

Challenges,  
Changes,  
and Choices:  
A Brain Injury  
Guide for Families  
and Caregivers



Carolyn A. Rocchio

Family Member of a Person  
with a Brain Injury

Founder of the Brain Injury  
Association of Florida

# Contents

Introduction .....	1
The Immediate Aftermath .....	2
Tips for Families and Caregivers .....	2
The Recovery Team .....	5
Later Days in the Hospital .....	6
Tips for Families and Caregivers .....	7
The Rehabilitation Phase .....	8
Tips for Families and Caregivers .....	9
Community Living .....	10
Tips for Families and Caregivers .....	12
Returning to Work .....	13
Tips for Families and Caregivers .....	14
Returning to School .....	14
Considerations for Spouses and Children of People with Brain Injury .....	15
Paying for Services .....	16
Public Programs to Pay for Health Services .....	16
Private Health Insurance .....	17
Public Programs Offering Direct Financial Support .....	18
Tips for Families and Caregivers .....	19
Housing and Long-Term Supports .....	20
Legal Issues .....	21
Outcomes .....	22
Become an Advocate .....	23
Information and Resources .....	24



## Introduction

According to the Centers for Disease Control and Prevention (CDC), 1.4 million Americans sustain a brain injury each year. Brain injuries may result from falls, motor vehicle-traffic crashes, assaults, and other incidents in which the head is forcefully struck or an object penetrates the skull. For some, the life-threatening nature of the injuries requires immediate hospitalization for extended treatment and rehabilitation. Others seen in emergency departments after sustaining a blow to the head, with or without loss of consciousness, are discharged with little or no information about the life-changing impact the injury may have in the weeks or months to come. Although this booklet is designed to assist families and caregivers of persons with severe brain injury, those whose injuries are categorized as mild may also find some of the tips and information beneficial. Each brain injury is different to some extent, so none of this information will apply to all families: choose the information relevant to your loved one.

This booklet is provided by the Brain Injury Association of America to prepare you for the journey toward recovery. In the following pages you will find information about the nature and consequences of brain injury; resource information to help with decision making; and practical suggestions about ways to help your family member, take care of yourself, and enlist the support of others.

## The Immediate Aftermath

The early hours, days and weeks after injury can be very confusing. You are immersed in the world of the intensive care unit (ICU) with its unfamiliar lifesaving equipment and techniques as well as different medical professionals. A “good day” of progress may be followed by a “down” day. Setbacks are common and do not necessarily imply a permanent reversal.

### *Tips for Families and Caregivers*

You may find it emotionally devastating when visitation restrictions do not allow your constant bedside vigil. But limiting visitation permits the staff to carry out many necessary procedures. As patients stabilize, they are normally transferred to a patient room within the general hospital population where visitation rules are more lenient.

Family members gathered in a waiting room or the patient’s room can put their time to good use by deciding amongst themselves who is most accessible for daily updates from the medical and nursing staff. Start a notebook for this information, collect business cards from the physicians treating your family member, and record questions. This information can then be passed along to other family members and friends.

During these first days, ask family and friends to help with chores you are unable to leave the hospital to do:

- Banking
- Laundry
- Preparing meals
- Mowing the lawn
- Driving the carpool
- Taking care of small children
- Taking care of pets



The person with the injury may need help for some time to come—and so may you—so look after yourself. Get enough sleep. Eat properly. Renew yourself in whatever way is meaningful to you. You will need your health and emotional well-being as your family member with the injury moves out of the critical phase and you become more involved in his or her rehabilitation.

When you visit your family member, even during an unresponsive stage, talk about current events, friends, family, and details about when, where, and why he or she is hospitalized. Reassure him or her that everything is being done to help.

Meanwhile, every member of the immediate and extended family will cope with the event in his or her own way. Some will choose to immerse themselves in the day-to-day struggle. Others may be unable to visit or be an integral part of the family from time to time. Everyone should respect the others' feelings. Given time, each person will develop coping mechanisms that work for him or her.

Begin collecting information you will need to manage insurance, determine eligibility for various governmental benefits, and file any recommended litigation. Have available

as many of the following items as possible:

- Social Security card (application for Social Security Administration programs should begin at once—check with the social services department of the hospital)
- Insurance card(s) (a copy of all policies in force, if possible)
- Driver's license
- Birth certificate
- School records
- Work records (when filing for Worker's Compensation)
- Tax return for at least the past year
- Information about assets owned by the person with a brain injury
- Information about family assets (important when applying for various governmental funds)
- Accident reports (if applicable)





## The Recovery Team

The licensed professionals involved in the care of your family member during recovery may include:

**Neurosurgeon:** A surgeon expert in diseases and conditions of the nervous system. Often the attending physician who manages the case.

**Neurologist:** A physician who specializes in the nervous system and its disorders.

**Pulmonologist:** A physician who manages problems with respiration and lung disorders.

**Physiatrist:** A physician who specializes in physical medication and rehabilitation.

**Orthopedic Surgeon:** A surgeon who specializes in diseases of the bones and treats injuries to the limbs and back.

**Neuropsychologist:** A psychologist with specialized training in relationships between the brain and behavior.

**Nurses:** Nursing staff provides direct patient care in all phases of the recovery process including administering oral and intravenous medications, positioning patients, and carrying out physicians' orders.

**Physical Therapist:** Evaluates components of movement, including muscle strength, tone, posture, coordination, endurance, and general mobility.

**Occupational Therapist:** Focuses on reestablishing the activities of daily living, self care, and upper body motor skills.

**Speech/Language Pathologist:** Responsible for evaluating and assisting with swallowing problems, communication difficulties, and cognitive deficits.

**Respiratory Therapist:** A person skilled in operating machines to aid breathing and keep the airway open.

**Social Worker/Case Manager:** A liaison between the professional team and other parties concerned with the patient.

Depending on the consequences of the brain injury, other professionals as appropriate may also include a neuro-ophthalmologist, behavioral optometrist, recreational therapist, biomedical engineer, certified driving educator, infectious disease specialist, orthopedist, and vocational rehabilitation specialist.

## Later Days in the Hospital

Once the individual is medically stable, the focus of treatment may shift to more rehabilitative efforts. Most medical problems will occur less frequently, but some may still appear (for example, catheters may cause occasional infections requiring antibiotics). The most specialized physicians will no longer be involved in the care of the patient as his/her condition improves. Some of the individual's mannerisms and characteristics will spontaneously begin to re-emerge and therapists will evaluate and work on those functions lost to the injury.

Some individuals become agitated during this time. This can be very frightening for family members, but in fact agitation in this early period is a positive sign that the brain is beginning to recover. Similarly, do not be discouraged if physical recovery seems to be proceeding more rapidly than intellectual recovery. It's hard to be patient, but it may be some time yet before cognition can even be evaluated.

Setbacks will become less frequent as your family settles into a routine of visitation and hopefulness. Be prepared to speak with hospital social workers, insurance case managers, rehabilitation evaluators, and representatives from state agencies or trust funds about benefits and payment of claims, eligibility for state-provided programs, legal issues, and discharge options.



### ***Tips for Families and Caregivers***

Reach out to the Brain Injury Association of America (BIAA) and the BIA affiliate in your state for information and educational materials. Information will be the key to understanding the consequences of brain injury and the expected course of recovery.

You can aid recovery during this stage by asking the physical therapist to demonstrate how to do range-of-motion exercises to augment the therapies provided. Ask the speech pathologist if you should bring items from home such as family pictures, a battery-operated musical device, or tape-recorded messages from friends. These familiar sounds and visual cues can help stimulate and orient someone emerging from a coma or at a low level of cognitive awareness.

## The Rehabilitation Phase

Following acute hospitalization and early rehabilitation, some individuals with brain injuries will be discharged into specialized rehabilitation programs to continue the recovery process. Others who have recovered more significantly may be referred to transitional programs to fine-tune cognitive and vocational skills before returning to the community. Still others may return to the community without follow-up services.

During this stage medical issues are no longer the primary concern. More emphasis is placed on cognition (the way a person interacts with his/her environment). The goals are to build skills and prepare for the future. Whether that means returning to school, work, the family home, a care facility, or another setting, the aim is to help the individual enjoy the highest possible quality of life.

A neuropsychologist will usually do an assessment at this point to evaluate what abilities the individual with a brain injury has preserved and what deficits he or she now has. This noninvasive, task-oriented evaluation helps the individual with the injury and the family better understand how the injury has affected intellectual functioning, and provides valuable information about strategies to compensate for deficits. It indicates the kinds of support the family member will need. It is vitally important that the professional present this information to the person with a brain injury and explain the results of the assessment to his/her whole family. This information is the basis for treatment and future plans.

## *Tips for Families and Caregivers*

An individual with a brain injury may not be fully aware of the impact of his or her injuries until he or she resumes old routines (personal care, for example). It can be very upsetting for the person when these realizations set in, and behavioral problems can surface. Although this increased insight is a sign of recovery, the family may need to provide greater support and be more vigilant to ensure safety and ease the person through this period. For example, a person with a brain injury may have lost the ability to organize and initiate activities. Carefully organizing your home can help such a person by decreasing frustration and providing choices and motivation.



Behavior problems may also be the result of late-onset, nonconvulsive seizures. You should have the individual evaluated for such “silent seizures” if you notice any of the following behavioral changes:

- Restless pacing
- Random, purposeless activity
- Complaints of foul odors
- Greater sensitivity to light and sound
- Hallucinations

Continue to gather information and connect with others to keep current. Join brain injury support groups and other groups for individuals with disabilities.

## Community Living

Everyone with a brain injury ultimately returns to a community, but many factors (including funding sources, care requirements, and support systems) will determine the most appropriate community setting. Many people with brain injuries return to their homes, but depending on their levels of recovery their needs can vary dramatically.

To begin with, common long-term physical problems may include:

- Hemiparesis (paralysis of one side of the body)
- Visual impairments
- Fatigue
- Loss of taste and smell
- Muscle spasms
- Slowness or difficulty with speech

When physical issues and mobility problems persist, home modifications may make it easier for you to provide necessary care.

You can get information about home modifications from rehabilitation centers, state agencies, and Web sites (such as those listed in the resource section). Funding sources for home modification vary from state to state but may include settlement payments, health insurance, state trust funds for brain injury, and other state programs (such as vocational rehabilitation, Medicaid, or Medicaid waivers).

Typically, persistent cognitive deficits are more disabling over the lifetime of the person with a brain injury than are physical problems and require more family support and monitoring. Some common cognitive problems include:

- Memory loss (more often affecting short-term than long-term memory)

- Difficulty recognizing one's cognitive deficits (difficulties in processing information or applying knowledge)
- Poor judgment
- Problems with alertness, attention, and concentration
- Difficulty in initiating, planning, and completing tasks
- Reduced ability to process information
- Confusion
- Spatial disorientation (where one's perception of direction does not agree with reality)



A person with brain injury may also have social or mood problems that limit his or her interactions with others:

- Anxiety and depression
- Impulsiveness and loss of inhibitions
- Emotional lability (mood swings)
- Egocentricity (self-centeredness)
- Agitation or outbursts
- Sexual dysfunction
- Difficulty maintaining relationships
- Feelings of loneliness

## ***Tips for Families and Caregivers***

Often, out of necessity, the family must assume responsibility for implementing a home-based behavioral plan. Although this may be difficult, it can be done. There are many excellent articles and booklets to help you (see the resource section below for suggested Web sites or visit [www.biausa.org](http://www.biausa.org) for the booklet *Behavioral Challenges after Brain Injury*). In general the following will make a plan more likely to succeed:

- Establishing a daily structure (consistent times for all activities)
- Making sure that all family members understand and reinforce the plan
- Allowing the person with a brain injury some choices and control
- Developing strategies to compensate for deficits (For example, use journals, day planners, watches with alarms, calendars, large-button preprogrammed telephones, and medication dispensers.)
- Rehearsing or role-playing to develop appropriate social skills
- Having the person wear an identification bracelet or Medic Alert jewelry in case of emergency

Once you understand your family member's preserved strengths (things he or she can still do well) encourage him or her to use those skills whenever possible. Always praise good performance to enhance self-esteem, which is usually diminished with brain injury.

Do not overlook the value of recreation. All cities and counties have recreation departments that sponsor activities, some specific to persons with disabilities. Call your local recreation department (usually listed under the name of your city or county in the phone book) for a schedule. Also consult



local gyms—most have fitness trainers who can help develop an appropriate workout program.

## **Returning to Work**

People with brain injury who reenter the work force may find it helpful to seek vocational rehabilitation services, particularly when they cannot return to previous employment. Mandated by federal law, vocational rehabilitation services can be found in every state. Services provided vary by state and may include neuropsychological evaluation, work hardening (preparing for work), job coaching, home and vehicle modifications, equipment, and supported employment.

The Americans with Disabilities Act mandates that employers provide reasonable accommodations. Employers may not inquire about the nature of a disability, but the employee must, with these modest accommodations, be able to perform the job.

It may make sense to consider part-time rather than full-time employment at least for a while, as fatigue is often a persistent problem after brain injury. For some people with more severe brain injuries, competitive employment may not be an option. In those cases a person may wish to test his or her work skills by volunteering, gaining experience that could lead to a job. Sheltered workshops are another option, providing safe, paid employment for people willing to work alongside those with other kinds of disabilities.

## ***Tips for Families and Caregivers***

When an individual with a brain injury visits a vocational rehabilitation office, a family member should go along to provide accurate information about that person's life both before and after the injury. If during rehabilitation medical professionals made recommendations about vocational training, be sure to share this information with the vocational counselor.

Unfortunately not everyone with a brain injury will return to the work force. Even if a person doesn't go back to work, it is still important for him or her to have a reason to get out of bed in the morning. Everyone should engage in meaningful activities: household chores, volunteer work, or activities at adult centers or brain-injury clubhouses (where available). Lack of purpose erodes self-esteem.

## **Returning to School**

A child who has sustained a brain injury is expected to return to the school system in time. Yet many children with brain injuries will have learning difficulties, from mild (problems integrating new information with previous knowledge) to much more severe. Under Public Law No. 94 - 142 children with disabling conditions are guaranteed a free and public education. In 1990, this law was expanded (Public Law No. 101 - 476) to include a category for children with traumatic brain injuries. Parents of children with brain injuries should understand and exercise these rights to the fullest, making sure they and experienced professionals are involved in developing their children's Individual Education Plans (IEPs). A good IEP is the one way to ensure a child's needs are properly met.

In addition, anyone injured before his or her eighteenth birthday is eligible for services under the Developmental Disabilities Act. Although the services provided are at each state's discretion, most states offer several, including respite care and expanded care under specialized waivers.

Do not assume educators know what your child needs after a brain injury. You must educate yourself and in turn educate others. In fact, you will most likely need to educate new teachers each year as your child advances in grade level. Taking an active role in planning and advocating for your child is the only way to ensure his or her rights will be properly exercised.

Several organizations (including Parent to Parent and the Family Network on Disabilities) provide parents with information about their children's rights and about what they must do to ensure their children receive an appropriate education. These organizations teach parents about their roles as nurturers and advocates and guide them to available community resources.

### ***Considerations for Spouses and Children of People with Brain Injury***

Spouses and children of people with brain injury have an additional burden of caring for individuals who may have once been the heads of their households. The nurturer now needs extensive support systems. This situation may disrupt the family dynamic, with emotionally charged consequences. Role reversals can lead to resentment when the uninjured spouse, by necessity, must become the breadwinner while still performing all the duties managed previously. These issues can strain marriages and create friction between children caring for a parent with brain injury.

Professional guidance can help families sort out these problems and begin to rebuild the family structure. Seek out others in similar situations through support groups, senior centers, day centers sponsored by religious and civic organizations, professional counselors, and either private or publicly funded services.

## **Paying for Services**

Finding the money to provide services, possibly a lifetime of services, can be a frustrating challenge. Eligibility criteria can be difficult to understand, and you need patience to work through the process.

## **Public Programs to Pay for Health Services**

Many funding programs, such as Medicaid and vocational rehabilitation, are a mix of state and federal funds. In the case of Medicaid, each state establishes its own reimbursement rate and the federal government matches that figure. Many states supplement the usually inadequate Medicaid payment, which causes confusion when people cross state lines and suddenly find themselves receiving less money.

Some states have developed programs and services through trust funds or waivers specifically for people with brain injury. In other states funds from general revenue, special trusts, or waiver programs cover groups such as adults with disabilities, the elderly, or the developmentally disabled. Some of these programs offer benefits on the basis of need. You can get eligibility information by contacting your local Medicaid office.

Also explore county programs with titles such as “medically needy,” “welfare,” or “indigent care.” Contact your local health department, Medicaid office, or developmental disability

council office for further information. Eligibility for these programs may be tied to federal need-based programs like Supplemental Security Income. Finally, some states provide funds for the victims of crimes. Information about these programs is usually available through the victims' rights advocate at your local police department.



### ***Private Health Insurance***

Private insurance gives you more options in selecting and paying for services, but policies offer different benefits. Even when hospitalization and rehabilitation are covered, there are usually caps on dollars, days, and units of service. When insurance is provided through a work-related group policy, benefits may terminate if the employee is unable to return to the job within a stated period. If that is the case, check with the employer's human resources department or benefits coordinator about extending coverage under the Consolidated Omnibus Reconciliation Act (COBRA). Be aware, however, that the former employee will be expected to pay the portion of the premiums the employer used to cover.

Companies employing a certain number of workers are required to provide insurance should a worker be injured on the job. Worker's Compensation provides for extended hospital and rehabilitation benefits, plus financial assistance based on the degree of disability.

## ***Public Programs Offering Direct Financial Support***

The most widely used financial-support programs are the three provided by the Social Security Administration (SSA). The first and most familiar pays workers of retirement age a portion of the money deducted from their paychecks over the course of their lives through the Federal Insurance Compensation Act (FICA).

The second, Social Security Disability Insurance (SSDI), is for workers disabled before the age of retirement. To be considered disabled a worker must (1) be unable to do any work and (2) have a disability expected to last for at least one year or result in death. A worker must have worked a certain number of quarters (periods of three months)—eligibility is based on a formula of age plus quarters worked. The monthly SSDI payment is based on wages earned at the time the worker was injured.

Do not be discouraged easily. Approval for SSDI is often fraught with delays and denials. After a second denial, however, you should contact an attorney specializing in Social Security law. At that point, the third attempt will take the form of an administrative hearing before a judge. If your application is approved, you will receive back payments retroactive to the date of the original application. A standard attorney's fee is 25% of the recovered funds, usually paid directly by SSA. Twenty-four months after approval, the injured person will be notified that he or she is eligible for the Medicare insurance program.

The third SSA program, Supplemental Security Income (SSI), covers some people who have never worked or who have insufficient work credits. All SSI recipients receive the same amount of money. Because Medicaid benefits are tied to SSI, often a hospital's social service department will have

an SSA representative on site to help establish eligibility for the program.

### ***Tips for Families and Caregivers***

- If the injury occurred on the job, immediately notify Worker's Compensation.
- Apply for SSA programs as soon as possible.
- Obtain a copy of all medical records and doctors' summaries.
- Make copies of all pertinent documents required for eligibility applications. Do not ever give anyone the original documents.
- If health insurance is provided through an employer, make every effort to continue coverage without interruption under COBRA.



## Housing and Long-Term Supports

One of families' greatest concerns is "how will my family member with a brain injury get care if and when I am unable to provide it?" Places and programs providing care vary. Not all will be ideal for you.

Nursing homes may be appropriate for those whose persistent medical needs require 24/7 nursing services. Other options include privately-funded long-term care facilities, subsidized supported living, group homes for those with developmental disabilities, boarding homes, and mental health facilities.

In certain locations, limited housing is available through the U.S. Department of Veterans Affairs (VA). To qualify for VA services, a non-combat-injured veteran must have been honorably or medically discharged and must have served a minimum of eighteen months.

States and counties provide long-term supports for certain groups, such as adults with physical or developmental disabilities and persons who are elderly. These programs provide respite for family members, in-home caregivers, companions, homemaking services, transportation, and other services that allow injured people to live at home and interact with the community. These programs have different names from state to state and even from county to county, so seek information from hospital or rehabilitation facility social services departments. Most will have booklets identifying community resources and organizations.

School systems provide day programs for adults with disabilities. These programs (called Exceptional Adult Basic Education, or EABE), focus on academics and skills-building and can offer up to 30 hours of self-help



instruction, vocational training, and social development per week. Contact your local school system for information.

## **Legal Issues**

It is a good idea to consult an attorney very soon after injury. Even if there are no grounds for a lawsuit, an attorney who knows about disability can set a course to ensure all avenues are explored, evidence is preserved, medical and public records are collected, and appropriate benefits are available when necessary. He or she will review all insurance policies in force at the time of injury, including auto and homeowners policies, to identify all possible funds to support medical and rehabilitation needs. He or she can also help you make plans for the future.

The Association of Trial Lawyers of America has a Special Interest Group for Brain Injury. These “neurolawyers” usually limit their practice to brain and spinal cord injuries, which makes them uniquely qualified to understand a brain injury, know the resources, and help preserve all possible benefits. It is not always possible to engage one of these high-profile attorneys, but it is also not always necessary that the attorney you hire be located in your immediate area.

In many cases the attorney continues to represent the person with brain injury long after the medical and rehabilitation providers have completed their work. This is particularly true when the individual may benefit from such legal options as a power of attorney or guardianship, or another legal remedy for protecting assets (e.g., a conservatorship, fiduciary trust, or special-needs trust).

For help selecting an attorney visit <http://personal-injury.lawyers.com/Personal-Injury-Selecting-a-Good-Lawyer.html>. (This Web site is provided by Lexis/Nexis, a legal information service, and Martindale-Hubbell, an international law directory.)

## Outcomes

Outcome is defined as a final product or end result. For clinicians, “outcome” may include set parameters that indicate reaching established short-term goals. For example, a speech/language pathologist specializing in swallowing will chart a successful outcome once the patient has regained the proper musculature to support safe swallowing and oral intake.

But for family members, the words on a patient chart do not define “outcome.” Families may interpret “outcome” as referring to the incremental changes and small gains that contribute to greater mobility or independence, or a higher quality of life.

All families are unprepared for brain injury and inexperienced in managing the many aspects of life after injury. Outcomes change over time: just as each of us changes, so do people with brain injuries. The “final product” or “end result” may not be known for months or years. Many individuals adjust well to disability and go on to productive and satisfying lives. In general, given time and appropriate information most families accept what they cannot change. There will always be a minority of families, however, who will search endlessly for the special program, alternative treatment, or method to “fix” their family member.

Families should never give up hope that science, technology and public awareness will ease the road ahead. Life goes on, albeit changed after brain injury, but the human spirit can move mountains.

## **Become an Advocate**

An old German proverb says, “When one helps another, both are made strong.” Becoming an advocate for yourself allows you to reach out to others who have traveled this road before you and found answers to many of your questions. Networks of advocates have created programs and services of value to you and your family.

At the larger level, legislative advocacy changes laws, and grassroots efforts affect every level of society. For example, although the term “traumatic brain injury” was first mentioned in the Individuals with Disabilities Education Act of 1990, the first formal act of Congress to acknowledge brain injury as a major disability population was not passed until 1996. That act—the Traumatic Brain Injury Act—was the direct result of brain injury advocates’ hard work.

Once they are on the road to recovery, many people with brain injuries find great personal satisfaction in advocacy. Contributing time and talent to a cause offers great rewards for persons with brain injuries and their families and caregivers. Their efforts force change, however slowly, improving the lives of the over five million Americans currently living with brain injury.

## Information and Resources

The Web offers far more information on brain injury than could possibly be listed here. When you visit any of the following sites, check the links section for even more information.

### Brain Injury Association of America

[www.biausa.org](http://www.biausa.org)

This easy-to-navigate website has an extensive menu of education articles, links to state affiliates, book store, research and much more.

### BIAA/National Brain Injury Information Center

800-444-6443

### Centers for Disease Control and Prevention (CDC)

[www.cdc.gov/ncipc](http://www.cdc.gov/ncipc)

800-CDC-INFO

800-232-4696

Find relevant fact sheets on brain injury and a special section on traumatic brain injury. CDC is a lead agency for statistics and research reports on the nation's health.

### Lash and Associates Publishing and Training

[www.lapublishing.com](http://www.lapublishing.com)

919-562-0015

Provides information and training about brain injury in adults and youths for educators, clinicians, therapists, families and persons with brain injury. A free catalog can be requested online along with one free tip card for first time customers.

### Family Voices

[www.familyvoices.org](http://www.familyvoices.org)

888-835-5669

Provides information, support and resources regarding health and advocacy for children with special health care needs.

## **National Dissemination Center for Children with Disabilities**

[www.nichcy.org](http://www.nichcy.org)  
800-695-0285

Clearinghouse on information and resources related to children with disabilities and state agency contact information.

## **Defense and Veteran's Brain Injury Center**

[www.dvbic.org](http://www.dvbic.org)  
202-782-6345

Information about services, supports, educational materials and research for veterans. Active duty military, and their dependents with TBI

## **Social Security Administration Disability Programs**

[www.ssa.gov/disability](http://www.ssa.gov/disability)  
800-772-1213

Excellent site for further information about Social Security programs for person with disabilities. Links explore return to work, special programs benefiting other members of the family and much more.

## **Well Spouse Association**

[www.wellspouse.org](http://www.wellspouse.org)  
800-838-0879

A support community for people caring for their ill spouses, whether due to illness, accident or disease.

## **Medicare**

[www.medicare.gov](http://www.medicare.gov)  
800-633-4227

The official site for information about Medicare Part D prescription drug coverage.

## **National Resource Center for Supportive Housing and Home Modifications**

[www.homemods.org/pages/faq.shtml](http://www.homemods.org/pages/faq.shtml)  
213-740-1364

Information about supportive housing and home modifications.

## **Wright State University**

[www.cs.wright.edu/bie/rehabengr/services/services.htm](http://www.cs.wright.edu/bie/rehabengr/services/services.htm)

Biomedical, Industrial, and Human Factors Engineering site for information about home modifications.

## **The Department of Justice**

[www.ada.gov](http://www.ada.gov)  
800-514-0301

The home page for the Americans With Disabilities Act, with links to all sections covered by the act to protect the rights of person with disabilities.

## **The National Association of Head Injury Administrators Technical Assistance Center**

[www.tbitalac.nashia.org/tbics](http://www.tbitalac.nashia.org/tbics)  
301-656-3500

A learning, collaboration, and benchmarking tool for the Grantees and other affiliates with the Federal Traumatic Brain Injury Program. Although primarily for the use of grantees, it has interesting links under “who to contact.”

## **The National Disability Rights Network**

[www.ndrn.org](http://www.ndrn.org)  
202-408-9514

The nation’s largest enforcer of the rights of persons with disabilities.

**Note:** Many other online sites can be found by entering “brain injury” on Google. Some of the sites found there are sponsored by service providers, lawyers, and individuals wishing to share information through informational websites and chat rooms.

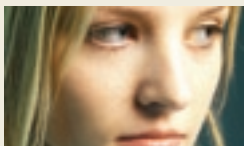
## ***About the Author***

CAROLYN ROCCHIO is a nationally recognized advocate, author, and speaker in the field of brain injury. She developed her expertise in brain injury following a 1982 auto crash in which her son sustained a severe traumatic brain injury. She is the author of *Ketchup on the Baseboard*, as well as numerous monographs and book chapters. She is the Founder of the Brain Injury Association of Florida and a member of the Traumatic Brain Injury Technical Assistance Center Steering Committee, U.S. Health Resources and Services Administration, Maternal and Child Health Bureau.

In October, 2003, Ms Rocchio received the James H. Bruce Lifetime Achievement Award from the Florida Department of Health, Brain and Spinal Cord Injury Program. She is also the recipient of several major national awards: the 1994 Jim and Sarah Brady Award for Public Service; the Association of Trial Lawyers of America 1997 Civil Justice Foundation Community Champion Award; the 2004 John Young Lectureship, Craig Hospital, Englewood, Colorado, the 2005 David Strauss Memorial Lectureship, and the North American Brain Injury Society 2005 award for Public Policy and Advocacy.

This booklet was supported by Cooperative Agreement number U17CCU323329-03 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent that official views of the U.S. Centers for Disease Control and Prevention.

*Challenges, Changes, and Choices: A Brain Injury Guide for Families and Caregivers* is one in a series of brochures on “Living with Brain Injury.”



Overcoming Loneliness



Preparing for Life after High School



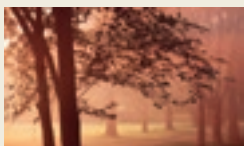
A Basic Legal Glossary



Employment



Substance Abuse



Depression

To order any of these booklets, please contact the Brain Injury Association of America at

**1.800.444.6443 or [www.biausa.org](http://www.biausa.org)**