities and roles can lead to a preoccupation with difficulties, obscuring the potential. Working in volunteer service can re-illuminate that potential.

**Many people value volunteer work because it leads to a sense of community.**

Working through volunteer groups, community organizations or religious groups provides a sense of roots and connectedness and can establish lifelong social ties and supports.

**It is possible to create your own volunteer option.**

We have listed a number of suggestions below. These are by no means all inclusive. Many individuals have volunteered in a family business or approached an organization with a new volunteer idea. Be aware, however, that the Department of Labor has guidelines regarding working without being paid. In most cases, volunteering is limited to non-profits and organizations with a volunteer program already in place. Volunteer options can be put together for jobs that are classified as "exempt" from Department of Labor guidelines. Provisions are made in the rules for "trainees" and "mentoring" but these approaches should be cleared

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through the Department of Labor. You also can be classified as an "unpaid family worker" in a family business.

Please see the section on "Other Roles" in this chapter for details on that option. You can call the Department of Labor (listed in the government section of the telephone book) for clarification, but remember that some employers may be putting themselves at risk in accepting your services for free. Volunteering on a regular basis at your local restaurant or down at the hardware store probably won't work.

In order to achieve a sense of freedom, personal growth, involvement and creativity in volunteerism it is vital that the volunteer have a sense of "ownership." This means that the volunteer has some role in the decision making and the development of the task. Volunteers are unlikely to feel "ownership" for a "busywork" task. On the other hand, an agency or program will only give true responsibilities to volunteers who are dependable and accurate. It is important to approach a volunteer position with the same work skills and responsibilities you would bring to a job.

### **Volunteer Options That Exist in Virtually Every Community:**

It is not possible to put together a list that is all inclusive; nor can this publication provide endorsements for the programs or agencies listed or assume responsibility for any of the programs

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mentioned below. The intention of these listings is to provide a sampling of services to generate ideas for volunteer work.

### **Religious Groups**

Individuals who already have a religious affiliation probably are aware of some of the opportunities that exist within their group. Churches and temples tend to be beehives of volunteer activities: classes to attend or to teach, newsletters and bulletins to write and print up, support and action groups, committees, musical performances, secretarial duties, maintenance and clean up chores, child care and children's activity groups, fund-raisers, community service and even quantity cooking. Their calendars and bulletin boards are a great way to find out how to access these opportunities. Let it be known to the organizers of these programs that they can call on you.

### **Political Candidates and Causes**

Volunteers are what make political organizations and activist groups viable. They answer phones, get out mailings, canvas voters and work in the polling places. They can lobby for legislation, serve on committees, organize letter-writing campaigns or participate in speakers' bureaus. In addition to political organizations, there are many advocacy groups for environmental, wildlife and consumer protection as well as for human and civil rights. The Colorado Attorney General's office uses volunteers to work with the public in its consumer protection section.

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The best way to access these volunteer opportunities is to ask yourself some questions first: Am I committed to this cause and do I support what they do? Do I have skills in persuasion and/or communication? What do I want to accomplish if I volunteer for this group?

Once you've formulated these answers for yourself, you are ready to select a political or activist group and tell them how you want to participate:

- Go to your local library and ask the reference librarian where you can find these groups listed;
- Check with your local legislator's office or local political party
- Look in the calendar of events of your local newspaper
- Check the bulletin boards at your grocery store, nearby college, etc.
- Request that they send you publications that describe their program.
- Neighborhood and Civic Associations

Who plants and tends the community flower beds? Who puts together the softball team? Especially in small communities, these activities are done by local people working for a stipend or as volunteers. These are usually positions that require a lot of energy, responsibility, follow through and often the ability to handle criticism gracefully. These opportunities can be accessed by contacting Civic Associations, the community or recreation center, the

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school, the homeowners' association or by organizing your neighbors yourself.

### **Professional Organizations, Labor Unions, Fraternal Organizations**

If you or a family member belongs to one of these groups, this may be an excellent volunteer opportunity for you. These groups exist to provide assistance and benefits to their members. Many of them also perform services for the community or adopt a particular charity. Examples of these groups are: Elks, Lions, B'nai B'rith, Knights of Columbus, Masons, Shriners, Jaycees, etc.

### **Self-Help Groups**

The purpose of self-help or support groups is to unite, educate, support and guide people facing similar challenges. Part of the idea is that we can benefit from the experiences and insights of other people instead of having to discover everything by ourselves. Support and self-help groups have been around for awhile and consequently there are groups for most disabling conditions. There are also a number of recovery groups for people after major illnesses or surgeries and rehabilitation groups for alcoholism, family violence and other disorders. People tend to share their emotions more easily with others who have confronted the same issues. Volunteering in such a group is an opportunity to comfort and teach. Volunteering with a brain injury support group is a chance to reassert to others and ourselves that a brain injury need not ruin a life.

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Self-help and support groups can be identified by calling hospitals and rehabilitation centers that offer treatment for the particular area in which you wish to work. You can also find Foundations and Societies (The Brain Injury Alliance of Colorado, for example, or the M.S. Society) on the Internet. They are also listed in the telephone book and in the reference section of the library under community services, human services or support groups. Newspapers also regularly publish a listing of support and self-help groups.

### **Community Services**

Hundreds of national, state and local programs exist to provide services for short term or ongoing needs. These include volunteer opportunities also exist in food banks, food reclamation programs, meal delivery programs, housing placement, home repairs, literacy and job training, referral services and telephone reassurance programs. Volunteers are used for homework assistance and mentoring programs for youth, independent living assistance, peer counseling, services to seniors, reading services, help with correspondence, help in filling out forms and tax counseling.

In Denver, the Mile High United Way has a large and active volunteer program which includes a constantly updated database of approximately 300 volunteer openings. They send out a shortened list quarterly--you can pick up a copy of United Way Volunteer Opportunities at

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your library. Outside of Denver, check the Internet or your phone book for the local United Way program. They will try to match you with the kind of placement you want.

The American Red Cross also relies on volunteers to staff its disaster services, transportation programs, organize blood pressure and health screening programs, offer grocery shopping and visitation services, do clerical support and transcribe materials into Braille. They offer free training programs for all volunteers. Look on the Internet for your local chapter or in your phone book under American Red Cross.

There are a number of other programs dedicated to providing education, assistance and working for prevention or care in specific areas of need. This listing includes Denver examples but many of these programs may exist in your local community as well. Look on the Internet by googling your community name together with "Human Services" or look under "Human Services" in your local phone book or on the Internet. Examples are Mothers Against Drunk Driving, March Of Dimes, Pregnancy Services, Catholic Charities, Jewish Family Services, and Interfaith Task Force.

Your County Community Services Department is another resource for volunteer service positions; follow the links on the Internet by pulling up your County's home page. Look in the

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Government (blue) listing section of your phone book. Examples: Volunteers of America uses volunteers to give individual attention to special needs children and a variety of other service positions that vary by local chapter. The Association for Retarded Citizens uses volunteers for special events and committee work. The Salvation Army uses volunteers for informal visits in nursing homes and hospitals as well as for their telephone reassurance program. Porter Hospice trains volunteers to help patients in long-term care facilities and at home. Volunteer ombudsmen with the Denver Regional Council of Governments help look into complaints and concerns of nursing home residents in the Denver area.

There are a number of Veterans' Programs (Vets Outreach, DAV, Vet Center, VFW) and Seniors Groups (too numerous to list here—get on the Internet and explore these areas in your own community or look in your phone book under Senior Citizens' Services) that need volunteers. Some of these programs will offer a transportation stipend or will arrange transportation to get you there.

### **Parks and Recreation Programs**

These programs are described in the Recreation portion of this manual. We are also mentioning them here because they have great volunteer opportunities. Many volunteers have found niches as assistant coaches, scorekeepers, front desk or weight room attendants. They

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have helped with disabled waterskiing and downhill skiing programs and summer camps for special needs kids. Some individuals have negotiated free use of sports facilities in exchange for their volunteer service. One young mother negotiated an exchange with her local YMCA: her volunteer typing for free day-camp for her kids. In fact, most YMCAs urge volunteer programs as part of scholarships that they offer to people in financial difficulty.

South Suburban Parks and Recreation District trains volunteer nature lovers to teach children about plants, wildlife and history of their environment. Most cities and counties use volunteer coaches in their recreational sports programs. Please see the listing of specific programs in the Recreation section.

### **Health**

Many volunteers think first of their local hospital when they are interested in a health-related field. Generally, volunteers in hospitals do clerical support work, gift shop staffing, special event programming and errand running. It helps the volunteer coordinator at the hospital to match you with a job you'll like if you can be clear in the interview about your skills and your expectations. Specialized programs in hospitals, hospices, nursing homes and long term care facilities need volunteers too. For example, the Johnson Adult Day Program uses volunteers for socialization and recreational activities for frail seniors and seniors with memory loss.

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Public Health programs use volunteers in immunization campaigns, health screenings and health fairs and public education programs. There are organizations of all kinds working for education and cure for specific diseases. Check the Internet for some of these near you, or look them up in your phone book: Alzheimer's Association, American Cancer Society, American Heart Association, American Diabetes Association, American Foundation for the Blind, Helen Keller Society, American Lung Association, Arthritis Foundation, Colorado Aids Project, 9 Health Fair, Epilepsy Foundation, M.S. Society, Easter Seals Society, Parkinson Association, Cerebral Palsy Association, Stroke Association, and the Brain Injury Alliance of Colorado.

### **Construction and Home Repair**

In Denver, there are a number of programs that provide weatherization, home repair and installation of ramps and grab bars for people with low incomes and the elderly. These include Brothers Redevelopment Volunteer Program, Seniors! Inc. and Seniors Resource Center.

Through the USA there are programs like "Rebuilding Together" that puts together volunteers to do home makeovers for people who are in need. "Homebuilders Institute" is another program in the Denver area that puts together donated supplies and willing volunteers. Another is "Habitat for Humanity." This program works with

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families unable to afford a home loan. The family and the volunteers work together to build a house using government and donated funds to purchase supplies.

Another volunteer opportunity for people with construction skill is with Volunteers for Outdoor Colorado or Wilderness on Wheels, working on building accessible hiking trails, boardwalks and camping areas. Most volunteer work takes place at the construction site.

### **Outdoor, Conservation, Animals and Wildlife**

National, State and local parks use volunteers as trail guides and for monitoring of the park. Colorado volunteers are particularly fortunate in the variety of park opportunities available nearby, from urban to wilderness. Look on the Internet or Government Pages in your phone book for specific listings under "Parks" for your City or County; or under Colorado "Natural Resources" for Colorado State Parks. The National Park Service has a publication called "Volunteers in the National Parks" that you can request on line or by calling the Park Service. Volunteers interested in working for the Forest Service should contact that Agency directly. Other Federal Agencies to contact are: Fish and Wildlife Service, Army Corps of Engineers, Bureau of Land Management, Soil Conservation Service and Bureau of Reclamation.

Volunteers in parks are sometimes asked to help collect seeds for re-

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vegetation projects or be involved in replanting damaged areas or maintaining trails. The Botanic Gardens in Denver and its associated Arboretum near Waterton Canyon have a variety of volunteer options in horticulture, naturalist programs and environmental research. The Botanic Gardens will provide specialized training for horticulture volunteers. Volunteers interested in wildlife can work with programs such as the Raptor Foundation which rescues injured eagles, hawks, owls, etc., and provides educational programs for schools and communities. Audubon Societies focus on scientific research (including periodic bird population counts), wildlife protection, and conservation education. The Sierra Club sponsors backpacking trips to clean up rivers and trails.

The Humane Society, Colorado Horse Rescue, Denver Dumb Friends League and various animal welfare societies work to improve conditions for lost or surplus horses, cats and dogs. (Look in the phone book under "animal shelters" for the one near you.) They also use volunteers to clean cages, feed and exercise animals and assist with office tasks.

A volunteer option for individuals interested in training dogs to assist blind people, deaf persons or wheelchair users is Assistance or Leader Dogs: check the internet or call your local Humane Society, School for the Blind or the Federation of the Blind, Canine Companions or Hearing Dogs for

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details.

Local zoos or nature parks often train volunteers as tour guides or in support services.

### **Museums/Cultural Programs/Libraries**

If you look "Museums" up in your telephone book you might be surprised at what is there. In Denver, for example, most of us know there is the Denver Art Museum, The Denver Museum of Nature and Science, and the Children's Museum. There are also several railroad museums, a variety of historical museums, and museums devoted to quilts, dolls, toys, model trains, and specialized art. Museum volunteer opportunities are not restricted to urban areas: even in a very small community you will probably find a historical museum. The volunteers in these museums often work with the public at information desks, conducting guided tours, running gift shops, or teaching school groups. Volunteers also do clerical activities or can be assigned technical duties like cataloging or working on research.

An advantage to working in a museum or a cultural program is that you are likely to receive training and be encouraged to develop an expertise in the subject area being displayed or taught.

In addition to the option of being a volunteer performer in local dance, theater and music organizations, many people participate in a variety of backstage tasks including ushering, ticket sales,

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constructing scenery, making costumes, office work and advertising.

Public television and public radio stations use volunteers in clerical tasks, administration, and programming.

Volunteers in libraries shelve books, help with storytelling or read-aloud programs, and serve in outreach programs to people with mobility or vision impairments that can't access the regular library facility: Libraries also often have literacy programs which use volunteer tutors. The Colorado Literacy Assistance Center can refer you to the literacy program nearest you. Art galleries use volunteers in much the same way as museums do. Volunteers are vital to the success of "Art Festivals" (such as the Cherry Creek Arts Festival which had three staff members and 983 volunteers). Creative Arts centers need volunteers for office work, newsletter and fundraising. ArtReach uses volunteers to bring art experiences to special populations throughout the year.

### **Books/Reading/Writing**

The Colorado State Library for the Blind and Physically Handicapped needs volunteers to read books for recordings that are then mailed out to individuals unable to read. They also use volunteers for a number of related support services in the recording process. Recording for the Blind, Inc. also uses volunteers, maintaining a library of over 75,000 cassette tapes

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which it loans to visually, perceptually or physically impaired persons. Most colleges and universities also need volunteer readers to record textbooks in their programs for students with disabilities. Contact the Disabled Student or Student Assistance programs on campus. The Red Cross recruits its volunteers to read mail, letters, newspapers, etc., to people with vision impairments or physical disabilities in their homes.

The Great Books Foundation provides training to volunteers, teachers and librarians to lead discussions.

If you like to write but feel you need structure to get it done, you share a common bond with nearly every creative writer on earth. That is why Writers' Groups are recommended and used by both beginning and experienced writers. These are groups that get together to read each other's work, make helpful suggestions and share ideas and tips. You can find a writers' group by calling the English Department of your local college or by asking at your library. Writers' groups are also formed at Writers' Workshops. These workshops are usually one or two day training programs offered by Continuing Education or Community Recreation programs for a fee. Writers' groups also advertise occasionally in writers' or literary magazines.

Community and neighborhood newspapers are often run on a voluntary

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non-profit basis, using volunteer writers, photographers, typists, cartoonists and illustrators, proofreaders, copyeditors and layout and paste-up specialists. Many organizations such as schools, churches, or service groups also have newsletters and look to volunteers to put them together.

### **Children/Youth Programs**

Public and private schools use volunteers to run special programs, including sports and after school activities and clubs, special classes in subject areas that are not regularly offered in the curriculum, vocational training, and tutoring.

Programs like Odyssey of the Mind and Invent America need coaches, judges and administrators. There are also a number of volunteers in every school who work as classroom and playground aides, clinic aides, library aides, lab assistants and who serve in fundraising programs. In addition to volunteers working directly with the students, there are volunteers on committees that work on educational issues and school/community concerns. Contact your local school or school district office.

Volunteers are the fabric of Girl Scouts, Boy Scouts, Campfire, 4-H, Boy's Clubs, Girl's Clubs, YMCA's and YWCA's, Junior Achievement and other programs designed to offer community service and educational opportunities to kids. You can find your local chapter in the phone book or on line.

Almost every non-profit organization that

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offers child care can use volunteers. If you are interested in working with young children in such a setting, check with recreational, religious and educational programs in your community.

### **Additional Resources**

Check your library's reference desk for the Encyclopedia of Associations. Each listing includes general information about the association, the number of active members, the mission statement, the availability of printed materials, etc.

Volunteer Vacations lists diverse volunteer activities all over the world, including such things as participating in whale watches, archaeological digs, state and national park programs and historic site restoration.

Mobility International USA helps place people with disabilities in international volunteer programs.

The Better Business Bureau or Chamber of Commerce in your area should be able to provide information on an organization that interests you.

### **Questions to Ask the Volunteer Organization:**

- ☐ What is the purpose (mission) of this organization?
- ☐ How many volunteers are there and what is the ratio of staff to volunteers? What volunteer jobs are available?
- ☐ Who is in charge? How are decisions made? What types of activities does this group do?

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- ☐ What is expected of a volunteer?
- ☐ How are volunteers trained?
- ☐ Is there ongoing supervision and support for volunteers?
- ☐ Are there possibilities for taking on more responsibility? Could this volunteer option turn into a paying job?
- ☐ Do you have printed materials I could read before making my decision? Are volunteers reimbursed for expenses like transportation?
- ☐ Why do you think people should volunteer for this organization?

### **Questions to ask Yourself**

What do I want from this volunteer position? Am I looking for a "cause"? For companionship? For a comfortable routine? To learn a new skill or test my abilities? A transition back to work? A chance to use a special talent? Will this group provide that opportunity?

- ☐ Do I know any of the people involved in this group?
- ☐ Am I comfortable here?
- ☐ Am I familiar with any of the causes or projects that this group is involved in?
- ☐ What skills, interests or abilities do I possess that I can use here?
- ☐ Am I willing to give this program the time and energy that is required?
- ☐ Does this organization "fit" with my personal goals and ideals?

### **Accommodating Part Time Work**

Actually part time work has some important advantages. After a disabling injury, return to work is more likely to be

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*After a disabling injury, return to work is likely to be successful if you start part-time.*

*It allows you to rebuild your endurance and carefully assess your abilities.*

successful if you start part time. It allows you to rebuild your endurance and carefully assess your abilities. If you add hours and responsibilities gradually, you are more likely to identify a problem area and develop a strategy or be able to seek help to deal with it.

While you are planning ahead, consult your physician regarding his opinion of a realistic plan for returning to work. The first step toward a successful transition back to work is a clear appraisal of any possible work limitations.

What if you find that you can do some aspects of the job but not others? Before making a decision to give up a job, have an open discussion with your employer. Alternatives like decreased hours or days or taking on less demanding work tasks are frequently possible. Job sharing, contract work and flex time are becoming more common all the time. For many people, the prospect of working fewer hours or in a less demanding job is not reassuring: they look at their finances and wonder how they can afford a cut in pay. Be thorough in uncovering any benefits that are due to you. Examine ways that you can combine part time work, private or group disability payments, Veteran's benefits, Social Security, Workers' Compensation or careful investment of any settlement money. Talk to a financial advisor about it. Find out if an addition of one benefit might result in the reduction of another.

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Some families maintain a financial level by combining a part time job with disability benefits, savings, and increased salary on the part of the spouse. Many families find it necessary to make financial adjustments by reducing expenses, however. It is also possible to supplement income and/or reduce expenses without working for "pay." A few of these strategies are discussed in the next section.

## **SUPPLEMENTING INCOME/ REDUCING COSTS WITHOUT RISKING BENEFITS**

### **Exchanging Services**

Consider these examples: a tenant negotiates reduced rent in exchange for light housekeeping and maintenance duties around the apartment building. For cleaning the pool twice a week, a man is allowed the use of a Health Club for free. One neighbor provides another neighbor with baby-sitting services in exchange for free meals. These are all valid ways to obtain necessary services or supplies without spending any money. Be aware, however, that sometimes "barter" has income tax implications.

### **Cooperatives**

A Cooperative is another form of shared service arrangement. Food cooperatives are formed by people who reduce food costs by pooling grocery funds and buying food in bulk quantities. Look in your phone book under "Food Co-ops" or check bulletin boards at groceries and food warehouses for information. Baby-sitting cooperatives exist in many communities to provide an

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exchange of baby-sitting services between families. Instead of paying a baby-sitter, you call a co-op member and cash in some baby-sitting credits that you earned by watching another member's kids. Often Co-ops spread by word of mouth: they are always recruiting new members. Call your local community center, school, or religious organization to ask if they know how to get in touch with your local Co-op; also check local bulletin boards. Baby-sitting Co-ops can function as support systems for parents and play groups for children; often lasting friendships form.

### **Service Credits**

The concept of "Service Credit Programs" as described in Ruth Fort's Spices of Life is simple and similar to the barter system and the co-ops. It is a system of volunteers who earn credits for their volunteer work. Each time volunteers perform services, they earn credits that can be saved, used immediately or donated to someone else. The "Service Credit" system recognizes that people who need help can also give help. **Value is not measured in money but in time spent or task accomplished.** The Internal Revenue Service has ruled that service credits are tax-exempt because they advance essentially charitable purposes. Many people who are uncomfortable with "charity" are willing to work with a Service Credit system because they have an opportunity to give back in return. For example, a man took a volunteer assignment of doing yard work

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for an elderly couple nearby. Later, when he needed transportation, he cashed in his credits by requesting a volunteer who could drive him. Often service credit programs have the backing of a hospital, social service agency or independent living program to guarantee the credits.

Typical service credit jobs are: at-home assistance, such as meal preparation, letter writing and reading, child care, respite care for family members, personal grooming assistance, peer counseling, household chores, such as light or heavy cleaning, lawn maintenance, home repair, laundry, gardening; or out of the house help, such as providing transportation or accompanying someone to the store, to the doctor or to a recreational event. Independent Living programs often have variations on the service credit idea. A service credit program can work in any community. Check with your local library for information on how to set up a service credit program.

### **Colorado Shares**

Another form of the service credit idea exists in the Colorado SHARE (Self Help And Resource Exchange) program. For two hours of documented volunteer service, this program provides boxes of food for approximately  $\frac{1}{4}$  of the grocery store price. There are no eligibility requirements. There are over 75 host sites around Denver. Sign up is usually held the first week of each month.

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Information on Low Income Assistance is discussed in Chapter 19: Financial Resources, starting on page 285.

Individuals and families who meet low income eligibility requirements may qualify for special assistance programs, including subsidized housing and food assistance programs. Your local Social Services or Family Services program can provide information for you. See the Chapter on Low Income Assistance in this book for more details.

### **Credits and Rebates**

Look into tax credits, utility and rent rebate programs as well. See the chapter on Meeting Basic Needs.

## **OTHER ROLES TO FILL**

### **Homemaker/Caregiver**

It is common that roles in the family will shift when one member has an injury or illness. What is important is that this shift happens in a careful way. If it happens without the full participation of all the family members it can be very difficult.

### **Accommodating a Change of Roles in the Family**

Here are some general approaches that should be used when roles are changed in any family:

- ☐ Keep communication open. Discuss role changes and decision making openly. Don't try to protect one another from difficult decisions.
- ☐ Realize that a shift in roles does not necessarily mean a swap of roles. Look at it more as a blending. Examine aspects of the former role

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that each of you wants to retain and how to accommodate it.

- ☐ Each family member should have certain assigned tasks in the family to avoid the tendency of "taking over" a role without talking about it first. Family members need to clarify any assumptions being made about which is the "right" way to approach a task.
- ☐ Don't eliminate a family member's duties without finding some new roles that can replace old ones. Work on flexible approaches. Be creative. For many families it helps to divide up responsibilities and stick to the list. Even when the family member is unable to actively contribute to chores, there are ways to contribute to the new direction of the family.

When an individual who was formerly working full time in a profession becomes a homemaker and/or caregiver, there are going to be some transitions. Life is less orderly, less structured, and much more spontaneous. Retain a sense of humor. Insert structure where you can. Realize that child care and homemaking are difficult jobs to do without support and miserable without transportation. Identify that support: Other family members? Being involved in a "Parent's day out" on a regular basis? Hiring a person to come in to clean once a week? Perhaps it would be helpful to set aside time to take a class or go to the recreation center.

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There are also a number of supports available for caregivers who wish to work on parenting skills. Check with your county social services for details. Families First has a parent support line that provides information on community resources. Mi Casa, Warren Village and Human Services, Inc. provide assistance in caregiving issues for single, low income parents.

Homemaker is now a Vocational Rehabilitation employment outcome. That means if you need training or equipment to successfully provide homemaking to your family, you can contact your local Vocational Rehabilitation office for assistance and funding.

### **Unpaid Family Worker**

Another vocational outcome that many people are unaware of is "Unpaid Family Worker." Many people have found that they can make a contribution to a family business even when they cannot work competitively. Ask your Voc Rehab counselor for help if this may be a goal for you. You may be provided with additional training or assistance to make this successful just as you would for a paying job. The rationale behind "unpaid family worker" is this: your contribution assists the family business; however it may be a hardship for the business to pay you. You benefit from advancing a business in which you have an investment as a family member.

Some individuals have tried this idea on their own by coaching and helping their spouse in the spouse's job. For example,

### **NOTES**

one woman goes into her husband's insurance office two days a week where she does filing and computer entries. He previously did this himself. Her work now frees up several hours of his time for sales calls, a more productive use of his time, ultimately to the benefit of both of them.

See the Employment section of this manual (pg. 259) for more information on training and support options for work.

## **GOING TO COLLEGE: EDUCATIONAL OPTIONS**

### **Why You Should Consider School or Retraining**

Some people view school as a means to an end; others view school as a fun activity. It can be either of those options. There are many possibilities, including vocational retraining programs specific for people with severe physical and cognitive disabilities; hands-on training programs with limited classroom or lecture demands; GED and literacy training; remedial classes in English and Math; Community Skills training programs; certificate programs; two year and four year degree programs; post-degree or graduate level programs; extension courses; and adult education programs.

A concern for people after a brain injury is the ability to pick up new learning. For many, learning is impaired by changes in cognitive areas. This does not mean that new learning is impossible; for most it

### **NOTES**

means that the method of learning and the efficiency of study has been changed or compromised. However, there are a number of alternative remedial techniques appropriate to the individual learning difficulties. These techniques are available in most of the educational settings mentioned above and will be described in detail later.

### **Getting Ready: GED and Remedial Coursework, Assessment tests, career exploration**

Most Community Colleges offer GED preparation classes, as does Emily Griffith Opportunity Center and the Adult Learning Programs in most counties. Look it up on the internet under GED and the name of your community. There are a number of adult literacy programs in the region which provide one-on-one tutors. Some also provide training in English as a second language. The Community College of Denver offers GED prep classes in Spanish. Your local school district can also be a good resource for GED preparation programs.

Jefferson County has an Adult High School program housed in McClain High School that offers structured classes culminating in a diploma for adults who would prefer to go that route.

Most community colleges and some universities require that you take assessment testing in basic skills prior to registering for classes. You can request that these tests be given in a quiet or un-timed environment if you have

## NOTES

evidence of a physical or a cognitive problem that would slow you down. These tests are helpful in establishing your current academic level and the schools use them for advising you regarding what courses to take. You can prepare for these tests: there are review booklets in most college bookstores or on line through the school's website.

Most community colleges offer remedial coursework if your tests suggest that you require extra review before moving on to college level classes. Generally credit from remedial or developmental classes will not apply to a degree.

If you just want to try an experimental class to see how it feels to be back in school, you can apply as a "special" or "non-degree seeking" student. As a special student, you will fill out a short, simple form for admission. You will not be required to provide test scores or transcripts. In most schools, you can take up to 12 hours as a special student before going through the standard application process.

Most schools provide classes or seminars in Study Skills or College Survival Skills. These are particularly useful for the returning student. They review strategies for taking good notes, time management, relieving test anxiety and in reading and research techniques. This can be an excellent first class after an injury because it teaches the essential strategies for studying.

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Career exploration classes are offered for people who are uncertain about their next step. These are generally self-paced, self-exploration classes that give you interest inventories and aptitude tests, coach you into self-discovery and then teach how to do the research to find out about the jobs that interest you. These classes require the ability to work independently, outside of the traditional structure of a classroom.

### **What to Look For: Evaluating Colleges, Vocational Schools, and Proprietary Schools**

The newspaper and television are filled with advertisements urging you to become a medical assistant or a paralegal or a truck driver or a model. These are for educational businesses or proprietary schools. These programs usually provide short-term, competitive, intense (all day, five days a week) training. Often the training is hands-on, with very little lecture-type teaching. They provide quick, functional training programs in a variety of fields.

When you visit these programs, you will probably encounter a salesperson (often called an “admissions counselor”) who will try to convince you that this program is perfect for you. Take some questions with you to the interview--unfortunately some disillusioned students have commented that what they understood from the sales visit turned out to be different from what was actually provided by some schools. Here are a few questions you should ask:

### NOTES

- ☐ How much is the tuition for the program from start to finish? What is the length of the program? How many students finish in that time period? What percentage of the students who start actually finish?
- ☐ If I take out a loan or pay the tuition amount and find I can't do the program after I've taken some classes, am I still responsible for the entire amount?
- ☐ What accommodations can you make for someone who may not be able to attend classes full time? Can I take a class over again if I have to? Do you provide tutoring help? What is the charge for tutors?
- ☐ What accommodations do you provide for someone who may have trouble reading or writing?
- ☐ Have you had students with disabilities successfully complete this program? Did that person then find a job in this field? How many Voc Rehab clients go here?
- ☐ What is the starting wage for graduates in this field?
- ☐ Do any of these classes transfer to a degree program at a college or university? Generally these programs will allow you to retake classes or will arrange for a tutor, but they are rarely set up to modify

schedules, waive requirements, or provide unusual accommodations. Ask also for any printed material they have that documents career placement of graduates.

Vocational training programs are also offered by most public school districts and by many community colleges (sometimes in conjunction with one another). They are often attended by both high school students and adult students. These provide hands-on training in a variety of fields. Training is provided in such fields as horticulture and landscaping, beautician, automotive repair, travel and hotel/hospitality fields, food service, electronics, etc. These programs are designed to meet the needs of students who are interested in a particular field and prefer to learn in a hands-on setting. They also provide a wide range of special accommodations for students with learning disabilities.

### **What services colleges provide**

Some colleges try to mainstream their disabled students as quickly as possible; others provide special support programs. Provisions for learning disabled students include:

- ☐ Tutors: in many colleges this service is free to disabled students. Smaller schools set up tutors through the student assistance center, while on large campuses you arrange for a tutor through the specific department of the class (i.e., math department, English department,

### **NOTES**

*Prepare for the next time someone asks you what you do...*

- etc.)
- ☐ Classroom and Study assistance: this includes note takers, lab assistance, special meetings with instructors, tape recorders, submitting papers on tape, scribes for tests, alternative assignments.
  - ☐ Provision of alternative testing: allowing time extensions for taking tests, oral exams, non-distracting environment.
  - ☐ Textbooks on tape: provided for persons who have difficulty reading.
  - ☐ Course load modifications: reducing the amount of courses the student is required to take each semester.
  - ☐ Registration assistance: Registration for classes can be confusing and frustrating. Arrangements can be made for pre-registration or registration assistance.

It is the student's responsibility to seek out this special assistance. To obtain these services, most schools require that you register with the Disabled Students program prior to the start of classes, usually providing them with some documentation, of your disability. You are not required to use the services if you find you don't need them; most students are glad to get the extra help, however.

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*At the college level, it is the student's responsibility to seek out special assistance.*

## **A FEW LAST THOUGHTS ON PRODUCTIVE ACTIVITY**

You will probably note that almost all of the suggestions on productive activity mentioned here involve leaving your house and going somewhere or being actively involved with other people.

There is a reason for that. Taking a walk, cutting the grass, fixing lunch or watching television are activities that can fill a day, but they have a passive, isolated quality. Few people can grow in isolation. Look for activities that can present opportunities for growth, for choices and for accomplishment.

Finally, there is one question from the Introduction that still hasn't been answered: what do you say when people ask "What work do you do?" It is amazing how many people who are involved in productive activity still answer this question with an embarrassed, "Ahh...nothing...I'm not working right now." It is like that mysterious answer, "I'm just a homemaker", suggesting that homemakers are less productive than people with paying jobs.

Prepare for the next time that someone asks you what you do. If you have been volunteering, you could say, "I've been working with (Red Cross, Girl Scouts, United Way, Parks and Rec.) doing (clerical work, teaching, social service, trail crew) and I find it to be a (satisfying, challenging, rewarding) experience." If you've been helping your family, you can say, "Since my injury, it makes the most sense for me to work at home." If you

## NOTES

have mixed feelings about your current role, you can even say, "I miss my old job sometimes but now I'm building a new life." You really don't owe anyone an apology or an excuse for not working for pay. You deserve to receive your disability benefits. You deserve to take the time you need to recover or retrain or readjust. You've paid your dues. Now concentrate on what you have to offer and what activities have meaning for you.

Emphasize to others and to yourself that you are making your own decisions about what you do, that retirement does not mean a loss of self-respect, and that some of the most productive ways of contributing to society do not involve paychecks.

## NOTES

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## **TRANSPORTATION**

Sharon Roth, Christy Dittmar, and Christine Callahan

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After your injury you may find yourself asking questions about how you can drive again and, if you are not driving right now, how will you get around?

The overall goal of this chapter is to provide you with places in your community or neighboring communities to begin looking for answers/options relating to transportation. This chapter will not answer all of your questions but will let you know what options you may have and how to create resources where none may exist.

The areas that this chapter will include:

1. Driver's License - When and how to get your License reinstated if you "lost" it following your injury.
2. Americans with Disabilities Act (ADA) - What is the ADA and what does that mean about transportation?
3. Resources to contact to determine transportation services in your community.
4. Determining what your specific transportation needs are.
5. Terminology related to various transportation services.

### **WHAT CAN I DO ABOUT GETTING MY DRIVING PRIVILEGES BACK?**



In the event that your driving privilege was revoked by your physician, there are some key points to understand.

1. We each hold the responsibility to notify the Department of Motor Vehicles (DMV) of any change in our driving status. In the event that you had a loss of consciousness, a seizure, or a change in your ability to drive, you are responsible for notifying the DMV. You are encouraged to talk to your physician about his/her opinion of your readiness to return to driving.
2. Your physician may have actually notified the Department of Motor Vehicle (DMV). The DMV will decide if your license will be cancelled or not. This is not legally required, but sometimes this is done with your safety in mind. This involves a series of steps to be outlined below.

**OR**

3. Your physician may have told you not to drive until you have a driving evaluation and/or training with a Certified Driver Rehabilitation Specialist (CDRS). The CDRS provides the information to your physician for final decision making about your license status. You currently hold your license but have not returned to driving. This procedure will be outlined in part 2 below.

**Steps for return to driving when your**

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### **physician has canceled your license:**

- 1 a. Make an appointment with your physician to discuss this situation.
- b. Your physician may refer you to a CDRS with an order for a driving evaluation. You will need a rehabilitation permit from the DMV in order to drive for the evaluation. The CDRS will give you the necessary information to get a rehabilitation permit. This can be complicated. Talk with the CDRS to help you through this process. To get this rehabilitation permit you will need to go to the DMV with your approved form (DR2401). You will need to take the written (or verbal form) of the test, pass the eye exam, and pay a fee. You can find a CDRS in your state by going to the website of the Association for Driver Rehabilitation Specialists. [www.driver-ed.org](http://www.driver-ed.org).
- c. The driving evaluation consists of two parts. The first is the clinical assessment, consisting of performance skills (motor, sensory, coordination, visual, perceptual, reactions and cognition). The second portion is the on-road assessment. This is done in the facility vehicle and considers the functional needs for driving, including any adaptive equipment needs. A full driving evaluation can take up to 3 hours and is often not covered by insurance.

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*Public transportation authorities may not discriminate against people with disabilities in provision of their services.*

- d. Following these steps, the CDRS will make a recommendation for return to driving, driving rehabilitation or driving cessation. This will all be communicated to the physician who will have the final say and will process the necessary forms with the DMV.
- e. In the event that you are approved for return to driving, you will go to the DMV with your approved form (DR2401), signed by the physician, You will need to take the driving test in your vehicle.

**Steps for return to driving when your physician has told you not to drive, but you still have a license.**

- 2 a. Make an appointment with your physician. Your medical record will reflect your ability to return to driving. In the event that you are driving outside of the physician's recommendations, you are at risk, and in the event of a motor vehicle accident (your fault or not), your record is open to legal sources. It may be determined that you were not following the medical advise of your physician. Therefore, you may be at risk for legal action. It is in your best interest to follow the advice of your physician. The Physicians have an ethical responsibility to talk to you about this issue.
- b. If your physician feels you are able to return to driving, you will have

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clearance to do so with a medical clearance form. If your physician wants you to have a driving evaluation to provide more information, you will get a referral to a CDRS.

- c. Since you have a current license, you will use it for the evaluation. The CDRS will make appropriate recommendations back to your physician for final decision making.

### **WHAT IS THE AMERICANS WITH DISABILITIES ACT AND HOW DOES IT IMPACT TRANSPORTATION?**

The Americans with Disabilities Act (ADA) is a civil rights law which is intended to eliminate discrimination against people with disabilities in all aspects of American life.

The law was signed in 1990 and has several key areas which it impacts. Those areas include employment, government services, public transit, public accommodations and telecommunications.

The transportation provisions of title II cover public transportation services, such as city buses and public rail transit (e.g. subways, commuter rails, Amtrak). Public transportation authorities may not discriminate against people with disabilities in the provision of their services. They must comply with requirements for accessibility in newly purchased vehicles, make good faith efforts to purchase or lease accessible used buses, remanufacture buses in an accessible manner, and, unless it would result in an undue burden, provide para-transit where

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they operate fixed-route bus or rail systems. Para-transit is a service where individuals who are unable to use the regular transit system independently (because of a physical or mental disability) are picked up and dropped off at their destinations for a small fee.

Many companies and/ or services are now conducting training of their employees on how to assist individuals. Training includes such issues as communications, how to load a wheelchair on a lift, how to secure a wheelchair into vehicles, first aid and some minimal medical information.

It is important to educate your local transportation services by offering to provide information as to how they may assist you and other individuals with disabilities.

To get further information on the ADA contact your local Government agency contact:

Office of Civil Rights  
Federal Transit Administration  
U.S. Department of Transportation  
888-446-4511 (voice/relay)  
[www.fta.dot.gov/ada](http://www.fta.dot.gov/ada)

### **LIST OF RESOURCES TO CONTACT FOR TRANSPORTATION OPTIONS**

**Bus Companies** – There are both public and county operated buses. Examples include the Regional Transportation Districts (RTD).

There are several Colorado transit links for

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individual counties and cities in Colorado. Please see [www.apta.com/links/state\\_local/co.cfm](http://www.apta.com/links/state_local/co.cfm) to find your city and county that will apply to you.

Check with customer relations representative for discount passes and special “para-transit” permits. “Access-A-Ride” is a para-transit (curb to curb) program developed by RTD to serve people unable to ride the regular bus routes. Call RTD for an interview, and they will complete a functional evaluation and a physicians’ statement to determine if you need this special service. They will provide free transportation from your home to the RTD office for this interview. We strongly urge people who might have difficulty explaining their brain injury in an interview situation to bring a family member or friend along to this interview. “Access-A-Ride” currently serves Arapahoe, Adams, Denver, Boulder, Broomfield, Douglas and Jefferson counties as long as the same trip could have been made on the regular RTD fixed-route bus system. Your trip must have a starting and ending point within ¾ mile of an RTD non-commuter fixed route. Reservations can be made up to three days in advance. Recurring trips, same day and times, at least three times per week, you may request access-a-Ride subscription service. They operate 365 days a year, seven days a week. Fares are based on twice the cash fare amount of regular fixed route service.

**Taxi Companies** –Also, check with your county department of social services to see if a “voucher” system is in place for discounted fares. Many state funded programs offer

## NOTES

medical and non medical transportation.

**Private Transportation Companies –**

These may include “ambulance companies” and usually provide transportation to medical appointments and/or therapy. Check to see if you’re insurance will cover this type of transportation.

**American Red Cross** – Some chapters of the American Red Cross provide transportation to medical appointments or therapy sessions during the day for a donation or they may have volunteers that could take you.

**Churches** – Some churches may offer transportation to their members to get to worship services and church sponsored activities.

**Universities** – Some colleges and universities may have Disabled students Assistance Program and may be able to advise you on resources and phone numbers.

**Centers for Independent Living** – These centers specialize in hooking up individuals with resources to encourage and increase independence.

**Easter Seals-** The Easter Seals Association is a great source for what is available in the community.

**United Way Agency** – The United Way often knows what resources are available in the community and to whom services are offered.

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**United Way 211- This agency**

maintains a database of programs, services and support groups that are available to the residents of Larimer, Jackson, Grand, Rio Blanco, Routt and Moffat Counties.

**Various Disability Groups** – Some organizations such as the Brain Injury Alliance of Colorado, the Multiple Sclerosis Society, etc. may be aware of special programs. Also look into Senior Organizations, they may be able to inform you of resources they have used and/or be able to assist you with your need.

**State Associations for Transportation Agencies** – In the State of Colorado we have the Colorado Association of Transit Agencies. This is the professional organization that transit companies belong too. Usually if a company or service exists they are members of this organization. This is an excellent source for resources and phone numbers. However you will then need to make contact with the companies you are given information on. See the website listed above under bus companies.

**County Department of Social Services**

– Look in the chapter on Getting Your Basic Needs Met for phone numbers for social services. Some programs are funded on a yearly basis and do not necessarily get advertised. Your county office of social services should know what programs are currently being offered.

**NOTES**

*What about car pooling with people that go to the same meeting?*



### **Hospitals and/or Rehabilitation Facilities**

– Sometimes hospitals have van shuttle service available for their patients to medical appointments. This is more of an exception than a rule, but it is certainly worth checking into.

### **Parks and Recreation Departments –**

Transportation is sometimes available to activities within some Parks and Recreation Districts. You need to contact your local district and speak to a “Special Needs Coordinator” or facility manager.

**Neighborhood Resources** – look into your home owners association and see if they have a listing of volunteers that could help transport you to medical or therapy appointments.

**Limousine Companies** – some limousine companies will transport to medical and therapy appointments.

### **OTHER IDEAS TO THINK ABOUT TO FIND TRANSPORTATION**

What about car pooling with people that go to the same meeting? You can offer to help pay for gas in exchange for a ride. Check out your city at [www.eRideShare.com](http://www.eRideShare.com) The eRideShare is a free service for connecting commuters, or travelers going the same way.

Transportation is a very true concern for people with brain injuries, especially with the ever rising gasoline prices. Please speak up about what your needs are or no one will

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know that the need exists or work to meet the need.

## **WHAT ARE MY TRANSPORTATION NEEDS?**

Make a list of all your transportation needs. Where do you need to get to? Try to think of all possibilities so that you can later look at what services may meet your needs.

- 1.
- 2.
- 3.
- 4.
- 5.
6. How many hours should I allow?

## **TRANSPORTATION?**

Please try to be specific so that when you contact services you can tell them exactly what times you need transportation (i.e. Tuesday evenings 7:00p.m. to 10:00p.m.)

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## WHAT TRANSPORTATION RESOURCES DO I HAVE IN MY COMMUNITY?

Make a list of resources you are aware of so that you may have them readily available

1. Name of Company/Service	Phone #
Days of Operation	Hours of Operation
Costs/Fees	
Reservations Procedures	
What Could I use this service for?	

2. Name of Company/Service	Phone #
Days of Operation	Hours of Operation
Costs/Fees	
Reservations Procedures	
What Could I use this service for?	

## PLACES I STILL NEED TO GET TO BUT DO NOT HAVE TRANSPORTATION FOR:

- 1.
- 2.
- 3.
- 4.
- 5.

## TERMS YOU MAY HEAR WHEN SEARCHING FOR TRANSPORTATION

**Para-transit** – Para-transit refers to a door to door service. This type of service requires a reservation.

**Demand Response** – This is another type of service which requires a reservation. A taxi service is considered demand response. What the term means is that when someone requests or “demands” a service there is a response.

**Fixed Route System** – This is a system that has a route that is the same day after day. An example of a fixed route system is a bus route that operates.

**SR 22** – This is high risk insurance that is often required if you have a license that has been revoked or suspended due to a poor driving record.

**CDRD** – This refers to a Certified Driving Rehabilitation Specialist.

## **BUILDING LEISURE PARTNERSHIPS**

*Stay Active. Get Healthy.*

### **Cheryl Catsoulis and Lisa Hart**

Cheryl Catsoulis, B.S., is the Director of Brain Injury Services at Greeley Center for Independence, Inc. and has over 25 years of experience in the field of Brain Injury as a C.T.R.S., Case Manager and Program Director. Lisa Hart, C.T.R.S., C.M.T., is Director of Therapeutic Recreation at Greeley Center for Independence, Inc. and has 27 years of experience in Brain Injury.

## Introduction

What did recreation and leisure look like before your traumatic brain injury? You may have hopped in the car or called a friend and met at the mall or basketball court. You had a group of friends and acquaintances from work or school and spontaneously planned get-togethers or a ski trip. You may have loved to read or paint or work on cars on your own.

But if you are living with a TBI, things have changed. You may not be driving, working or going to school. Your familiar group of friends and co-workers may not come around much anymore. You may not be able to concentrate on reading or can't physically use your automotive tools. You might be feeling a bit lost. "What do I do with my time?" "How do I get satisfaction and enjoyment from this new life ahead of me?"

There's a lot to think about now. Your personality, physical abilities, emotional and health issues may be different. You also need to consider things like transportation, money, making new friends, finding accessible places, and learning new skills.

**Finding a partner, advocate or buddy can make this less overwhelming. To be successful, to find satisfaction and enjoyment in recreation and leisure, you need to build leisure partnerships. You will need to build and nurture that relationship so it is**

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*To be successful, to find satisfaction and enjoyment in recreation and leisure, you need to build leisure partnerships.*

satisfying for both of you. And you will need to “think outside of the box” as you explore and consider recreation options, opportunities and community resources.

### **Suggestions on Finding and Enlisting Your Leisure Buddies or Support Team**

- **People who have asked to help:**  
Since your injury, many people have probably asked you or your family, “How can I help?” “What can I do for you?” At the time, you may not have been able to think about or tell folks how they could help. Ask them now. “Hey, I need some help getting back into some fun and enjoyment. Can you partner up with me or do you know someone who would like to help me out?” At this point, you may not even know WHAT it is they can do. Just see if they are interested and willing.
- **Go to your friends and previous co-workers.** Make that initial contact and let them know you are struggling with your recreation. Ask if they can partner up with you or do they know someone who can. Always remember to ask that last part. They may know someone else who would love to help you out.
- **Make new contacts through the TBI community.** Contact BIAC for

### NOTES

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*Try these strategies  
to find and enlist  
your leisure  
buddies or support  
team*

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information and resources. Go to your local TBI Support Group, the Hangout, OURS Group, or Lunch Bunch. Contact healthcare, rehabilitation and post acute providers.

- **Apply for the Colorado Brain Injury Program:** Your Traumatic Brain Injury has affected your quality of life and recreation pursuits. With financial resources, you may be able to build a partnership to help you reach your recreation and leisure goals.
- **Explore other options in your community.** There are many service organizations, high schools and colleges, and clubs that may interest you. When you live in a very small community, your options may look different. If you live in a small community, these may be harder to find. You may find a buddy/partner at the local diner, hardware store or library. You may need to rely more on family and friends or be creative with other contacts.
- **Build a team, not just one buddy.** You may have a lot of leisure time whereas your partner or buddy may have limited time available. Build a team of reliable partners to help you fill your time with meaningful, enjoyable activities.

### **Build Relationships**

- **Start out slowly** by visiting with people at your home where you have

### NOTES

familiar support (family or caregivers), especially if this is a new person in your life or if you have medical, behavioral or other issues that require additional training or understanding. Sometimes the “new you” may be confusing or intimidating even for close friends.

- **Explore mutual interests.** Do you both enjoy card games or watching sports? Do you both have a favorite TV show that you hate to miss-watch it together. Discover more about each other as you spend time together at home. During this time, have a familiar person available just in case you need some help.
- **Try new things of interest to each other.** Maybe you can teach dominoes to your buddy. Or your buddy can help you learn to knit. This is a great opportunity to expand your horizons. Keep an open mind.
- **“Loosen the reins”** As you get more familiar and comfortable with each other, “loosen the reins”. Familiar family and caregivers don’t need to be around as much. They can leave you and your buddy alone for periods of time.
- **Start getting out of the house.** Again, you may want familiar caregivers around at first if necessary. Then as everyone is comfortable, go out on your own, just you and your buddy.

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*“What’s out there?”*

- **Expand this relationship**, as you all feel comfortable. Remember, some relationships/partnerships may not get past a certain point. One of your buddies may not want to leave the house. That's okay. That is a good reason to have a team of leisure buddies.

### **Explore Community Resources**

- **“What’s out there?”** As you get out of the house more, you will need to consider “What’s out there?” You, your family and your buddies will need to do some research to see what is available in your area. Start your own notebook with the names, numbers and information you have gathered. Even if the resource isn’t right for you, you may be able to help someone else.
- **Start with some of the same TBI resources** discussed earlier such as Support Groups, BIAC, Outpatient Rehabilitation Centers, Adult Day Treatment and Adult Day Programs. You, your buddies or your family/caregiver, may need to make several phone calls to see what is out there. Don’t give up if someone says, “We can’t help you.” ALWAYS ask, “Do you someone else I should call?” Get a name and a phone number if they make a suggestion.
- **Contact your Community Recreation Center.** If you are in a small community that does not offer programs to meet special needs, call one of the key

## NOTES

*“What’s out there?”*

programs listed with the RESOURCES such as Denver Special Needs Program or Ft Collins Adaptive Recreation Opportunities. They may be able to give you some ideas.

- **Check out opportunities through local churches, schools, and libraries.** The church may have a mission group that interests you. The schools usually have drama, music and performance events to attend. Libraries frequently have a variety of activities such as book clubs, movies or lectures open to the public.
- **What special interest stores are in your area?** Craft and hobby stores, garden centers, and camera shops offer classes on a regular basis as well as clubs that meet on a regular basis.
- **Do you belong to a service organization or social club** such as The Elks, Optimists or VFW? With your partner, maybe you can get involved with the organization again.
- **Check out your local Calendar of Events**, which is usually published in the local paper or online at the Chamber of Commerce. What is happening in your community and how can you get involved? This is a great time to think outside of the box. Maybe it's not something you've ever done before – try it anyway. You may meet some new people or find a new interest.

## NOTES

**CREATE** a lasting partnership with your buddies:

**Consistency**

**Recognition**

**Education**

**Appreciation**

**Training**

**Enthusiasm**

- **Are you able to volunteer?** There are a variety of volunteer opportunities in most communities. Again, contact your TBI resources, hospitals, schools, food bank, churches, shelters, parks and recreation department, Humane Society, Police or Fire Department, Military Base or Post, assisted living or nursing homes.

### **Sustaining Your Leisure Buddies or Team**

- **These partnerships are evolving and changing constantly.** Be patient. Don't push your buddy into something they do not want to do. Visiting at home may be just fine with one buddy; another may prefer to do things in the community.
- **Your buddies need good reasons to continue with the relationship.** It is up to you and your family/caregiver to nurture the relationship to make it grow and sustain it for a long time.
- **What is the motivation for your buddy to continue?** It could be your winning personality and sweet smile but don't count on that forever. To CREATE a lasting partnership, your buddies need:
  - Consistency
  - Recognition
  - Education
  - Appreciation
  - Training
  - Enthusiasm

**Consistency-** Set a consistent or regular time and place to meet. Have a plan set so you

### NOTES

*\*\* Ask if your local Parks & Recreation Department has a Therapeutic Recreation Specialist or a Special Needs Program \*\**

both know what you will be doing. Have a consistent family member or caregiver present until you both feel comfortable stepping out on your own.

**Recognition-** Recognize the evolving or changing nature of these relationships. Know the comfort level of your buddy and don't push beyond their limits. Don't force or rush a relationship. Slow and steady wins the race. You may not be successful at your first attempts to find a leisure buddy. Recognize that this is not failure on anyone's part. Don't give up. Recognize that there are still more options out there.

**Education-** TBI may be new to your buddy. Provide them with some written information from BIAC or from your Rehabilitation Team. Don't overwhelm them! There is so much to learn about brain injury.

**Appreciation-** Take every opportunity to express your sincere appreciation for what they are doing with you. Send a card or hand written note on a regular basis. Have their favorite beverage or snack available when you meet. If you can, offer to pay for gas, admission to events or the meal. Take their interests into consideration when you make plans. Adjust your schedule to accommodate their needs. Ask about their family or pets. Tell them in person how much you appreciate them and all they do.

**Training-** Offer opportunities for special training related to you and the field of brain injury. Check out the Brain Injury 101 sessions through BIAC. Maybe

## NOTES

### *Participation in recreation and leisure*

- *Enhances your social network*
- *Gives your caregivers respite, and*
- *Improves your quality of life*

**GET ACTIVE.  
LIVE HEALTHY.**

this is something you could do together. Make arrangements with your rehabilitation team or Home Health provider to provide special training for your buddy.

**Enthusiasm-** Make your time together fun and enjoyable.

Some things are just easier to do with another person. Finding a leisure buddy can make reintegration into the community a more enjoyable and lasting experience. Participation in recreation and leisure enhances your social network, gives your caregivers respite and improves your quality of life.

*Get Active. Live Healthy.*

## GENERAL RESOURCES

- Brain Injury Alliance of Colorado
- Local Support Groups or Chapters
- Chamber of Commerce and Tourism
- Phonebooks (Yellow Pages and Government Pages)
- Newspaper, TV and Radio for Calendar of Events
- Local Parks and Recreation Departments
- Senior Programs
- Libraries
- State and National Parks
- Churches and Church Groups
- Services Clubs (ELKS, Lions, Knights of Columbus, Red Cross)
- Community Colleges/Universities
- Local High Schools
- Special Interest Clubs (Book Clubs, Hiking Clubs, etc.)
- Hospitals and Rehabilitation Centers
- Mental Health Centers
- Health Clubs
- Magazines
- Craft/ Hobby Stores (Michaels, Hobby Lobby, Joann's, Archivers, Ceramic Shops)
- Camera/Photography Stores
- Garden Centers/Nurseries
- YMCA/YWCA

## **INTRODUCTION TO COMPLEMENTARY & ALTERNATIVE MEDICINE**

**Terry Chase, MA, ND, RN**

Terry Chase has been the Coordinator of the Patient & Family Education Program at Craig Hospital since 1996.



As a health care consumer interested in Complementary & Alternative Medicine (CAM), it is in your best interest to work with your primary doctor about using any of these alternative treatments. Not all CAM therapies practiced outside of traditional medicine have been studied and deemed safe and effective especially for people with traumatic brain injury (TBI). This chapter is intended as a primer or introduction to CAM, so that you can be informed and knowledgeable about treatments and are able to get more information if needed. Much of the information in this chapter has been adapted from the National Center for Complementary and Alternative Medicine website ([www.nccam.nih.gov](http://www.nccam.nih.gov)). See the reference section at the end of this chapter for additional resources.

### **What is Complementary & Alternative Medicine?**

The National Center on Complementary & Alternative Medicine (NCCAM) a component of the National Institutes of Health, defines complementary and alternative medicine (CAM) as a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. (NCCAM, 2006) While scientific evidence exists regarding some CAM therapies, there are key questions that are yet to be answered through well-designed scientific studies-- questions such as whether these therapies are safe and actually work for

*Much of the information in this chapter has been adapted from the National Center for Complementary and Alternative Medicine website:*

[www.nccam.nih.gov](http://www.nccam.nih.gov)

the diseases or medical conditions for which they are used.

What is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge. There are five categories, or domains of CAM as classified by NCCAM:

### **Alternative Medical Systems**

Alternative medical systems are built upon complete systems of theory and practice. Often, these systems have evolved apart from, and earlier than, the conventional medical approach used in the United States. Examples of alternative medical systems that have developed in Western cultures include homeopathic medicine and naturopathic medicine. Examples of systems that have developed in non-Western cultures include traditional Chinese medicine and Ayurveda.

### **About Acupuncture**

The term "acupuncture" describes a family of procedures involving the stimulation of anatomical points on the body using a variety of techniques. The acupuncture technique that has been most often studied scientifically involves penetrating the skin with thin, solid, metallic needles that are manipulated by

the hands or by electrical stimulation. Practiced in China and other Asian countries for thousands of years, acupuncture is one of the key components of traditional Chinese medicine.

A 1997 report from the National Institutes of Health (NIH) stated that acupuncture is being "widely" practiced—by thousands of physicians, dentists, acupuncturists, and other practitioners—for relief or prevention of pain and for various other health conditions. According to the 2002 National Health Interview Survey, an estimated 8.2 million U.S. adults had ever used acupuncture, and an estimated 2.1 million U.S. adults had used acupuncture in the previous year.

Acupuncture needles are metallic, solid, and hair-thin. People experience acupuncture differently, but most feel no or minimal pain as the needles are inserted. Some people feel energized by treatment, while others feel relaxed. Improper needle placement, movement of the patient, or a defect in the needle can cause soreness and pain during treatment. This is why it is important to seek treatment from a qualified acupuncture practitioner.

Treatment may take place over a period of several weeks or more. Ask the practitioner about the estimated number of treatments needed and how much each treatment will cost. Some insurance

## NOTES

*...Meditation,  
prayer, mental  
healing, and  
therapies that use  
creative outlets  
such as art, music  
or dance...*

companies may cover the costs of acupuncture, while others may not.

## Mind-Body Interventions

Mind-body medicine uses a variety of techniques designed to enhance the mind's capacity to affect bodily function and symptoms. Meditation, prayer, mental healing, and therapies that use creative outlets such as art, music, or dance are still considered CAM. Generally, mind-body medicine focuses on the interactions among the brain, the rest of the body, the mind, and behavior and the ways in which emotional, mental, social, spiritual, and behavioral factors can directly affect health.

### About Meditation

The term *meditation* refers to a group of techniques, most of which started in Eastern religious or spiritual traditions. These techniques have been used by many different cultures throughout the world for thousands of years. Today, many people use meditation outside of its traditional religious or cultural settings, for health and wellness purposes.

In meditation, a person learns to focus his attention and suspend the stream of thoughts that normally occupy the mind. This practice is believed to result in a state of greater physical relaxation, mental calmness, and psychological balance. Practicing meditation can change how a person relates to the flow of emotions and thoughts in the mind.

## NOTES

*4 common elements of meditation:*

- *A quiet location*
- *A specific, comfortable position*
- *A focus of attention*
- *An open attitude*

Negative side effects of meditation have not been noted when combined with conventional medical treatments.

Most types of meditation have four elements in common:

**A quiet location.** People who meditate usually prefer a quiet place with as few distractions as possible. This can be particularly helpful for beginners.

**A specific, comfortable posture.** Depending on the type being practiced, meditation can be done while sitting, lying down, standing, walking, or in other positions.

**A focus of attention.** Focusing one's attention is usually a part of meditation.

**An open attitude.** Having an open attitude during meditation means letting distractions come and go naturally without stopping to think about them. When distracting or wandering thoughts occur, they are not suppressed; instead, the meditator gently brings attention back to the focus.

People use meditation for various health problems, including, depression, mood and self-esteem problems, anxiety, pain, stress, relaxation, insomnia and other sleep disorders. Other mind-body therapies include: guided imagery,

## NOTES

humor therapy, music therapy and biofeedback.

### **About Tai Chi**

Tai chi (pronounced "tie chee") is a mind-body practice that originated in China as a martial art. A person doing tai chi moves his body slowly and gently, while breathing deeply and meditating (tai chi is sometimes called "moving meditation").

A person practicing tai chi moves her body in a slow, relaxed, and graceful series of movements. One can practice on one's own or in a group. The movements make up what are called forms (or routines). In tai chi, each movement flows into the next. The entire body is always in motion, with the movements performed gently and at uniform speed. In addition to movement, two other important elements in tai chi are breathing and in tai chi practice, it is considered important to concentrate; put aside distracting thoughts; and breathe in a deep, relaxed, and focused manner.

Tai chi is practiced for a variety of health purposes:

- A low-impact form of exercise.
- As a weight-bearing exercise benefiting the bones.
- As an aerobic exercise.
- To improve physical condition, muscle strength, coordination, and flexibility.

### **NOTES**

- To improve balance and lower risk of falls, especially for the elderly.
- To ease pain and stiffness--for example, from arthritis.
- To improve sleep.
- For overall health and wellness.

## **Biologically Based Therapies**

Biologically based therapies in CAM use substances found in nature, such as herbs, foods, and vitamins. Some examples include dietary supplements, herbal products, and the use of other so-called natural but as yet scientifically unproven therapies. A dietary supplement is a product (other than tobacco) taken by mouth that contains a "dietary ingredient" intended to supplement the diet. Dietary supplements are sold in grocery, health food, drug, and discount stores, as well as through mail-order catalogs, TV programs, the Internet, and direct sales.

People take supplements for many reasons. Some uses of dietary supplements have become part of conventional medicine. For example, scientists have found that the vitamin folic acid prevents certain birth defects, and a regimen of vitamins and zinc can slow the progression of the eye disease age-related macular degeneration.

On the other hand, some supplements are considered to be CAM--either the supplement itself or one or more of its

## **NOTES**

*Dietary supplements are sold in grocery, health food, drug, and discount stores, as well as through mail-order catalogs, TV programs, the Internet, and direct sales.*

uses. An example of a **CAM supplement** would be an herbal formula that claims to relieve arthritis pain, but has not been proven to do so through scientific studies. An example of a **CAM use of a supplement** would be taking 1,000 milligrams of vitamin C per day to prevent or treat a cold, as the use of large amounts of vitamin C for these purposes has not been proven.

There are several ways to get information on supplements that are based on the results of rigorous scientific testing, rather than on testimonials and other unscientific information.

- Ask your health care provider. Even if your provider does not happen to know about a particular supplement, he/she can access the latest medical guidance about its uses and risks.
- Dietitians and pharmacists also have helpful information. Pharmacists can also look at your current medication regimen and investigate if supplements will counteract or interfere with your meds.
- You can find out if there are any scientific research findings on the CAM supplement in which you are interested. NCCAM and other Federal agencies have free publications,

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clearinghouses, and databases with this information.

If you are interested in using supplements, it is **especially important** to talk to your provider about:

- Replacing your regular medical care with one or more supplements.
- About your current medications (whether prescription or over-the-counter). Some supplements have been found to interact with medications (see box below).
- Chronic medical condition or longstanding health problem.
- Plans for surgery. Certain supplements may increase the risk of bleeding or affect anesthetics and painkillers.
- Pregnancy or nursing a baby.
- Giving a child a dietary supplement. Supplements can act like drugs, and many have not been tested in pregnant women, nursing mothers, or children. Do not take a higher dose of a supplement than what is listed on the label, unless your health care provider advises you to do so. If you experience any

## NOTES

side effects that concern you, stop taking the supplement, and contact your provider.

### **Supplements and Drugs Can Interact**

St. John's Wort can increase the effects of prescription drugs used to treat depression. It can also interfere with drugs used to treat HIV infection, to treat cancer, for birth control, or to prevent the body from rejecting transplanted organs.

Ginseng can increase the stimulant effects of caffeine (as in coffee, tea, and cola). It can also lower blood sugar levels, creating the possibility of problems when used with diabetes drugs.

Ginkgo, taken with anticoagulant or anti-platelet drugs, can increase the risk of bleeding. It is also possible that ginkgo might interact with certain psychiatric drugs and with certain drugs that affect blood sugar levels.

There are many supplements, as well as many prescription drugs, that come from natural sources and are both useful and safe. However, "natural" does not always mean "safe" or "without harmful effects." For example, consider mushrooms that grow in the wild--some are safe to eat, while others are poisonous.

### **Manipulative and Body-Based Methods**

Manipulative and body-based methods in CAM are based on manipulation and/or movement of one or more parts of the body. Under the umbrella of manipulative and body-based practices is a heterogeneous group of CAM interventions and therapies. These include chiropractic and osteopathic manipulation, massage therapy, reflexology, rolfing, Bowen technique, Trager bodywork, Alexander technique, Feldenkrais method, and a host of others.

## About Massage Therapy

The term massage therapy covers a wide group of practices and techniques. There are over 80 types of massage therapy. In types of massage therapy, the therapists press, rub, and otherwise manipulate the muscles and other soft tissues of the body, often varying pressure and movement. They most often use their hands and fingers, but may use their forearms, elbows, or feet. Typically, the intent is to relax the soft tissues, increase delivery of blood and oxygen to the massaged areas, warm them, and decrease pain.

A few popular examples of this therapy are as follows:

In **Swedish massage**, the therapist uses long strokes, kneading, and friction on the muscles and moves the joints to aid flexibility.

A therapist giving a **deep tissue massage** uses patterns of strokes and deep finger pressure on parts of the body where muscles are tight or knotted, focusing on layers of muscle deep under the skin.

In **trigger point massage** (also called pressure point massage), the therapist uses a variety of strokes but applies deeper, more focused pressure on myofascial trigger points--"knots" that can form in the muscles, are painful when pressed, and cause symptoms elsewhere in

## NOTES

*Typically, the intent of massage therapy is to relax the soft tissues, increase delivery of blood and oxygen to the massaged areas, warm them, and decrease pain.*

the body as well.

More recently, a 2002 national survey on Americans' use of CAM (published in 2004) found that 5 percent of the 31,000 participants had used massage therapy in the preceding 12 months, and 9.3 percent had ever used it. According to recent reviews, people use massage for a wide variety of health-related intents: for example, to relieve pain (often from musculoskeletal conditions, but from other conditions as well); rehabilitate sports injuries; reduce stress; increase relaxation; address feelings of anxiety and depression; and aid general wellness.

Professionally trained massage therapists work in a variety of settings, including private offices, hospitals, other clinical settings, nursing homes, studios, and sport and fitness facilities. Some also travel to patients' homes or workplaces to provide a massage.

Massage therapy treatments usually last for 30 to 60 minutes; less often, they are as short as 15 minutes or as long as 1.5 to 2 hours. Therapists usually try to provide an environment that is as calm and soothing as possible (for example, by using dim lighting, soft music, and fragrances).

During treatment, you will lie on a special padded table or sit on a stool or chair. You might be fully clothed (for example, for a "chair massage") or partially or fully undressed (in which case you will be

## NOTES

covered by a sheet or towel; only the parts of your body that the therapist is currently massaging are exposed). Oil or powder helps reduce friction on the skin. The therapist may use other aids, such as ice, heat, fragrances, or machines. He may also provide recommendations for self-care, such as drinking fluids, learning better movement, and developing an awareness of your body.

## Energy Therapies

Energy therapies are methods that focus primarily on the flow of energy around and through the body. **Biofield therapies** are intended to affect energy fields that purportedly surround and penetrate the human body. The existence of such fields has not yet been scientifically proven. Some forms of energy therapy manipulate biofields by applying pressure and/or manipulating the body by placing the hands in, or through, these fields. Examples include qi gong, Reiki, and Therapeutic and/or Healing Touch. **Bioelectromagnetic-based therapies** involve the unconventional use of electromagnetic fields, such as pulsed fields, magnetic fields, or alternating-current or direct-current fields.

## About Reiki

Reiki is a therapy that the practitioner delivers through the hands, with intent to raise the amount of ki in and around the

## NOTES

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*Talk to your primary health care provider(s) about therapies you are considering. Ask about its safety, use, effectiveness, or possible interactions with medications.*

\*\*\*

client, heal pathways for ki, and reduce negative energies. Reiki can be practiced in several ways: on its own, along with other CAM therapies, and along with conventional medical treatments.

When a practitioner performs Reiki, usually the client sits or lies comfortably, fully clothed. The practitioner places her hands on or slightly above the client's body, using 12 to 15 different hand positions, with the intent to transmit ki. The hands are positioned with the palms down, fingers and thumbs extended. Each hand position is held until the practitioner feels that the flow of energy has slowed or stopped, typically about 2 to 5 minutes. Some Reiki practitioners believe they are helped by "spirit guides" for proper flow of the energy.

Practitioners perform Reiki most often in offices, hospitals, clinics, and private homes. The practitioner and client determine the number of sessions together. Typically, the practitioner delivers at least four sessions of 30 to 90 minutes each.

Depending on their level of training, people can perform Reiki on themselves as well as on people who are either close by or at some distance away (even at a long distance). In the latter case, Reiki is a type of "distant healing."

## NOTES

## **General Guidelines for Finding a CAM Practitioner**

Before selecting a CAM therapy or practitioner, talk with your primary health care provider(s). Tell them about the therapy you are considering and ask any questions you may have. They may know about the therapy and be able to advise you on its safety, use, and effectiveness, or possible interactions with medications. Here are some suggestions for finding a practitioner:

-Ask your doctor or other health professionals whether they have recommendations or are willing to make a referral.

-Contact a nearby hospital or a medical school and ask if they maintain a list of area CAM practitioners or could make a recommendation. Some regional medical centers may have CAM centers or CAM practitioners on staff.

-Ask if your therapy will be covered by insurance; for example, some insurers cover visits to a chiropractor. If the therapy will be covered, ask for a list of CAM practitioners who accept your insurance.

-Contact a professional organization for the type of practitioner you are seeking. Professional organizations can be located by searching the Internet or directories in libraries (ask the librarian).

## NOTES

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*Medicine: Principles and Practices* (2007). J McElligott, AM Davis, JS Hecht, S Kothari, JA Muenz & GG Wang. Demos: NY

*Traumatic Brain Injury: Diagnosis, Acute Management & Rehabilitation. Evidence-based Best Practice Guideline*, July 2006. Wellington, NZ. NZ Guidelines Group



**GETTING YOUR BASIC NEEDS MET:  
Food, Utilities and Medical Needs**

Diane Vigoda

Diane Vigoda, LCSW, CCM is a social worker who has been working in the ABI field in Denver since 1988.

## **Introduction**

Trying to locate a specific item and/or service can be a frustrating experience. It can be difficult enough to ask for help, but it is just as difficult to ask the right questions in order to get your needs met. When someone has a disability, services that individuals and families may have taken for granted previously (such as transportation) may now need to be specifically accessed. Who do I call? What do I do? Where do I go for help?

It is rare when the individual and/or family's income is not impacted following a brain injury. This loss of income may not only affect housing (being able to pay rent and/or mortgage on present home and/or apartment, accessibility and the need for modifications to present home), but also may affect areas of food, utilities, and medical care (prescriptions).

The focus of this chapter will be on resources available to help with food, utilities, and medical care. Additionally, programs available through county social service agencies will also be discussed.

## **FOOD**

Noted psychologist, Abraham Maslow, has said that an individual must take care of his/her basic needs for survival, before addressing any other needs. Food is included in this category.

## **Social Service Programs**

### NOTES

*It can be difficult enough to ask for help, but it is just as difficult to ask the right questions in order to get your needs met.*

## **Food Stamps**

This program is administered through the appropriate county department of Social Services. The Food Stamp Program provides a card that can be used at various supermarkets and food stores, to help pay for food. The amount of Food Stamps that you and/or your family may qualify for is dependent upon income. Expenses such as rent, utilities, etc. are additional factors used in determining eligibility amounts.

## **Commodity Supplemental Food Program**

This program is provided through the Colorado Department of Human Services, and provides basic staple food products to individuals/ families in need. Contact the Food Distribution Program of the Colorado Department of Human Services:

1575 Sherman Street  
Denver, Colorado 80203.  
Telephone number: 303-866-5106 for eligibility requirements.  
[http://www.colorado.gov/cs/Satellite/CDH S-FDP/FDP/1251567032013](http://www.colorado.gov/cs/Satellite/CDH%20S-FDP/FDP/1251567032013)

## **Colorado Department of Human Services**

Department of human services listed to search for an office by county.  
[http://www.colorado.gov/cs/Satellite/CDH S-Main/CBON/1251590215770](http://www.colorado.gov/cs/Satellite/CDH%20S-Main/CBON/1251590215770)

## **Other Food Resources**

## **NOTES**

- 1) Food Bank of the Rockies**  
10975 East 47<sup>th</sup> Avenue  
Denver, Colorado 80239  
(303)-371-9250 or (877) 460-8504  
<http://www.foodbankrockies.org>
- 2) Catholic Charities** (available at different site locations throughout the Denver metro area). 4045 Pecos Street  
Denver, Colorado 80211  
Call (303)742-0828  
<http://www.ccdenver.org>
- 3) Contact United Way #211 or (303) 433-8900 for the food bank location in your area code.**<http://www.unitedwaydenver.org>
- 4) Hunger Free Colorado**  
<http://www.hungerfreecolorado.org>  
Phone Number: (855) 855- 4626  
Get connected to food and nutrition resources in Colorado by calling the Hunger Free Colorado hotline number.

## **UTILITIES**

- 1) LEAP** is a program that provides financial assistance for winter home heating costs. Apply through county Social Services Offices (Colorado listings were noted in this section).

## **NOTES**

For more information on eligibility for Medicare and Medicaid, refer to the Advocating for Financial Resources in chapter 19 (page 285)

Call (866) 432-8435  
<http://www.denvergov.org/leap>

- 2) **Catholic Charities** has emergency funding to help pay utilities. Contact (303)-742-0828 for additional information.  
4045 Pecos Street  
Denver, Colorado 80211  
<http://www.ccdenver.org>
- 3) **Public Service Company of Colorado.** Offers special payment plans for customers who need assistance due to temporary financial hardships.
- 4) **Various church organizations in the community**
- 5) **Contact United Way #211 or (303)-433-8900 for additional resources in your area.**  
<http://www.unitedwaydenver.org>

### **MEDICAL/MEDICATIONS/ EQUIPMENT**

Most medical insurance plans cover a designated amount for medical appointments, for medical equipment and for prescription medications. Even the best coverage does not cover 100% of these costs. Generic drugs are cheaper than brand name medications, but the costs can still add up. Medicare (Part A and B for medical, and Part D for

### NOTES

medications), and Medicaid (through County Social Services) can help with these costs, but do not cover 100% of costs. **For additional information regarding eligibility, for Medicare and Medicaid, please refer to the Advocating for Financial Resources Chapter in this book.**

**Providers:**

- 1) Colorado Indigent Care Program (CICP).** Call (303) 866-3513 for the closest participating facility; an intake is done to establish yearly deductible and co-pays.  
<http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1214299805914>
- 2) Metro Community Provider Network.** Sliding scale medical services at clinics around metro Denver. Contact (303) 761-1977.  
<http://www.mcpcn.org>
- 3) Denver Health Medical Center.** A sliding scale fee is used to determine fees for service, with clinics located throughout the City and County of Denver. Only Denver County residents may access these services. Contact (303) 436-6000 for additional information.  
777 Bannock Street  
Denver, Colorado 80204  
[www.denverhealth.org](http://www.denverhealth.org)
- 4) University of Colorado Health Sciences Center.** Provides

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Colorado residents with emergency treatment and medications, on a sliding scale fee. **Denver County residents need to access Denver Health Medical Center.** Contact (720) 848-2300, for additional information.

13001 East 17<sup>th</sup> Place  
Aurora, Colorado 80045  
<http://www.ucdenver.edu/anschutz/Pages/landing.aspx>

**5) Veterans Administration.**

Contact (303) 399-8020(extension #2895 or #5137) or determine eligibility.

1055 Clermont Street  
Denver, Colorado 80220  
<http://www.denver.va.gov/>

**6) Inter-Faith Task Force.** Has limited emergency funds for general and medical expenses (direct medical care and prescriptions). Must be residents of Arapahoe County (excluding Aurora), Jefferson County (south of Hampden Avenue), and northern Douglas County. Contact (303) 789-0501, for eligibility requirements.

3370 S. Irving Street  
Englewood, Colorado 80110  
<http://www.ifcs.org>

**7) Colorado Brain Injury Program.**

See chapter on BIAC and the Colorado Brain Injury Program.

NOTES

**8) Access information using the internet.** Contact the drug manufacturers directly, to inquire about programs for funding medication needs. Contact information and applications can be found on the internet (can access internet at the local library, if you do not have a computer). Other websites include: access [www.drugassistant.com](http://www.drugassistant.com) and/or [www.scbn.org](http://www.scbn.org). The National Conference of State Legislatures has a website that reviews all state medical and pharmaceutical assistance programs. Access them at <http://www.ncsl.org/issues.../health/state-pharmaceutical-assistance-programs.aspx>

**9) Resources available in the Denver area, for loaner medical equipment:**  
**The Assistance League of Denver**  
(303)-322-1688  
1400 Josephine Street  
Denver, Colorado 80206  
<http://www.denver.assistanceleague.co>

m

**The Dominican Sisters**  
(303)-322-1413  
2501 Gaylord Street  
Denver, Colorado 80205  
<http://www.dominicansisters.org/>

**The American Legion**  
(303)-914-5585  
7465 East 1<sup>st</sup> Avenue Suite D

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Denver, Colorado 80230  
<http://www.coloradolegion.org>

**10)** Contact the **United Way** (303)-  
433-8900 or #211 for additional  
resources.  
<http://www.unitedwaydenver.org>

NOTES

**THE BRAIN INJURY ALLIANCE OF COLORADO AND  
THE COLORADO BRAIN INJURY PROGRAM**

## THE BRAIN INJURY ALLIANCE OF COLORADO

BIAC was originally named the Colorado Head Injury Foundation, and was founded in 1980. It is a private, not-for-profit corporation serving persons with brain injury, their families, and the community. BIAC'S mission is to improve the quality of life for people with brain injuries by connecting survivors with resources to help navigate the path of rehabilitation

- BIAC's activities are made possible by grants, donations, sponsorships, and special events. The organization offers the following services and activities:
- **Recreation Programs: Challenge By Choice** – Week-long educational, social and recreational and creative opportunities for adults with brain injury
- **Brain Injury Professional Networks (BIPNs)** – Groups of providers who work together to enhance the system of supports for survivors across the state
- **Colorado Brain Injury Program Adult Services** - Application intake and eligibility determination for the state-wide program which provides case management services to adults who have sustained a TBI
- **Colorado Youth Brain Injury Connections** – A part of the Colorado Brain Injury Program,

### NOTES

*BIAC is a private, not-for-profit corporation serving persons with brain injury, their families, and the community.*

BIAC provides state-wide intake and referral of youths in the community with *any type of brain injury* to receive care coordination and education consultation

- **Conference** - Annual educational event and networking opportunity for individuals with brain injuries, families and professionals
- **Community Outreach & Education** – Presentations, exhibits, and seminars to encourage prevention and increase public awareness of brain injury (*Calendar*)
- **Energy Outreach Colorado (EOC)** – Financial assistance with heating and electricity bills for individuals and families facing life changes after brain injury
- **Information and Resources** – Support, information and referral
- **Breaking News Emails** - Regular communication including brain injury related articles, news, and information on state-wide events and meetings (sign up for mailing list on right side of any page)
- **Pikes Peak Challenge** – Annual hike to the summit of Pikes Peak to increase brain injury awareness and raise money to support our programs
- **Public Policy** – State and federal legislative advocacy to encourage policies for brain injury prevention and establishment of an organized system of care, which includes appropriate services and benefits for persons with brain injury

## NOTES



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

The Brain Injury Alliance of Colorado provides intake, eligibility and referral services for the program.

- **Resource Directory** – Database of brain injury related resources, available for public access on our website
- **Support Groups** – State-wide meetings to provide education, recreation, and emotional support to individuals with brain injury, family members, and friends.

You can become an active part of BIAC. Join a local support group, volunteer as a camp counselor or become involved in committee work. Visit our website at [www.biacolorado.org](http://www.biacolorado.org) or call us at 303-355-9969.

## **THE COLORADO TRAUMATIC BRAIN INJURY PROGRAM**

The Colorado Brain Injury Program was established in 2002 to provide statewide coordination and services to children and adults with TBI, support educational programs about TBI, and to fund TBI research.

The program is supported through surcharges on traffic ticket violations for speeding, DUI, DWI and violators of the children's motorcycle helmet law. It is administered through the Colorado Department of Human Services' Division of Vocational Rehabilitation and has a volunteer community Board of Directors, appointed by the Governor. The fund contracts with various government and private agencies to meet its goals.

### **Services**

## NOTES

## NOTES

Individuals receiving assistance from the Colorado Brain Injury Program receive care management services. Care management provides clients with skills they can use through their lifetime and connects them to community resources. The adult services offered by Colorado Brain Injury Program are offered state-wide to all Coloradans who are living with the effects of a Traumatic Brain Injury (TBI). All services are available free of charge. The Brain Injury Alliance of Colorado provides assistance with the application process and determines eligibility for all who apply. Once accepted, Rocky Mountain Human Services provides case management to each individual. Some features of the program include:

- Case management tailored to your individual needs
- Case management services to support rehabilitation through:
  - Connecting individuals to resources
  - Assistance in finding affordable care
  - Providing support and advocacy
  - Continuity of care
  - Promotion of independence and integration through self-advocacy\*
  - Opportunities to meet face to face with a Brain Injury

## NOTES

Support Specialist in your community

- Staff who are Certified Brain Injury Specialists and continue to receive ongoing education on brain injury to best support clients, family and the community
- Focus on building awareness around TBI through outreach efforts across the state

### \*What is Self-Advocacy?

Self advocacy is learning how, when, and where to make decisions that are in your own best interest.

It involves:

- Knowing your rights and options for accommodations
- Being assertive to make sure your rights are respected
- Knowing and talking about what you want
- Being confident in making choices

Being your own self advocate can build a path that will guide you toward your most desired life outcomes. Your Brain Injury Support Specialist (BISS) will partner with you to develop self-advocacy skills.

### **What Services Can A Brain Injury Support Specialist Help to Access?**

#### Cognition/Mental Health

- Connection to providers in your community
- Identification of affordable services
  - Sliding scale
  - Accepts Medicaid/Medicare
  - Assistance finding funding for services

## NOTES

- Access to Support Groups
  - For family and survivors
- Assistive Technology Library
- Group psychotherapy offered
- Social skills
- Self Advocacy skills

### Daily Living/Education/Home

- Assistive Technology/Computer training
- Connection to Employment Resources
- Employment conferences and workshops
- Budget Assistance and Financial Management
- Connection to Resources to support independent life skills/organization

### Benefits

- One on one support to assist with applications and/or applying for benefits
- Income benefits
  - Social Security Disability Income, Social Security Income, Aid to the Needy and Disabled (A and D)
  - LEAP/Energy Outreach Colorado (Utility assistance)
  - Food Stamps
  - Waiver Programs
  - Health Insurance
    - Medicaid, Medicare, etc.

### Physical Well Being/Health

- Identify resources for adaptive equipment/Durable Medical Equipment
- Assistance finding potential funding for:



- Gym membership
- Yoga
- Water therapy
- Massage
- Chiropractic
- Acupuncture
- Physical therapy
- Identification of resources available for vision/physical therapy
- Dental

### **Classes & Workshops**

Individuals in the brain injury community have access to a variety of programs, workshops, and classes related to brain injury. State-wide classes and workshops cover topics such as:

- Budgeting and money management
- Navigating employment support
- Organization
- Social skills/networking

### **Program Eligibility**

To be eligible for Colorado Adult TBI Connections, you must meet all the following criteria:

- Have a medically documented traumatic brain injury, resulting in ongoing impairment of cognitive or physical function
  - **Medical documentation is currently accepted from the following sources: MD, DO, PA-C, NP. Documentation also accepted from practitioners with a Ph.D., Psy.D., or Ed.D. who are currently *licensed at the***

## NOTES

***doctoral level as  
Psychologists.***

- Be a resident of Colorado (physically living in the state of Colorado)
  - Complete a lawful presence verification process by signing the included affidavit in the application, presenting a valid form of proof of citizenship/lawful presence, and presenting a valid form of identification.

**Commonly accepted documents which serve as both Proof of Citizenship/Lawful Presence AND Identification include:**

- Valid Colorado Driver's License or ID Card
- Out of State Driver's License (excluding HI, IL, MD, NE, NM, UT, or WA)
- U.S. Passport
- Foreign Passport with photo or U.S. Visa
- Valid Military ID

[For More information about accepted documents, please click here](#)

- Complete and return the application

A traumatic brain injury (TBI) is defined as an injury to the brain caused by an external force. Causes of TBI include, but are not limited to: falls, motor vehicle-traffic, motorcycle accident, struck by/against, sporting related injury, assaults, and blast injuries.

NOTES

Causes of brain injury that ***do not qualify*** for assistance from the Colorado Brain Injury Program are: anoxia, stroke, aneurysm, congenital abnormality, disease, and surgical intervention.

### **Program Guidelines**

Eligible applicants will be served on a first come, first serve basis  
A program participant may receive case management services for a period of two years.

### **Application Process**

Please download, print, and complete the appropriate form from the hyperlinks below. Please be informed that the application process can take up to 30 days or more, depending on the availability of Medical Records documenting TBI. Once we have all the information needed to fully process an application it is approved and sent to Rocky Mountain Human Services TBI Support. We will call you or inform you by letter if there is additional information needed to process your application.

- [First Time Application](#)
- [First Time Application \(Spanish\)](#)

### **Program History and Structure**

The Colorado Brain Injury Program is a part of the Colorado Department of Human Services, Division of Vocational Rehabilitation and is significantly funded by the Colorado Brain Injury Program. The Colorado Brain Injury Program was established in 2002 to provide case management and services to children and adults with traumatic brain injuries, provide education, and fund research

NOTES

NOTES

regarding brain injury in Colorado. Revenue for the Colorado Brain Injury Program comes from surcharges placed on traffic ticket convictions for speeding, the children's helmet law, DUI, and DWAI. The Colorado Department of Human Services (CDHS) contracts with The Brain Injury Alliance of Colorado to provide application intake and eligibility for the Case Management and Services portion of the Colorado Adult TBI Connections Program. If you have questions about the program or require assistance with completing your application, please contact our intake coordinator, Max Winkler

## **REFERENCES**

BIAC website, [www.biacolorado.org](http://www.biacolorado.org)

BIAC brochure

Colorado Brain Injury Program brochure

Colorado Brain Injury Program website, [www.tbicolorado.org](http://www.tbicolorado.org)

Colorado TBI Program Report to the General Assembly, January – December, 2007



## Community Resources

### **Resources for Parents:**

- **Brain Injury Alliance of Colorado (BIAC)**  
1385 South Colorado Boulevard  
Suite 606 Building A  
Denver, Colorado 80222  
Phone: 1-800-955-2443 or (303) 355-9969  
[www.biacolorado.org](http://www.biacolorado.org)
- **Brain Injury Association**  
Phone: 1-800-444-6443  
[www.biausa.org](http://www.biausa.org)
- **Brain Injury: A Manual for Educators**  
<http://www.cde.state.co.us/HealthAndWellness/BrainInjury.htm>
- **BrainSTARS Manual**, (2002), Calvery & Dise-Lewis, Children's Hospital, Denver, CO (available through Lash & Associates Publishing)
- **CDE Concussion Guidelines**  
<http://www.cde.state.co.us/healthandwellness/braininjury>
- **Colorado Department of Education:**  
**Brain Injury: A Manual for Educators**  
<http://www.cde.state.co.us/cdesped/sd-tbi>
- **Colorado Traumatic Brain Injury Trust Fund**  
1575 Sherman Street 4<sup>th</sup> floor  
Denver, CO 80203  
Phone: 1-888-331-3311  
Look into the Youth Brain Injury Connection (YBIC), funded by the TBI Trust Fund, accessed through BIAC.  
[www.tbicolorado.org](http://www.tbicolorado.org)

- **Colorado Website:**  
[www.cokidswithbraininjury.com](http://www.cokidswithbraininjury.com)
- **Division of Vocational Rehabilitation**  
Phone: (303) 866-4150 or 1-866-870-4595  
<http://www.colorado.gov/cs/Satellite/CDHS-SelfSuff/CBON/1251580884712>
- **Educational Dimensions of Acquired Brain Injury**, (1994),  
Savage & Wolcott (Eds.), Austin, TX: PRO-ED, Inc.
- **Elvin: The Elephant Who Forgets** by Heather Snyder
- **Health Care Program for Children with Special Needs (HCP)**  
4300 Cherry Creek Drive South  
Denver, CO 80246-1530  
Phone: 1-800-886-7689 ext. 2370 (main line) or (303) 692-2370  
Email: [cdphe.psdrequests@state.co.us](mailto:cdphe.psdrequests@state.co.us)  
[www.colorado.gov](http://www.colorado.gov)
- **Lash and Associates Publishing**  
[www.lapublishing.com](http://www.lapublishing.com)
- **PEAK - Parents Education and Assistance for Kids**  
A federally funded, independent agency helping parents understand and better utilize the special education process to develop appropriate educational programs for children and youth with disabilities in Colorado.  
611 North Weber Suite 200  
Colorado Springs, CO 80903  
Phone: (719) 531-9400 or 1-800-248-0251 (Colorado only)  
or email at [parentadvisor@peakparent.org](mailto:parentadvisor@peakparent.org) or  
[info@peakparent.org](mailto:info@peakparent.org)  
[www.peakparent.org](http://www.peakparent.org)

- **PEP - Parents Encouraging Parents**

Conferences sponsored by the Colorado Department of Education for parents of children with disabilities. For more information contact:

**PEP** Hotline: Colorado Department of Education  
1560 Broadway Suite 1175

Denver, CO 80202

Phone: (303) 866-6843

Email: DeLinda Rose [rose\\_d@cde.state.co.us](mailto:rose_d@cde.state.co.us)

<http://www.cde.state.co.us/cdesped/PEP.asp>

**Resources for Veterans:**

- **American Legion, The**

The American Legion is the nation's largest veteran's organization providing free, professional assistance, for any veteran and veteran's survivor, to file and pursue claims before the DVA. It also assists deployed service member's families with practical and emotional support, and it offers temporary financial assistance to help families meet their children's needs.

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

- **AMVETS**

Provides information and counseling to veterans on matters such as education, disability compensation, employment, hospitalization, pension, and other benefits.

<http://www.amvets.org>

- **Blinded Veterans Association (BVA)**

The Blinded Veterans Association strives to locate blinded veterans who need services, guide blinded veterans through the rehabilitation process, and act as advocates for them and their families in both the private and public sectors. The



organization promotes access to technology and the practical use of the latest research.

**[www.bva.org](http://www.bva.org)**

- **Client Assistance, Protection and Advocacy (CAP)** Each state offers CAP and Protection Advocacy (P&A) Systems. These programs offer valuable resources to people with traumatic brain injury and their families who meet eligibility criteria. In the event an individual is not found eligible for services, the CAP or P&A System will provide assistance to locate other resources.
- **Defense and Veterans Brain Injury Center**  
[www.dvbic.org](http://www.dvbic.org)
- **Department of Veterans Affairs**  
[www.va.gov](http://www.va.gov)
- **Disabled American Veterans (DAV)**  
Provides counseling services to veterans with disabilities and advocates on behalf of the veterans.  
<http://www.dav.org>
- **“Homecoming: Dealing with Changes and Expectations”** by Ilona Pivar, Ph.D.
- **“Homecoming: Tips for Reunion”** by Pamela J. Swales, Ph.D.
- **Homeless Veterans Program**  
<http://www.va.gov/homeless>
- **Iraq War Clinician Guide**, 2<sup>nd</sup> Edition; only available online at <http://www.ncptsd.va.gov>

- **Military Order of the Purple Heart of the USA (MOPH)**

The Military Order of the Purple Heart represents combat wounded veterans in the Nation's Capitol. This means that the voice of the combat wounded veteran is heard in Congress, at the Department of Defense, and at the Department of Veteran's Affairs. The MOPH is constantly alert to any legislation which affects its members. The MOPH also works on combat veterans' behalf.

(703) 642-2054

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

- **National Amputation Foundation, Inc. (NAF)**

The National Amputation Foundation (NAF) offers valuable assistance to veterans of World War I, II, Korea, the Vietnam Conflict, Desert Storm, and Iraqi Freedom. The foundation has expanded its facilities and also includes civilian amputees.

(516) 887-3600

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

- **National Center for PTSD**

[www.ptsd.va.gov](http://www.ptsd.va.gov)

- **National Military Family Association (NMFA)**

Serving the Families of Those Who Serve, The National Military Family Association serves the families and survivors of the seven uniformed services through education, information and advocacy. NMFA is the only national organization dedicated to identifying and resolving issues of concern to military families.

(800) 260-0218

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

- **Paralyzed Veterans of America (PVA)**  
Provides services to veterans with disabilities on matters such as service-connected disability compensation, loan guarantees, medical care, educational benefits, government insurance, and benefit claims and appeals.  
<http://www.pva.org>
  
- **Physical Medicine & Rehabilitation Services (PM&RS)  
National Program Office Special Programs**  
1-813-972-7688  
[www.polytrauma.va.gov](http://www.polytrauma.va.gov)
  
- **Polytrauma Rehabilitation Centers**  
[www.polytrauma.va.gov](http://www.polytrauma.va.gov)
  - **Minneapolis**  
1-866-414-5058 x3235  
[www.polytrauma.va.gov/facilities/Minneapolis.asp](http://www.polytrauma.va.gov/facilities/Minneapolis.asp)
  
  - **Palo Alto Health Care System**  
(650) 493-5000 x66764  
[www.polytrauma.va.gov/facilities/Palo\\_Alto.asp](http://www.polytrauma.va.gov/facilities/Palo_Alto.asp)
  
  - **Richmond**  
1-804-675-6548  
[www.polytrauma.va.gov/facilities/Richmond.asp](http://www.polytrauma.va.gov/facilities/Richmond.asp)
  
  - **Tampa**  
1-813-979-3671  
[www.polytrauma.va.gov/facilities/Tampa.asp](http://www.polytrauma.va.gov/facilities/Tampa.asp)
  
  - **San Antonio**  
(219) 617-5300 x18262

[www.polytrauma.va.gov/facilities/San\\_Antonio.asp](http://www.polytrauma.va.gov/facilities/San_Antonio.asp)

- **“Returning from the War Zone: A Guide for Families of Military Personnel”** (National Center for PTSD); only available online at <http://www.ncptsd.va.gov>
- **TRICARE Health Benefits**  
<http://www.tricare.mil/>
- **Veterans Affairs Health Benefits**  
[www.va.gov/healthbenefits](http://www.va.gov/healthbenefits)
- **Veterans of Foreign Wars (VFW)**  
Provides counseling services to veterans with disabilities and advocates on behalf of the veterans.  
<http://www.vfw.org/Assistance>
- **Veterans Industry**  
<http://www.va.gov/health/cwt/>
- **Vocational Rehabilitation and Employment Program (VR&E)**  
Website: [www.vba.va.gov/bln/vre](http://www.vba.va.gov/bln/vre)  
Application: [www.vabenefits.vba.va.gov/vonapp/main.asp](http://www.vabenefits.vba.va.gov/vonapp/main.asp)
- **“Warzone-Related Stress Reactions: What Families Need to Know”** by Julia M. Whealin, Ph.D.

### **Technology Resources:**

- **Ablelink Technologies**

618 North Nevada Avenue  
Colorado Springs Co 80903  
Phone: (719) 592-0347  
Email: [info@ablelinktech.com](mailto:info@ablelinktech.com)  
[www.ablelinktech.com](http://www.ablelinktech.com)

- **Assistive Technology Partners**  
(Denver, CO)  
MAIN: 303.315.1280  
CLINIC: 303.315.1282  
<http://www.ucdenver.edu/academics/colleges/medicalschoo/Programs/atp/Pages/AssistiveTechnologyPartners.aspx>
- **Colorado Assistive Technology Partners**  
University of Colorado at Denver and Health Sciences Center  
601 East 18<sup>th</sup> Avenue Suite 130  
Denver, Colorado 80203  
Phone: (303) 315-1282  
Email: [GeneralInfo@AT-Partners.org](mailto:GeneralInfo@AT-Partners.org)  
[www.AssistiveTechnologyPartners.org](http://www.AssistiveTechnologyPartners.org)

### **Housing Resources:**

- **Atlantis Community, Inc.**  
Available to provide consultation for other groups to complete projects  
201 S. Cherokee  
Denver, Colorado 80223  
Phone: (303) 733-9324  
<http://www.accil.net/Atlantis.html>
- **Center for Accessible Housing School of Design**

Focus on planning, design, production, construction and renovation, management, financing, and marketing of housing to meet the needs of people with disabilities.

North Carolina State University Box 8613

Raleigh, NC 27695-8613

Phone: (919) 515-0825 Voice and TDD

<http://www.ncsu.edu/ncsu/design/cud/>

- **Colorado Association of Homes and Service for the Aging (CAHSA)**

1888 Sherman Street Suite 610

Denver, Colorado 80203

Phone: (303) 837-8834

Email: [cahsa@aol.com](mailto:cahsa@aol.com)

- **HUD Region VIII**

Region VIII covers Montana, Wyoming, Utah, Colorado, South Dakota and North Dakota.

Phone: (303) 844-4061 Monday-Friday 8:00 a.m. to 4:30 p.m.

Address: 1405 Curtis, Denver, CO 80202

<http://www.hud.gov/offices/pih/pha/contacts/states/co.cfm>

- **HUD Region VI**

New Mexico is included in Region VI. Ft. Worth, Texas

Phone: (817) 885-5531

<http://www.hud.gov/offices/pih/pha/contacts/states/co.cfm>

- **Independent Living Research Utilization**

Phone: (713) 520-0232

2323 S. Shepherd, Suite 1000

Houston, Texas 77019

Phone: (713) 520-0232

<http://www.ilru.org>

### **Home Mortgage for Low Income:**

- **Colorado Department of Revenue (Annual) Tax/Rent/Heat Rebate**

You can apply retrospectively for two years. Eligibility is based on: residency, non-dependency, age or disability, payment of property tax, rent, heat expenses, and income. \$7,500 for single persons and \$11,200 for married persons. Phone: (303) 534-1209 or 1-800-332-2087

- **Colorado Housing Assistance Corporation**

Phone: (303) 572- 9445

<http://www.coloradohousingassistance.org/>

- **Colorado Housing and Finance Authority**

Phone: (303) 297-2432

<http://www.chfainfo.com/>

- **Public Housing Agencies**

Public Housing Authorities (PHA's) are available throughout the state. PHA's have both family and elderly units; however, the availability changes frequently. Generally, the PHA's have units only within their geographic area which will help you if you are restricting your search to a specific area. Each PHA has different regulations.

You may contact the Colorado Division of Housing at 303-866-2033

### **Assistance for Legal Issues related to Housing:**

- **Colorado Civil Rights Division Central Office**

Phone: (303) 894-2997 or (800) 262-4845

TDD: (303) 894-7832

<http://www.dora.state.co.us/civil-rights>

- **Metro Denver Fair Housing Center**  
2855 Tremont Place  
Denver, Colorado 80205  
Phone: (303) 296-6949  
<https://dmfhc.org/fair-housing/>
- **U.S. Department of Housing and Urban Development**  
1670 Broadway  
Denver, Colorado 80202  
Phone: (303) 672-5437 or (800)-877-7353  
<http://www.portal.hud.gov/hudportal/HUD>

**Dispute Assistance Resources:**

- **Community Housing Services**  
1212 Mariposa Street  
Denver, Colorado 80204  
Phone: (303) 831-1750  
<http://www.chsico.org>
- **Legal Center for people with Disabilities**  
455 Sherman Street  
Denver, Colorado 80203  
Phone: (303) 722-0300  
<http://www.thelegalcenter.org/>

**Referral Resources:**

- **Disability Information and Referral Services (DIRS)**  
Phone: 420-2942 or 1-800-255-3477 (TDD)
- **United Way Information and Referral**  
Mile High United Way advances the common good by creating opportunities for a better life for all in our community. Our focus is on school readiness, youth success and adult self-sufficiency



- the building blocks for a good quality of life. We work with hundreds of local nonprofit partners, government agencies, policy-makers, and businesses to deliver services to the Denver-Metro area. Our 2-1-1 call center offers a free, multi-lingual service that refers callers to non-emergency health and human services. To access these services, dial 2-1-1 on your phone or download the app (Colorado 211) for iPhone or Android devices and be instantly connected to Denver services.

Phone: (303) 433-8900 or #211  
<http://www.unitedwaydenver.org>

### **Home Repair Resources:**

- **Brothers Redevelopment**  
Phone: (303) 202-6340  
<http://www.brothersredevelopment.org>

### **Home Buying Assistance for people with disabilities in the Denver /Metro Area:**

- **Division of Vocational Rehabilitation**  
Division of Vocational Rehabilitation Administrative Office  
Toll Free at 866-870-4595 or, in the Denver metro area, call 303-866-4150.  
<http://www.cdhs.state.co.us/dvr/>
- **Hero Alliance**  
11177 West 8<sup>th</sup> Avenue  
Lakewood, Colorado 80215  
Phone: (720) 941-8901 or 1-888-401-4376  
[www.heroalliance.org](http://www.heroalliance.org)

- **Weatherization and Repair assistance**  
Contact county Social Service agency

### **Transportation Resources:**

- **Colorado Transit**  
[www.apta.com/links/state\\_local/co.cfm](http://www.apta.com/links/state_local/co.cfm)
- **eRideShare**  
[www.eRideShare.com](http://www.eRideShare.com)
- **Office of Civil Rights**  
Federal Transit Administration U.S. Department of Transportation  
Phone: 888-446-4511 (voice/relay)  
[www.fta.dot.gov/ada](http://www.fta.dot.gov/ada)

### **Recreational Resources**

- **Boulder Parks and Recreation**  
(Boulder, CO)  
EXPAND Journeys: Fitness, leisure and adventure programs for adults with mild brain injury.  
Phone: 303-413-7200  
[www.bouldercolorado.gov](http://www.bouldercolorado.gov)  
(*click* DEPARTMENTS *click* PARKS AND RECREATION  
*Choose a Category* EXPAND)
- **Denver Parks and Recreation – Special Needs Program**  
(Denver, CO)  
TRAC: Transition to Recreational Activities in the Community provides 1:1 services as individuals with disability learn to use Parks and Recreation center and programs independently.  
Phone: 303-839-4801 or 303-839-4803  
[www.denvergov.org/parksandrec](http://www.denvergov.org/parksandrec)

Search: Special Needs Program

- **Fort Collins Parks and Recreation -Adaptive Recreation Opportunities**  
(Fort Collins, CO)  
Phone: 970-221-6655  
[www.fcgov.com/aro](http://www.fcgov.com/aro)
- **Parks and Recreation Departments**  
(Ask if your local department has a Therapeutic Recreation Specialist or a Special Needs Program) The following programs have a strong track record of working with persons with Brain Injury.

**TBI Support Groups:**

- **Brain Injury Alliance of Colorado (BIAC)**  
(Denver, CO)  
Phone: 303-355-9969 or 800-955-2443  
[www.biacolorado.org](http://www.biacolorado.org)

**Outdoor Recreation and Sports:**

- **Adaptive Action Sports**  
(Gunnison, CO)  
Phone: 619-770-8262 or 760-846-1076  
<http://www.adacs.org>
- **Adaptive Adventures**  
(Evergreen, CO)  
Phone: 303-679-2770 or 877-679-2770  
[www.adaptiveadventures.org](http://www.adaptiveadventures.org)
- **Adaptive Sports Association of Durango**  
(Durango, CO)  
Phone: 970-259-0374

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

- **Adaptive Sports Center of Crested Butte**  
(Crested Butte, CO)  
Phone: 970-349-2296  
[www.adaptivesports.org](http://www.adaptivesports.org)
- **Breckenridge Outdoor Education Center (BOEC)**  
(Breckenridge, CO)  
Phone: 970-453-6422  
[www.boec.org](http://www.boec.org)
- **CADENCE, The Center for Therapeutic Riding**  
(Durango, CO)  
Phone: 970-749-7433  
<http://dev.cadenceriding.org/>
- **Challenge Aspen**  
(Snowmass Village, CO)  
Phone: 970-923-0578  
<http://www.challengeaspen.org>
- **Colorado Challenge Center**  
(Littleton, CO)  
Phone: 303-933-8788, ask for Paula Schutpatch
- **Colorado Discover Ability Integrated Outdoor Adventure**  
(Grand Junction, CO)  
Phone: 970-257-1222  
[www.coloradodiscoverability.com](http://www.coloradodiscoverability.com)

- **Colorado Division of Wildlife**  
 (Denver, CO)  
 Phone: 303-291-7485  
 For information on accessible sites, free fishing licenses and more, visit their website  
[www.wildlife.state.co.us](http://www.wildlife.state.co.us)  
 Search: Disability Information then select Disabled Accessibility
- **Colorado Therapeutic Riding Center, Inc.**  
 (Longmont, CO)  
 Phone: 303-652-9131  
[www.ctrinc.org](http://www.ctrinc.org)
- **Craig Hospital**  
 (Englewood, CO)  
 Phone: 303-789-8000  
[www.craighospital.org](http://www.craighospital.org)
- **Cuchara Mountain Sports Center for the Disabled**  
 (La Junta, CO)  
 Phone: 719-384-6580  
 Email: [roycethePT@juno.com](mailto:roycethePT@juno.com)
- **Foresight Ski Guides, Inc.**  
 (Denver, CO)  
 Phone: 303-506-3859  
[www.foresightskiguide.org](http://www.foresightskiguide.org)
- **Golf 4 Fun**  
 (Denver, CO)  
 Phone: 303-995-1353  
<http://www.golf4thedisabled.org/>
- **Ignite Adaptive Sports**  
 (Boulder, CO)

Phone: 303-506-0927 or 303-506-6738  
<http://public.igniteadaptivesports.org/>

- **Keystone Adaptive Center**

Phone: 370-453-5633 or 800-383-2632  
<http://www.keystoneressort.com/ski-and-snowboard/ski-and-ride-school/adaptive-programs.aspx>

- **Medicine Horse Center Equine Assisted Therapies**

(Mancos, CO)  
Phone: 970-533-7403  
[www.medicinehorsecenter.org](http://www.medicinehorsecenter.org)

- **National Sports Center for the Disabled**

Phone: (303) 316-1518 or (970) 726-1518  
[www.nscd.org](http://www.nscd.org)

- **Pikes Peak Therapeutic Riding Center**

(Elbert, CO)  
Phone: 719-495-3908  
[www.pptrc.org](http://www.pptrc.org)

- **Professional Association of Therapeutic Horsemanship International (PATH)**

(Denver, CO)  
Phone: 800-369-7433  
<http://www.pathintl.org/>

- **Rocky Mountain Handicapped Sportsman's Association**

(Denver, CO)  
Phone: 303-934-9540  
[http://www.spokesnmotion.com/programs\\_links/resource.html?content\\_item\\_id=206](http://www.spokesnmotion.com/programs_links/resource.html?content_item_id=206)

- **Telluride Adaptive Sports Program**  
(Telluride, CO)  
Phone: 970.728.5010  
[www.tellurideadaptivesports.org](http://www.tellurideadaptivesports.org)
- **U.S. Association of Blind Athletes (USABA)**  
(Colorado Springs, CO)  
Phone: 719.866.3224  
[www.usaba.org](http://www.usaba.org)
- **Vail Adaptive Ski Program**  
(Vail, CO)  
Phone: 970-754-3264  
[www.vail.snow.com/winter/ss.adaptive.asp](http://www.vail.snow.com/winter/ss.adaptive.asp)
- **Visually Impaired & Blind Skiers (VIBeS)**  
(Colorado Springs, CO)  
Phone: 719-593-1982  
[www.coloradovibes.org](http://www.coloradovibes.org)

**Arts and Culture Resources:**

- **ArtReach**  
(Denver, CO)  
Phone: 303-433-2882  
[www.artreachdenver.org](http://www.artreachdenver.org)
- **Art Therapy Association of Colorado** (Denver, CO)  
Phone: 720-874-8686  
[www.arttherapy-co.org](http://www.arttherapy-co.org)
- **Colorado Association of Music Therapy**  
(Littleton, CO)

Email: [info@musictherapycolorado.org](mailto:info@musictherapycolorado.org)  
[www.musictherapycolorado.org](http://www.musictherapycolorado.org)

- **Horticultural Therapy Institute**  
(Denver, CO)  
Phone: 303-388-0500  
[www.htinstitute.org](http://www.htinstitute.org)
- **VSA Arts Colorado- (Formerly A Very Special Arts)**  
(Denver, CO)  
Phone: 303-777-0797  
<http://accessgallery.org/>

### **Alternative and Complementary Medicines Resources:**

- **Healthfinder**  
Government site that includes information on hot topics, medical dictionaries, and online journals. This site also includes content in Spanish.  
[www.healthfinder.gov](http://www.healthfinder.gov)
- **Intelihealth**  
Includes information on drugs, diseases and other medical conditions. Includes a link to Harvard Medical School's Consumer Health Information.  
[www.intelihealth.com](http://www.intelihealth.com)
- **NCCAM Complementary and Alternative Medicine (CAM) Citation Index**  
Searchable database of journal citations on complementary and alternative medicine.  
[www.nccam.nih.gov](http://www.nccam.nih.gov)



- **PDR.net**  
The Physician's Desk Reference site contains up to date drug information. This site can also be used to check for drug interactions  
[www.pdr.net](http://www.pdr.net)
- **WholeHealthMD**  
Founded to provide consumers with professional guidance on the many benefits of integrative medicine. Check out the Healing Center and Reference Library for specific ailments.  
[www.wholehealthmd.com](http://www.wholehealthmd.com)

### **Sources of Information on Dietary Supplements:**

- **Office of Dietary Supplements (ODS), NIH**  
E-mail: [ods@nih.gov](mailto:ods@nih.gov)  
[ods.od.nih.gov](http://ods.od.nih.gov)
- **U.S. Food and Drug Administration (FDA)**  
Center for Food Safety and Applied Nutrition  
Toll-free in the U.S.: 1-888-723-3366  
[www.fda.gov](http://www.fda.gov)

### **Suicide Prevention Resources:**

- **American Association of Suicidology**  
<http://www.suicidology.org>
- **American Foundation for Suicide Prevention**  
<http://www.afsp.org>
- **National Suicide Prevention Lifeline**  
Phone: 1-800-273-TALK
- **Suicide Prevention Resource Center**  
<http://www.sprc.org>

## **MY SELF ADVOCACY INFORMATION SHEET**

Take this with you to meetings or other self advocacy activities. You can copy this sheet and put it in your day planner if you wish. Use pencil for the things that may change.

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

\_\_\_\_\_

PHONE NUMBER(S): \_\_\_\_\_

### **EMERGENCY CONTACT:**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

### **MY PRIMARY PHYSICIAN:**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

### **OTHER PHYSICIAN:**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

### **MY FUNDING INFORMATION:** (insurance, Medicaid, etc.)

Plan: \_\_\_\_\_

Case Manager, if applicable: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

My policy or plan #: \_\_\_\_\_

Other Funding info: \_\_\_\_\_

### **OTHER IMPORTANT MEMBERS OF MY TEAM** (therapist, case manager, friend):

Name and role/job: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Name and role/job: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

(my self advocacy info, pg. 2.)

Name and role/job: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Name and role/job: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Name and role/job: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

MY CURRENT MEDICATIONS (use pencil – keep up-do-date):

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

Name: \_\_\_\_\_ Dose: \_\_\_\_\_ Purpose: \_\_\_\_\_

**OTHER IMPORTANT PEOPLE OR AGENCIES AND NUMBERS:**

1.

2.

3.

4.

5.