

Skill Pack for Families to Better Understand Hospital and Rehabilitation Process and Brain Injury

Distributed by



One voice leading the brain injury community of North Carolina.

Offering help, hope, and a voice for people with brain injury and their families.

PO Box 10912
Raleigh, NC 27605
Tel: 919-833-9634 or 800-377-1464
Fax: 919-833-5415
www.bianc.net

<p>Asheville CarePartners Rehabilitation Hospital 68 Sweeten Creek Rd. Asheville, NC 28803 828-377-0208 1-866-890-7801</p>	<p>Charlotte Carolinas Rehabilitation 1100 Blythe Blvd. Charlotte, NC 28203 704-960-0561</p>	<p>Greenville PO Box 30496 Greenville, NC 27858 252-561-6886</p>	<p>Raleigh 2113 Cameron St. Suite 242 Raleigh, NC 27605 919-833-9634 bianc@bianc.net</p>	<p>Winston-Salem Wake Forest Baptist Health Sticht Center - 3rd Floor Medical Center Drive Winston-Salem, NC 27517 336-882-1911 336-713-8582</p>
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Communicating with Hospital & Medical/Rehabilitation Professionals

Many families feel confused and overwhelmed during the patient's hospital stay. Families have found the following suggestions helpful. The contact sheet on the reverse side helps you organize medical contacts.

Asking for information

- Ask which doctor is in charge of the patient's care. Find out the best time to talk with the doctor and how to contact him/her.
- Nurses have the most contact with the patient each day. Ask which nurse can be the communication link with you and your family. Ask whether this changes each day, evening, shift or weekend, if inpatient.
- Ask all therapists to describe what they do and why it is important. Ask for suggestions on what you can do between therapies to help the patient. Write down their names and contact information.
- Ask hospital professionals to tell you their names and what part they play in the patient's care. Writing down names may be helpful.
- Ask how the medical team will update you on the patient's progress. Arrange for a family member to be present if possible.
- Ask how to arrange meetings with doctors, therapists and specialists. You may request a meeting any time. Before any meeting, write down questions and use your notes.
- Ask how to get involved in the patient's care and how decisions about treatment will be made.

Tips for understanding information

- Select one person in your family to be the communication link with hospital staff.
- If you don't understand something, ask that it be repeated or stated differently. Ask where you can find more information to read.
- Ask hospital staff for an interpreter if English is not your primary language. Try not to rely on family members to interpret, as this may be upsetting and difficult for them.
- Take notes or use a tape recorder (with permission) to help you remember important information and instructions.

- Ask for written information to help you understand brain injury.

Planning ahead

- Plan the next steps with hospital professionals. Ask when the patient may be discharged from the hospital or therapy and what problems you may expect.
- Request a list of traumatic brain injury resources to contact in the future if necessary.
- Keep copies of important information, such as consultants' reports and discharge summaries. Start a 3-ring binder to keep them organized and in one place in case you need them later.

Finding a balance

- The challenge for families and professionals is to find a balance between hope for the patient's recovery and the limitation of the current condition.
- Don't expect professionals to give precise predictions for the patient's recovery.
- Know that you are on a sensitive journey where you will experience loss and gain.
- There is life after brain injury.

Professionals you may work with

See Glossary of Terms for definitions

- Chaplains
- Consulting Physicians
- Driver Rehabilitation Specialists
- Neuropsychologists
- Neuropsychiatrists
- Occupational Therapists
- Psychiatrists
- Physical Therapists
- Recreation Therapists
- Registered Dietitians
- Rehabilitation Nurses
- Respiratory Therapists
- Social Workers/Care Coordinators
- Speech-Language Pathologists
- Therapeutic Recreation Specialists
- Vocational Services/Vocational Rehabilitation

Physician Contacts

Doctor's name _____
 Specialty _____
 Mailing address _____

 Telephone _____
 E-mail _____
 Best time to meet or talk _____
 Best way to contact _____
 Best way to leave message _____
 Notes _____

Doctor's name _____
 Specialty _____
 Mailing address _____

 Telephone _____
 E-mail _____
 Best time to meet or talk _____
 Best way to contact _____
 Best way to leave message _____
 Notes _____

Other contacts

Name _____
 Position/Title _____
 Telephone _____
 E-mail _____
 Notes _____

Name _____
 Position/Title _____
 Telephone _____
 E-mail _____
 Notes _____

Nursing Contacts

Unit or floor _____
Unit nurse _____
Contact for daily update _____
 Telephone _____
 Best time to meet or talk _____
Alternative for daily update _____
 Telephone _____
 Best time to meet or talk _____
1st shift nurses _____

2nd shift nurses _____

3rd shift nurses _____

Unit clerk/secretary _____

Discharge Planner Contact

Name _____
 Department _____
 Mailing address _____

 Telephone _____
 E-mail _____
 Best time to meet or talk _____
 Best way to contact _____
 Most reliable way to leave message _____

Insurance Care Manager/Liaison Contacts

Name _____
 Specialty _____
 Mailing address _____

 Telephone _____
 E-mail _____
 Best time to meet or talk _____
 Best way to contact _____
 Most reliable way to leave message _____
 Notes _____

Reactions and Coping after Brain Injury for Families

Each family is different but many share common reactions when a member has a brain injury.

Panic

Worries about whether your family member will survive are common during the early days of a brain injury. You may find yourself breathing rapidly, unable to sleep, having trouble eating, and crying uncontrollably at times. These are normal reactions.

Shock

Many families say they felt that, “*This can’t be happening*” or “*It doesn’t feel real.*” While you may be aware of what’s happening around you, it may be difficult to remember information or conversations. You may have a hard time taking in what has happened and understanding all the new medical terms and procedures.

Anger

You may feel angry that this has happened. You may even find yourself angry with the patient for getting hurt. You may be angry with someone you feel has caused or been involved with the injury. Some families become angry with hospital staff and question what they are doing and how they are treating the patient.

Guilt

You may feel that you could have prevented the injury. You may find yourself thinking about how you could have done things differently or better in the past. You may even feel guilty or angry. Talk about your feelings with someone you can trust or a staff member. It is important to get these feelings “off your chest” rather than struggling with them alone.

Isolation

You may feel distant or disconnected from others, even other family members and close friends. While you may feel that others can’t possibly understand what you are going through, it is important to reach out and ask family and friends for comfort, support, and help.

Hope

As the medical crisis passes, your worries about survival will change to hopes for recovery. Although any medical complications or setbacks may cause

new worries, even the smallest changes or signs of progress may raise your hopes.

Suggestions for coping

Each person reacts differently to stress. Siblings and family members may have different coping skills. Some of these suggestions may help...

- **Write information down in a journal or notebook**
Use this to keep track of questions. Eventually this may become a source of information to share with the patient as recovery progresses
- **Set up phone tree, Facebook page or Caring Bridge page to keep in touch with friends**
Identify one person for family and friends to call for information or to keep the pages updated.
- **Rotate family visits**
Develop a schedule to rotate family visits. Give yourself time to leave the hospital just to get away or do errands. By arranging for someone else to stay with the patient, you can do what you have to and not worry that the patient is alone.
- **Allow others to help**
When someone offers, say “yes.” Be specific about what kind of help you need. It may be taking out the trash, grocery shopping, caring for pets, picking up your children after school, preparing checks to pay bills, or making a meal – whatever helps you and your family.
- **Talk about your feelings**
Holding your emotions inside just builds up more tension. Share your positive and negative feelings with family members, friends and hospital staff. They can only give you emotional support if they know how you are feeling.
- **Be kind to yourself**
Wearing yourself out helps no one. Take time out for walks, exercise, or meet a friend. Eat nutritious meals and snacks. Try to get some sleep.
- **Talk with other families**
Other families you meet in the hospital may understand your feelings as they are in similar situations.

- **Attend a Support Group**

There are over 30 brain injury support groups across North Carolina. For the most up-to-date list visit www.bianc.net or call 800-377-1464.

Information for Caregivers

Caregiving is important and can be a very demanding task. You should take care of yourself along with your loved one. Below are common questions concerning brain injury

When will my family member get better?

Each brain injury is different as is each person's recovery time. If your family member has had a mild brain injury, symptoms may seem to resolve gradually over a period of months. Someone that has suffered a severe brain injury may require months even years to recover. Unfortunately your family member may never be the person that he/she once was. Each person is unique and so is the recovery time.

What is causing my family member to act so differently than before their accident?

Although a brain injury may not have caused any physical changes, the brain has suffered internal damage. Our brain controls our emotions and feelings, which can affect how a person acts. It is hard to realize that although a loved one may look the same, they may act like a different person. Accepting these changes will be difficult and may be accompanied by a sense of loss. If these feelings lead to depression it is important to seek professional help.

How do I deal with my loved ones unpredictable behavior?

When a person's part of the brain that controls laughter, crying, or anger has been damaged; your family member may cry or laugh much easier. They may have more outbursts of anger, may act inappropriately, or do impulsive things. This unpredictable behavior can lead to health and safety concerns for both you and your loved one. It is very important to get assistance from therapists or medical professionals to help deal with mood swings. Medication, behavioral interventions or therapy may be required.

I am feeling overwhelmed...Help!

It is easy for one to feel overwhelmed when faced with caring for your loved one. Seek assistance in dealing with the emotional toll that a brain injury may have on you and your family members.

Psychologists, social workers, counselors, and clergy are all professionals that can offer the support you may need. An individual surviving a TBI may change and some of their personality traits may not return. It may be important to allow yourself and encourage friends and other family members to take time to grieve for the loss of the person you knew and get to know the person you bring home, for who they are now. They may look the same but not be quite the same. Brain Injury affects each person in a unique way. Needs may change over time. Pace yourself.

How do I know that I need help?

- Do you feel isolated and alone?
- Do you have feelings of guilt, anger or frustration?
- Do you feel hopeless?
- Are you having trouble sleeping?
- Are you having trouble taking care of your own needs?

Some strategies for caregivers

- Take care of yourself- rest when you can, eat right, make time for you.
- Try to get and stay organized
- Be patient
- Accept the situation
- Be flexible
- Get counseling for you and or family members
- Ask family members for help
- Help your loved one become more independent
- Seek outside help
- Join a support group
- Be knowledgeable- if you can't find the answers ask a professional.

Questions to ask/Notes to Myself

The Brain

Injury to the Brain

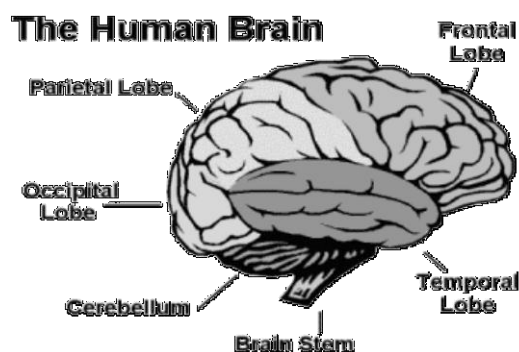
A traumatic brain injury (TBI) is an injury to the brain that is caused by an external physical force. Every injury to the brain has different effects or consequences. An acquired brain injury (ABI) can include stroke, tumor, or anoxic injuries and TBI.

During trauma, the primary injury occurs. The brain can move around inside the skull from the force of the head hitting an object or surface. This can cause bruising or bleeding in the brain. Portions of the brain may be twisted or torn as it moves around inside the skull. This may happen when the head is violently thrust back and forth during a collision or fall, or if the person is shaken. A primary injury can also occur if a penetrating wound, such as a gunshot, injures the brain.

Secondary injury occurs after the initial trauma. Usually this is caused by increased pressure inside the skull as the brain swells and presses against it. Fluid and blood can also build up in the brain. Medication and/or surgery may be needed to relieve the pressure.

Understanding the Brain

The brain has three main sections. They are the brain stem, the cerebellum, and the cerebral cortex.



The Brain Stem controls basic functions needed for survival, like breathing, digestion, and heart rate. It also controls a person's arousal abilities, for example, being awake and alert. The individual may have difficulty breathing and need a ventilator. The brain stem is located at the top of the spinal cord and at the base of the brain.

The Cerebellum coordinates how the body moves, as well as balance and muscle coordination. It is

located above the brain stem toward the back of the brain. When the cerebellum is injured, an individual may have uncoordinated jerking movements, lose balance easily or appear awkward or clumsy.

Cerebral Cortex is the control center for the highest levels of thinking, moving and behaving. It is divided into two hemispheres. The right hemisphere of the brain controls the left side of the body; the left hemisphere controls the right side. *Each cerebral hemisphere has four lobes.*

Frontal lobes control the "executive" functions such as planning, organizing, problem solving, behavior, memory and emotions. The frontal lobes are in the front of the brain behind the forehead.

When the frontal lobes are injured, the individual may express thoughts without filtering out what should or should not be said. The individual may act impulsively without considering safety or consequences.

Temporal lobes control the body's ability to identify smells and sounds, and hearing. These lobes help the person sort new information. The left temporal lobe helps a person understand language and use verbal memory. The right temporal lobe helps the person understand music and remember what has been seen. The temporal lobes are located on the right and left side of the head, just above the ears.

When the temporal lobe is injured, an individual may have difficulty recognizing pictures, faces, words and names. Hearing may be affected as well as the ability to remember what has been seen or heard.

Parietal lobes contain the primary sensory cortex, which controls sensation, such as touch and pressure. They help the person understand what words mean. These lobes help in judging depth and perception as the patient moves. The parietal lobes are located behind the frontal lobes at the top of the brain.

An injury to the parietal lobe may result in difficulty finding one's way around new and familiar places. The ability to sense if a surface is hot or cold when touched may be affected.

Occipital lobes process visual information, such as the ability to recognize shapes, colors, letters, and words. It is the area that controls vision. The occipital lobes are located toward the lower back or rear of the brain.

When the occipital lobe is injured, the individual may have difficulty reading, writing or with mathematics. Identifying color shades, shapes, or patterns may be difficult.

Changes after Brain Injury

Changes after a brain injury depend on which areas of the brain are affected and the severity of the injury. Use these lists to checkmark affected areas. These will change over time as the patient progresses. Possible consequences of a brain injury include:

Physical consequences

- Headaches
- Seizures
- Muscle spasticity
- Changes in vision or hearing
- Loss of smell or taste
- Fatigue, increased need for sleep
- Balance and coordination difficulties
- Difficulty swallowing
- Changes in sensitivity to touch
- Weakness or paralysis
- Changes in appetite
- Changes in sleep patterns
- Increased sensitivity to smells, light or sounds

Cognitive (thinking and learning) consequences

- Amnesia
- Short-term memory loss
- Long-term memory loss
- Slowed ability to process information
- Difficulty organizing and planning ahead
- Poor judgment

- Inability to do more than one thing at a time
- Lack of initiating or starting activities
- Easily distracted
- Disoriented or confused to surroundings
- Shorter attention span
- Says or thinks same thing repeatedly

Communication consequences

- Slurred or unclear speech
- Difficulty finding the right word
- Difficulty staying on topic
- Trouble listening
- Dominating conversations
- Difficulty reading
- Rate of speech too fast or too slow
- Things taken too literally
- Difficulty understanding what is said

Emotional/Behavioral consequences

- Increased anxiety
- Depression
- Self-centered behavior or thinking
- Easily irritated, angered or frustrated
- Overreacts, cries or laughs too easily
- Different sexual behavior
- Impulsive, acts or talks without thinking
- Mood swings
- Stubbornness
- Dependent or clinging behavior

References

Brain Injury Fact Sheet from BIA of America; New York TBI Grant Project, When Your Head Has Been Hurt (with Pan African colors) (2000); Arizona Governor's Council on Spinal and Head Injuries; When Your Child's Head Has Been Hurt; Training Manual for Certified Brain Injury Specialists, Brain Injury Association of America, 2nd edition, 1998; and Brain Injury: A Guide for Family and Friends, University of Iowa (2000).

Coma

Coma is common following a brain injury, but it is difficult for health care professionals to predict how long it may last. Characteristics of a patient in a coma are:

- Eyes closed; patient looks asleep.
- Does not speak or respond when spoken to.
- Does not follow spoken commands.
- Unaware of surroundings.
- Does not respond to touch, sound, or light.

Coma is a state of unconsciousness from which a person cannot be aroused.

It is not known how much a patient in a coma hears, understands, or feels. Families, visitors and staff should talk and behave as though the person can hear and understand.

Glasgow Coma Scale

The Glasgow Coma Scale is a general guide for measuring the depth of coma and the alertness and responsiveness of a patient after a brain injury.

The Glasgow Coma Scale is based on measuring:

- Eye opening
- Verbal or spoken responses
- Motor or physical responses

Each response has a score. Total scores range from a low of 3 to a high of 15. The lower the score, the more complicated or severe is the brain injury.

Glasgow Coma Scale				
Activity	Score	Infant Response	Child Response	Adult Response
Eye Opening	4	Spontaneous	Spontaneous	Spontaneous
	3	To speech or sound	To speech	To speech
	2	To painful stimuli	To pain	To pain
	1	None	None	None
Verbal	5	Appropriate words/sounds; social smile; fixes and follows	Oriented appropriate to age	Oriented to person, place, month, year
	4	Cries but consolable	Confused	Confused
	3	Persistently irritable	Inappropriate words	Inappropriate words
	2	Restless/agitated	Words not understandable	Words not understandable
	1	None	None	None
Motor (Physical)	6	Spontaneous movement	Obeys commands	Obeys commands
	5	Localizes pain	Localizes pain	Localizes pain
	4	Withdraws to pain	Withdraws to pain	Withdraws to pain
	3	Abnormal extremity flexion	Abnormal extremity flexion	Abnormal extremity flexion
	2	Abnormal extremity extension	Abnormal extremity extension	Abnormal extremity extension
	1	None	None	None

Brain Injury	Score
Mild	13-15
Moderate	9-12
Severe	8 or less

Figuring out the Score

The Glasgow Coma Score is figured by adding one score from each category.

$$\text{Eye} + \text{Motor} + \text{Verbal} = \text{Total Score}$$

Ask if this Scale has been used and if the answer is yes, ask staff to explain the score and whether it has changed over time. Ask staff to explain unfamiliar terms and ask questions.

Families often see small changes that may not show up on the scores. Let staff know what you observe.

Early Stages of Coma Recovery

Emerging from a coma is a gradual process of becoming more responsive and aware of people and surroundings. As the awareness improves, confusion may increase. The patient may not recognize family members or close friends. The person may become angry, shout, swear and try to hit people. Noise, light, touch or movement may trigger extreme reactions.

These are **normal** reactions as the person emerges from a coma and are usually temporary. They are signs of progress but can be very unsettling for families to observe.

How families can help during coma recovery

- Keep talking, noise, touching and general activity to a minimum as these things can increase the patient's confusion and agitation.
- Give reassurance. Briefly explain what happened and state where the patient is. Repeat this as the patient may have difficulty taking in new information and remembering it. Talk in normal voice.

- Tell what time of day it is, but keep it simple.
- State who you are and who else is there.
- Touch when you speak to help the patient figure out who you are and where you are if this does not cause agitation.
- Bring in something familiar, such as a picture, favorite blanket or tape of a special song or music.
- Avoid arguing.
- Avoid asking questions; instead tell the person what to do or what is happening.
- Give information instead of asking questions.
- Give visual information to help orient the patient. Post a calendar and mark off the days. Use signs as reminders of where the patient is.
- Write a short description about your family member, describing their interests, likes, dislikes, family, etc. This will help the medical treatment team to know the patient better.

Rancho Scale

Most individuals with brain injury progress through somewhat predictable stages, although every one moves through at a different pace. The Rancho Los Amigos Scale of Cognitive Recovery is a 10 stage scale that is widely used in hospitals and rehabilitation centers. It tracks recovery and is used to help design treatment goals. To learn more about this scale, ask a professional or visit

www.waiting.com/rancholosamigos.html

References

- Crowley, C. and Smith, N. When Your Child has a Brain Injury: What You Need to Know. Charlotte, NC: Carolinas Rehabilitation and The Hemby Pediatric Trauma Institute, 1996.
- Houston, J., Warnock, L. & Lash, M. Traumatic Brain Injury in Children and Teens: A Guide for Families. Hanover, NH: NH EMSC Project at Dartmouth Medical School, 1998.

Brain Injury Resources

Brain Injury Associations

Brain Injury Association of North Carolina

Brain Injury Association of North Carolina
BIANC has five regional Brain Injury Resource Centers. Support groups across the state offer persons with brain injury and their family members opportunities to meet others in similar circumstances. Contact BIANC for a support group near you.

NC Family Hotline BIANC: 1-800-377-1464

Website: www.bianc.net

Brain Injury Resource Center - Raleigh

P.O. Box 10912
Raleigh, NC 27605
919-833-9634

Brain Injury Resource Center - Charlotte

Carolinas Rehabilitation
1100 Blythe Boulevard
Charlotte, NC 28203
704-960-0561

Brain Injury Resource Center - Greenville

PO Box 30496
Greenville, NC 27858
252-561-6886

Brain Injury Resource Center – Asheville

CarePartners Rehabilitation Hospital
68 Sweeten Creek Rd.
Asheville, NC 28803
828-377-0208
1-866-890-7801

Brain Injury Resource Center – Winston-Salem

Wake Forest Baptist Health
Sticht Center - 3rd Floor
Medical Center Drive
Winston-Salem, NC 27517
336-882-1911 and 336-713-8582

Brain Injury Association of America

1608 Spring Hill Road, Suite 110
Vienna, VA 22182
National Family Helpline: 1-800-444-6443

Need Training: Call BIANC 919-833-9634

<http://nctbitraining.org/> (5 modules of self study with a test at the end of each module)

www.braininjury101.org (5 web-based videos)

Community Resource Information

You can also order booklets on concussion (falls and lots of other topics) and other materials from:

- **Centers for Disease Control**
Concussion and Brain Injury (and lots of others)
This is available in both Spanish & English
Web: www.cdc.gov/ncipc/tbi

Dept of Health and Human Services:

DHHS' Division of Mental Health/Developmental Disabilities/Substance Abuse Services is the lead agency for access to services in the public sector. Traumatic brain injury is included in the state and federal definition of developmental disability. In NC, there are supports available for individuals of all ages. Call 919-733-7011 to locate the program/local management entity nearest you.

(web site www.dhhs.state.nc.us/mhddsas)

If you are having a difficult time accessing services call the Advocacy and Customer Service section at the Division of MH/DD/SAS at 919-715-3197.

Department of Social Services

Agency provides assistance for Medicaid eligibility and other government assisted programs. Phone number for each county is listed in the blue pages of the phone book under County Government as Social Services. Contact 919-733-3055.

Division of Vocational Rehabilitation

Vocational rehabilitation services help individuals with a disability prepare for and obtain employment. The NC Division of Vocational Rehabilitation offers a wide variety of services to help an individual return to work. The phone number for each county is listed in the blue pages of the phone book under State Government as Vocational Rehabilitation. Contact 919-855-3500.

Client Assistance Program

Provides information, advice and advocacy to persons with disabilities who are applying for Vocational Rehabilitation or Independent Living. Contact 1-800-215-7227.

Vocational Rehabilitation Independent Living

(VRIL) Helps eligible individuals with severe disabilities obtain services. Provides an alternative to institutionalization, improve function in home and community Contact 919-855-3524 for the office nearest you.

United Way

United Way provides referral and information services. Some agencies offer free services to eligible individuals in crisis situations. To locate a United Way, call 919-834-5200 or visit the web site, www.unitedway.org

Other State Resources

- **Council on Developmental Disabilities**
Telephone 919-420-7901 or www.nc-ddc.org
- **Division of Medical Assistance (Medicaid)**
Telephone 919-855-4100
- **Disability Rights NC**
Telephone 877-235-4210
- **Office on the Americans with Disabilities Act**
Telephone 919-733-0054
- **Social Security Administration**
Telephone 1-800-772-1213 or www.ssa.gov

Brain Injury Websites

Brain Injury Association of North Carolina
www.bianc.net Articles about mild traumatic brain injury, general brain injury, pediatric brain injury, and advocacy. Lots of articles and links and a statewide Resource Directory.

Brain Injury Association of America
www.biausa.org Information on prevention, treatment and rehabilitation. Lists all state Brain Injury Associations.

Brain Injury Information Page
www.tbilaw.com Information about brain injury, concussion, coma and head injury for TBI survivors, spouses and caregivers. The Brain Injury Law Group will help survivors find a lawyer in their state if needed.

Defense and Veteran Brain Injury Center
www.dvbic.org

Head Injury Hotline for Survivors
www.headinjury.com Information and support for persons with brain injury and families. Maintained by survivors of brain injury.

Model System Knowledge Translation Center

Learn about new research findings.
<http://www.msktc.org/tbi/factsheets/index.asp>

Lash & Associates Publishing/Training Inc.
www.lapublishing.com Information and resource center on children and adults with brain injury. Includes publications, free articles and forums for survivors and families. Specializes in effects on learning for students and resources for schools.

National Information Center for Children and Youth with Disabilities
www.nichcy.org
Information for parents on federal laws for special education, including rights and responsibilities of parents. Has a Fact Sheet on Traumatic Brain Injury and listing of resources for North Carolinians. Many pamphlets are free.

NC Assistive Technology Program
www.ncatp.org provides assistive technology services statewide to people of all ages and abilities.

The Perspectives Network
www.tbi.org Information and support for persons with brain injury and their families, including personal stories and medical articles.

Traumatic Brain Injury Resource Guide
www.neuroskills.com Articles and information on traumatic brain injury research as well as products relating to brain injury. Includes an online bookstore. Organized by Centre for Neuroskills.

Traumatic Brain Injury Survival Guide
www.tbiguide.com Online book about brain injury in clear and easy to understand language written by Dr. Glen Johnson.

While You Are Waiting
www.waiting.com Basic education about traumatic brain injury. Helpful for families during early stages of medical care. Excellent resource for friends and relatives at home waiting for news.

The Role of Brain Injury Rehabilitation

A woman who had a brain injury in 1990 made these comments concerning the need for rehabilitation services and difficulties associated with under diagnosis of TBI.

"I am 16 years post-accident. However, getting here was not an easy task. Taking the advice of very educated doctors, my husband brought my broken body home after being in the hospital in critical condition for two weeks. My family did not worry about my brain injury, at least not out loud. They tended to the visible injuries, thanking God every day that my daughter and I had survived the accident. Who ever heard of a brain injury that doesn't kill the person or put them in a lifelong coma? Right?"

Becoming better wasn't nearly as hard as finding the right place to get better. I would readily like to see the health community and general population informed about all the problems associated with a brain injury. I am hoping that the next person with a brain injury gets directed to immediate care, not a band aid excuse of 'Don't worry- it will all work itself out'."

Brain Injury Ombudsman Program

Ombudsman is a Swedish term meaning "citizen advocate". Our Ombudsmen are *volunteers* who have personal experience with brain injury. Brain Injury Ombudsmen are available to assist with training, provide educational materials, consult with or visit schools or nursing homes, assist in resolving complaints, and to help survivors, families, and care givers find peer support.

Call your BIANC office to try to resolve an issue or to locate resources in your area. Ask how you can speak with an Ombudsman or let us know if you would like to share your personal experiences to give another survivor or family your support and help.

Call BIANC (800) 377-1464 for information.
Make a Referral to Brain Injury Ombudsman
Program - (919) 651-9760

Visit www.bianc.net website and look for Ombudsman Tab under Resources for more information.

Elements of TBI rehabilitation

According to Cope (1995) comprehensive TBI rehabilitation consists of at least the following elements:

- The rehabilitation physician (usually a physiatrist) and rehabilitation nurse have special training in diagnosing and treating people with disabilities. Their goal is to help the patient function as independently as possible.
- The prevention of secondary deterioration is important. Evidence clearly confirms that specific interventions can prevent deterioration and complications. These interventions may not reliably occur in non-rehabilitation environments.
- Rehabilitation builds upon natural recovery processes.
- Rehabilitation interventions are incremental and work toward functional gains. The challenges of mobility, self-care, and communication can be overwhelming for the patient. This may result in a hopeless "giving-up" response by the patient. Over time and with comprehensive rehabilitation, progress can occur.
- An optimal environment for neurological recovery is provided by rehabilitation settings.
- Various compensatory techniques are provided and taught to promote recovery.
- Adaptive and specialized equipment, such as wheelchairs or orthotics, are available in this setting
- Environmental modifications are available. These include architectural and transportation interventions. Even more important may be interventions in the patient's social milieu, which include modifications at home, at work and in the community.

Rehabilitation Centers and Services serving North Carolina

Visit www.bianc.net and see the Resource Book for a full listing of all Rehabilitation and Residential services, local support groups, Neuropsychologists, and other NC resources.

- Benfield & Podger Associates: Hickory
Pat Benfield (828) 304-9096
- Brain Rehab Specialist: Charlotte
Sylvia Whitmire, MA, LPC, BCIA-C
(704) 224-6069
- Brain Injury Association of NC (800) 377-1464
www.bianc.net or bianc@bianc.net
- Bryant T. Aldridge Rehabilitation Center: Rocky Mount, (252) 962-3700, www.nhcs.org
- Cape Fear Valley Rehabilitation Center: Fayetteville, (910) 615-4000
www.capefearvalley.com
- CarePartners Health Services: Asheville
(828) 277-4800, www.carepartners.org
- Carolinas Center for Development and Rehabilitation: Charlotte, (704) 442-7272
- Carolina Neuroservices - The Head Injury Center: Charlotte, (704) 366-9930
www.carolinaneuroservices.com
- Carolinas Rehabilitation: Charlotte
(877) 734-2251
www.carolinasrehabilitation.org
- Cary Health and Rehabilitation Center: Cary
(919) 851 8000
- Cone Health Rehabilitation Services: Greensboro (336) 832-4000 (IP)
(336) 271-2054, www.conehealth.com
- Cumberland Hospital for Children and Adolescents: New Kent, VA
(800) 368-3472, www.cumberlandhospital.com
- Dept. of Neuropsychology and Behavioral Medicine, Piedmont HealthCare: Statesville
(704) 873-1100
- Florida Institute for Neurological Rehabilitation: Wauchula, FL (800) 697-5390, www.fnr.net
- Forsyth Rehabilitation Center: Winston-Salem
(336) 718-6700 www.forsythmedicalcenter.com
- GatewayClubhouse: Raleigh (919) 231-3325
www.gatewayclubhouse.org
- Hemby Pediatric Trauma Institute, Carolinas Medical Center: Charlotte, (704) 355-8465
- High Point Regional Rehabilitation Center
(336) 878-6915, www.highpointregional.com
- Hinds' Feet Farm: www.HindsFeetFarm.org
Huntersville, (704) 992-1424
Asheville, (828) 274-0570
- Independent Living Rehabilitation Program: Raleigh, (919) 715-0543
- Learning Perspectives, Inc. (910) 362-9474
www.learningperspectives.com
- Learning Services North Carolina Programs
(888) 419-9955 www.learningservices.com
- Lenox Baker Children's Hospital: Durham
(919) 684-6669
- LifeSpan Incorporated: Charlotte
(704) 944-5100, www.lifespanservices.org
- Lifequest, Inc: Washington
(252) 975-7070 (Psychosocial program)
- Mackowsky Visual Learning & Rehabilitative Clinic: Raleigh (910) 944-0195
- Maria Parham Medical Center: Henderson
(252) 438-4143, www.mphosp.org
- MENTOR ABI
(800) 203-5394, www.mentornetwork.com
- The Mentor Network: Raleigh
(919) 790-8580, www.nc-mentor.com
- Neurological Rehabilitation Living Centers: Virginia Beach, (757) 481-7565
- New Hanover Regional Medical Center: Wilmington (910) 343-7000 www.nhrmc.org
- Regional Rehabilitation Center
Vidant Medical Center: Greenville,
(252) 847-4400
www.vidanthealth.com/rehab
- ReNu Life: Goldsboro (group homes)
(919) 734-0266, www.renulife.org
- Shepherd Center : Atlanta, GA
(404) 352-2020, www.shepherd.org
- Triangle Aphasia Project, Unlimited
Maura English Silverman, M.S., CCC/SLP: Cary
(919) 650-3854, maura@aphasiaproject.org
- UNC Health Care's Rehabilitation Center, NC Memorial Hospital: Chapel Hill, (919) 966-5929
<http://www.uncrehabcenter.org/>
- Wake Forest Baptist Health, J. Paul Sticht Center on Aging and Rehabilitation: Winston-Salem
(336) 713-8500, www.wakehealth.edu
- WakeMed Rehab: Raleigh
(919) 350-7876, www.wakemed.org
- Whitaker Rehabilitation Center, Winston-Salem
(336) 718-5780 www.forsythmedicalcenter.org

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Glossary of Terms About Brain Injury

Families often find it difficult to understand medical terms. This Glossary provides a sample of terms commonly used after a person has a brain injury.

A

Abstract thinking Ability to apply a concept or idea unrelated to a specific object to new situations.

Acute care Hospital with medical staff, including physicians, nurses and other staff.

Acute rehabilitation program Early phase of rehabilitation beginning as soon as patient is medically stable. Includes an interdisciplinary team of professionals.

Acquired Brain Injury (ABI) an injury to the brain occurring after birth that is not hereditary, congenital or degenerative; does not refer to brain injuries induced by birth trauma.

ADA Americans with Disabilities Act.

Advance Directive Term used for a living will.

ADL Activities of Daily Living (dressing, bathing, toileting, eating, etc.)

AFO Ankle-foot orthosis; a short leg brace

Ambulate to walk.

Amnesia loss of memory.

Anterograde amnesia – loss of memory for events after the brain injury.

Retrograde amnesia – loss of memory for events for a period of time before the brain injury.

Post traumatic amnesia (PTA) – amount of total memory loss after the brain injury that can range from a few seconds to months.

Aneurysm a balloon-like deformity in the wall of a blood vessel. The wall weakens as the balloon grows larger and may eventually burst, causing a hemorrhage.

Anoxia lack of oxygen to the brain.

Anticonvulsant medication can decrease possibility of seizures.

Aphasia loss of ability to express oneself and/or to understand language that is caused by damage to brain cells.

Aspiration fluid or food enters the lungs through the windpipe. Can cause a lung infection or pneumonia.

Ataxia problem with muscle coordination caused by lesion of the cerebellum or basal ganglia. Can interfere with a person's ability to walk, talk, eat, and self-care.

Attention Ability to focus on a given task or set of stimuli for a necessary period of time.

B

BIAA Brain Injury Association of America

BIANC Brain Injury Association of North Carolina

Bilateral pertaining to right and left sides of body.

Biofeedback process in which information not ordinarily perceived (heart rate, skin temperature, etc.) is recorded and relayed back instantaneously as a signal so the individual becomes aware of any alteration in recorded activity.

Brain injury damage to the brain that results in impairments in one or more functions.

Brain stem lower extension of brain located on top of spinal column. Neurological functions of the brain stem are necessary for survival (breathing, heart rate) and for arousal (being awake and alert).

C

Catheter a flexible tube for withdrawing fluids from, or introducing fluids into, a cavity of the body. Frequently used to drain the urinary bladder.

CBIS Certified Brain Injury Specialist

CDC Center for Disease Control and Prevention

Cerebellum portion of the brain (located in the back) which helps coordinate movement.

Cerebral infarct when blood supply is reduced below a critical level to a specific region of the brain and brain tissue in that region dies.

Cerebrospinal fluid (CSF) special fluid that bathes the brain inside the skull.

Clonic Alternating contraction and relaxation of muscles.

Closed head injury an injury to the brain without penetration of the skull.

Cognitive education specialist acts as liaison with school.

Cognitive impairment difficulty with basic brain functions – perception, memory, attention or reasoning.

Coma state of unconsciousness from which the patient cannot be awakened or aroused, even by powerful stimulation; lack of any response to one's environment. Defined clinically as an inability to follow a one-step command consistently. Glasgow Coma Scale score of 8 or less.

Competency or **Capacity** a legal term that basically reflects a mental ability to understand the nature and effect of one's acts.

Complex Partial Seizures formerly known as psycho-motor or temporal lobe seizures, consciousness is impaired. May be a warning or aura seizures usually last one to three minutes and may be followed by some confusion.

Comprehension understanding spoken, written, or general communication.

Concentration maintaining attention on a task over a period of time; remaining attentive and not easily diverted.

Concrete thinking unable to generalize between situations.

Concussion the common result of a blow to the head or sudden deceleration sometimes causing confusion and causing an altered mental state, either temporary or prolonged.

Confabulation conversation which the person believes to be true, and is an attempt to fill in memory gaps.

Confidentiality basic tenet in health care respecting confidential nature of patient information.

Confusion a state in which a person is bewildered, perplexed, or unable to self-orient.

Coup-Contrecoup Effect when the back of the head is struck and the front of the brain is injured by the brain bouncing back and forth or side to side.

CT Scan/Computerized axial tomography series of X-rays taken at different levels of the brain that give direct images of skull and intracranial structures. Often taken soon after the injury to determine if surgery is needed. Scan may be repeated later to see how the brain is recovering.

Cue signal or direction to help a person do an activity.

D

Decubitus discolored or open area of skin damage caused by pressure.

Diffuse Axonal Injury (DAI) injuries caused by individual nerve cells stretching and breaking throughout the brain.

Disinhibition inability to control (inhibit) impulsive behavior and emotions.

Discharge Planner person who helps with the transition from the hospital to the home or care facility

Disorientation not knowing where you are, who you are, or current date. Staff often speak of being oriented three times referring to person, place, and time.

Dysarthria difficulty forming words or speaking because of weakness or incoordination of muscles used in speech.

Dysphagia difficulty swallowing.

E

Echolalia imitation of sounds or words without comprehension.

Edema collection of fluid in the tissue causing swelling.

Electrocardiogram (ECG/EKG) recording made by electrode pads on chest to monitor heart rate and rhythm.

Electroencephalogram (EEG) procedure that uses electrodes on the scalp to record electrical activity of the brain.

Electromyography (EMG) insertion of needle electrodes into muscles to study electrical activity of muscle and nerve fibers.

Emotional lability involuntary, uncontrolled laughing or crying.

Endotracheal tube a tube that serves as an artificial airway that is inserted through the patient's mouth or nose.

Executive functions controlled by the frontal lobes and include planning, prioritizing, sequencing, self-monitoring, self-correcting, inhibiting, initiating, controlling behavior.

Extremity an arm or leg.

F

Flaccid lacking normal muscle tone; limp.

Flexion bending a joint.

Frontal lobe front part of the brain; involved in planning, organizing, problem solving, selective attention, personality, and a variety of higher level thinking.

Functional ability to use skills in useful activities in a reasonable amount of time.

G

Gait training instruction in walking, with or without equipment.

Gastrostomy tube a tube inserted through a surgical opening into the stomach. Places liquids, food, or medications into stomach when person is unable to take them by mouth.

Glasgow coma scale a standardized system used to assess degree of brain impairment and to identify seriousness of injury in relation to outcome. Involves three areas: eye opening, verbal responses, and motor responses.

Guardian of the Estate person who cares for the property of the ward.

Guardian of the Person person who cares for the personal needs of the ward.

Guardianship a legally enforceable arrangement under which one person, the guardian, has the legal right and duty to care for another, the ward.

H

Hematoma collection of blood in tissues or a space following the rupture of a blood vessel. Types include:

Epidural Hematoma – outside the brain and its fibrous covering but under the skull.

Subdural Hematoma – between the brain and its fibrous covering (dura).

Intracerebral Hematoma – in brain tissue.

Subarachnoid Hematoma – around surfaces of the brain, between the dura and arachnoid membranes.

Hemianopsia loss of half the visual field in one or both eyes.

Hemiparesis weakness of one side of the body.

Hemiplegia paralysis of one side of body.

Hemorrhage bleeding that occurs following damage to blood vessels.

Hypertension elevated blood pressure exceeding 140/90 mm Hg.

Hypotension low blood pressure (below 90/50).

Hypoxia decreased amount of oxygen getting to the brain.

I

ICP intracranial pressure.

ICU intensive care unit.

Impulse control ability to withhold verbal or motor responses or anticipate consequences while completing a task.

Incontinent inability to control bowel and bladder functions

Indwelling Catheter foley catheter that remains in the bladder and drains urine continuously.

Independent ability to perform a task without assistance or supervision.

Informed Consent a patient's consent to healthy care based on a full disclosure of facts necessary to make an intelligent decision.

Initiation refers to individual's ability to begin a series of behaviors directed toward a goal unless prompted.

J

Jargon spoken language that has a normal rate and rhythm but is full of nonsense words.

JCAHO Joint Commission on the Accreditation of Health Care Organizations, a national accreditation agency with standards for rehabilitation programs.

K

Kinesthesia sensory awareness of body parts as they move.

L

Lability notable shifts in emotional state (ex. Uncontrolled laughing or crying).

Lethargic awakens with stimulation; drowsy but awake.

Limbic System located in the middle of the brain, the limbic system sits on top of the brain stem and is involved in emotions and basic elemental feelings.

Living Will a document in which a competent adult provides written instructions to a physician on the provision, withholding or withdrawing of life-sustaining procedures when the individual is in a terminal or permanently unconscious condition.

Long term memory ability to easily recall feelings, events, ideas, and other information from a long time ago, usually prior to brain injury.

M

Medicaid state and federal program of public assistance to persons of all ages whose income and resources are insufficient to pay for health care.

Medicare hospital and supplementary medical insurance for disabled or aged persons under the Social Security Act.

Memory ability to retain and recall information.

Mobility ability of an individual to move within, and interact with, the environment.

MRI magnetic resonance imaging, high tech diagnostic tool to display tissues unseen in X-rays or other techniques.

Myoclonic Seizures sudden brief contraction of muscle groups, producing rapid jerky movements in one or more extremities of the entire body.

N

Nasogastric tube (NG tube) a tube that passes through the patient's nose and throat and ends in the patient's stomach that can be used for feeding or suction.

Neglect paying little or no attention to a part of the body.

Neuron cells in the brain that send and receive information.

Neurologist a physician who specializes in the nervous system and its disorders.

Neuropsychologist a psychologist who specializes in evaluating (by tests) brain/behavior relationships, planning training programs to help the survivor of brain injury return to normal functioning and recommending alternative cognitive and behavioral strategies.

NIDRR The National Institute on Disability and Rehabilitation Research, under the US Department of Education, provides funding for research and demonstration projects on various aspects of disability and rehabilitation.

NPO Latin initials for "nothing by mouth." This means no liquids or foods for a set period, usually in preparation for certain tests, or when the person cannot safely swallow.

O

Occipital lobe region in the back of the brain, which processes visual information.

Occupational therapist therapeutic use of self-care, work and play activities to increase independent function, enhance development and prevent disability.

Ombudsman is a Swedish term for Citizen Advocate. BIANC has Brain Injury Ombudsman volunteers to help survivors and families.

Orthosis splint or brace designed to improve function or provide stability.

P

Paraparesis weakness of lower limbs.

Parietal lobe one of the two parietal lobes of the brain located behind the frontal lobe at the top of the brain.

Partial Seizures Arise from disturbances in specific, localized areas of one hemisphere of the brain; sub classified as simple partial or complex partial.

Patient's Rights Rights that an individual may exercise in addition to basic citizenship rights provided under the Constitution and other laws. Federal law provides patient's rights under the Medicare and Medicaid law. Patient's rights are also often a statutory set of rights in state law.

Perception ability to make sense of what one sees, hears, feels, tastes or smells. Perceptual losses are often very subtle and the patient and/or family may be unaware of them.

Perceptual motor interaction of vision with motor activities, such as eye-hand coordination.

Perseveration uncontrolled, involuntary repetition of speech or activity.

Person Centered Treatment Planning

Inclusion of the individual, whenever possible, in the development and design of the treatment plan as well as discussion of expected discharge site, outcome criteria, goals, objectives, and treatment methods.

Physiatrist physician specializing in physical medicine and rehabilitation; some are experts in neurologic rehabilitation.

Physical therapist evaluates movement, including muscle strength, muscle tone, posture, coordination, endurance, and general mobility.

Positive Reinforcement The addition of something enjoyable that follows a behavior and makes it more likely to occur.

Post concussion syndrome group of symptoms after a concussion that may include memory changes, mood swings, poor concentration, headache, dizziness, depression, and anxiety.

Post Traumatic Stress Disorder (PTSD) the diagnosis given to individuals with specific psychological symptoms following a traumatic event in their lives. Symptoms include: intrusive thoughts and memories of the traumatic event (flashbacks), emotional numbness, avoiding reminders of the trauma, and hypervigilance (overly alert) to possible dangers.

Problem-solving ability to use cognitive processing to figuring out how to do a task.

Prognosis prospect for recovery from a disease or injury based on nature and symptoms of the case.

Prone lying on stomach.

Psychologist professional specializing in counseling, including adjustment to disability. Uses tests to identify personality and cognitive functioning.

Q

Quadripareisis weakness of all four limbs.

R

Random movement an action or process of moving without obvious aim, purpose, or reason.

Range of motion (ROM) active or passive movement of a joint.

Recreation therapist responsible for developing a program to help persons with disabilities plan and manage leisure activities.

Rehabilitation comprehensive program to help individuals reach optimal mental and physical abilities or adjustment after an illness or disability and return to the community or highest level of independent function and quality of life.

Respiratory therapist provide respiratory or breathing treatments and ventilator management.

Restraint any physical, mechanical, chemical or other means of restricting movement or access to one's body, against one's will.

S

Seclusion isolating a person from others and physically preventing the individual from leaving a confined area.

Section 504 part of the Rehabilitation act of 1973 that requires schools receiving federal funding to provide reasonable accommodations to allow an individual with a disability to participate.

Seizure uncontrolled discharge of nerve cells that may cause loss of consciousness, confusion,

or loss of bowel and bladder control, and tremors. Usually lasts only a few minutes.

Sensation feeling stimuli in taste, smell, hearing, vision, hearing and touch.

Sequencing keeping track of the correct order of events for body movement and language.

Shunt procedure to draw off excess fluid in brain. Surgically placed tube running from ventricles; deposits fluid into abdominal cavity, heart or large veins of the neck.

Skull fracture breaking of bones surrounding the brain. In a depressed skull fracture, the broken bone exerts pressure on the brain.

Social worker acts as liaison between professionals and others including: family, funding sources, friends and representatives of past or future placements.

Spasticity involuntary increase in muscle tone that occurs following injury to the brain or spinal cord, causing muscles to resist being moved.

Speech and language pathologist include prevention, identification, diagnosis, consultation, and treatment of patients regarding speech, language, oral, and pharyngeal sensorimotor function.

Supine lying on back.

T

TBI Model Systems research centers involved in prospective, longitudinal multi-center efforts to examine the course of recovery outcomes following TBI.

Temporal lobes there are two temporal lobes, one on each side of the brain located about the level of the ears. These lobes allow a person to tell one smell from another and one sound from another. They also help sort new information.

Thrombosis blood clot.

Tone the tension in resting muscles and the amount of resistance that is felt when a muscle is moved.

Tonic excessive muscle tension/contraction.

Tonic-Clonic Seizures formerly known as grand mal, there is abrupt loss of consciousness. Body stiffens in tonic contraction at onset. Person may cry out, drop unconscious to the ground, roll up eyes or turn to the side, and bite tongue.

Torticollis twisted position of the neck.

Tracheostomy temporary surgical opening at the front of the throat providing access to the trachea or windpipe to assist in breathing.

Traumatic Brain Injury (TBI) an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning.

Traumatic Brain Injury Act passed in 1996, this federal legislation expanded efforts for effective prevention, biomedical research and the improvement of services through state demonstration projects.

U

Unilateral pertaining to one side of the body.

V

Ventilator machine that helps an individual breathe, keeps airway passages in the throat clear and provides adequate oxygen to the body.

Ventricles, brain four natural cavities in the brain filled with cerebrospinal fluid. Outline of one or more of these cavities may change when a space occupying lesion (hemorrhage, tumor) develops.

Vocational evaluation comprehensive process that systematically uses work, real or simulated, as a focal point for assessment and vocational exploration.

Vocational services/vocational rehabilitation assists in choosing, getting, or keeping a job.

Void to urinate.

W

Wheelchair tolerance amount of time a person is able to sit in a wheelchair, determined by the skin's response to pressure while sitting and ability to sit without excessive fatigue.

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