What to Expect from your Brain Injury Physician

By: Nathan D. Zasler, MD, FAAPM&R, FACRM, FAARPM, DAAPM, CBIST

As someone who has been in the field for nearly a quarter of a century, my perspectives about what is important for me as a brain injury physician and for my patients has clearly evolved. Based on my extensive experience in treating several thousand patients with TBI over the last 23 years, I can offer some unique perspectives of what people need in a TBI physician. If I had to condense what patients and families most expect from their doctor, it could be best summarized as good "CARE," specifically, "c" for compassion, "a" for accountability, "r" for research-based interventions, and "e" for education.

I have found that the ability to communicate with patients and demonstrate compassion is one of the first steps in establishing a productive physician-patient relationship and certainly important in maintaining one. Major components of being compassionate include taking the time to listen to patients and their family, speaking in a way that is understandable to those involved, being empathetic and providing information in a direct yet hopeful manner, neither “writing people off” nor “promising the world.”

Being accountable to patients and their family is also important. Accountability can take many forms and may extend beyond just the physician to the patient’s staff. Some common accountability issues include being available when there are problems or questions, being able to provide justification for treatment recommendations by providing a good reason, being able to discuss procedural risks and complications if they occur, being able to say you were wrong if you were, among other issues.

I think it is also important to base clinical decisions on evidence-based medicine found in medical literature. Certainly, medicine is both a science and an art, but there is often an absence of adequate use of scientific literature and approach as related to diagnosis, prognosis and treatment of persons with TBI. It is critical for doctors to keep up with the scientific literature and also have the clinical experience to allow them to make sound clinical decisions in the absence of evidence-based medicine.

Other things that patients and their families should expect from a good brain injury physician include a holistic approach to patient assessment and management, functionally based approaches to treatment (as opposed to doing tasks that have no relevance to that individual’s real world demands) and adequate monitoring and ongoing re-evaluation of the treatment plan being implemented.

For physicians to truly be good at managing individuals with TBI, they obviously need to keep up with current literature. Also, they need to treat enough patients to truly understand the nature and wide spectrum of both impairment and disability. Although knowledge is important, bedside manner and ability to communicate are also critical physician traits that are particularly important when dealing with any type of disability. Finding a physician with this combination of skills is challenging. My best advise is to talk with other patients about their physician experiences and inquire with advocacy organizations such as local or regional Brain Injury Association offices in order to get recommendations of who might be best qualified to meet your needs.

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Life and Work After TBI

Looking for Work After Brain Injury: The Art of Negotiation and Compromise

Finding a job that suits your needs after TBI can be difficult. Survivors of TBI often need to ask potential employers directly for fair treatment and help with special needs before they can begin work. Negotiation and compromise can help you find and keep the best job for you. Let’s start with some definitions!

**Negotiation**: a process of talking about different solutions to find the one that benefits both the employee and the employer.

**Compromise**: finding agreement through negotiation or through mutual acceptance; making a deal.

Why are negotiation and compromise important when looking for or keeping jobs?

- Negotiation helps you work with someone else toward a solution that benefits both persons
- Negotiation helps you get your needs met
- Having the ability to compromise helps you keep a job
- After starting work, the ability to compromise can help you keep positive relationships with your boss and co-workers

After TBI it is sometimes difficult to compromise. Persons with TBI may not be as flexible as they used to be. Communication and thinking problems that can occur with TBI can make it hard to negotiate.

Causes of failure in negotiation:

- Failure to listen to or see others’ points of view
- Having low control over strong emotions

Use the following questionnaire to rate yourself. It is important to be honest with yourself.

<table>
<thead>
<tr>
<th>How am I at Negotiation and Compromise?</th>
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<tr>
<td>If you agree at all with an item, check the box next to it.</td>
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1. I find it hard to speak up for what I want. □
2. If I try to negotiate, someone will laugh at me. □
3. I take it personally when someone offers me pay I think is too low. □
4. I want to start at the top when I get a new job. I shouldn’t have to do work that is beneath me. □
5. I will only take jobs that let me wear my favorite patched jeans and sneakers. □
6. I don’t believe I should have to compromise. Why can’t others be the ones to give in? □
7. I’ve never been good at negotiating and I never will be. □
8. I want to accomplish my goals and think it is a waste of time to stop and talk things over or negotiate. □
9. It shouldn’t bother anyone around me for me to clean my ears with my car keys. I have wax build up. □
10. If I am lucky enough to get a job I sure don’t want to ask for anything else, even if I don’t like the situation much. □

If you checked any items, you might benefit from learning better negotiation and compromise skills.

Continued on page 3
Here are some work situations in which negotiation and compromise can be useful:

- Pay - You can politely ask how rates are decided, if they have a system to reconsider wages based on experience or length of time you have worked, don't take it personally, ask about a timetable for rates and increases.
- Work schedule - Find out if they are only hiring for part time or a certain schedule, you can ask for specific days or times.
- Dress and appearance -- Professional appearance at work is important. You may have to compromise and change your dress to fit the workplace. How you are groomed, what you wear and your personal habits might make others feel uncomfortable.
- Responsibilities – Wanting a higher prestige level? Ask about employer's support of training and advancement.
- Qualifications – You can convince an employer to hire you with the idea that you will improve your qualifications over time.

Here is a guide for improving your negotiation and compromise skills:

Top 10 Tips for Building Your Negotiation and Compromise Skills:

1. Speak up politely about what you want to do or need for your situation.
2. Try to be flexible.
3. Listen actively and try to understand where others are coming from or what they are dealing with.
4. Manage your feelings by taking deep, slow breaths and letting them out slowly. Tell yourself “I believe I can stay on top of these feelings.”
5. Look for ways to give and take that will result in a win-win outcome for everyone.
6. Start from a positive and complimentary position that shows you appreciate the employer’s situation: “I know your company needs someone to cover the midnight to 7 a.m. shift. Is there someone I could share that position with so I can get the rest I need in the very early morning hours?”
7. Be pleasant but firm when someone seems to be trying to take advantage of you. Example: “I would certainly like to help you but I prefer a later work shift.”
8. Don’t take it personally if the employer or leader does not give in.
9. Know your strengths well enough to offer them in exchange for other qualifications the boss may like.
10. Don’t give up too quickly in your efforts to negotiate or compromise.

(Excerpt from Virginia Clubhouse Vocational Transitions Program, Session 12. Niemeier, Kreutzer, & DeGrace, 2007). Stay tuned for the next chapter in the series Life and Work after TBI.

Support Groups

There are 22 TBI support groups who meet throughout the state of Virginia. To find the support group closest to your location please visit the Brain Injury Association of Virginia’s website at http://www.biav.net or call (804) 355-5748.

Richmond BIAV Chapter Support Group
- Days: Every 3rd Monday of the month
- Time: 6:15 pm – 7:45 pm
- Location: Auditorium of Children’s Hospital at 2924 Brook Road
- Contact: Call Christine Baggini at the BIAV office, (804) 355-5748.

Richmond Supportive Survivors
- Days: Every Tuesday
- Time: 6:00 pm – 8:00 pm
- Location: Food Court at Regency Square Mall
- Contact: Call Ted Taylor at (804) 852-6644 before coming for the first time.
was also having major anxiety and panic attacks. I have never experienced these attacks before. The medication did lessen my symptoms, but I was always extremely tired and couldn’t do daily functioning things. I would have to watch Oprah or Dr. Phil on satellite 3 and 4 times in a row the same day, on different channels because I couldn’t remember what I had watched. I enjoyed borrowing books from the library and looking at the home décor ideas and pictures. The next day I would get the same books out, not really remembering the same pictures. I couldn’t remember what I was reading, even simple sentences.

One of the counselors I have been seeing thought that I might have a brain injury as well, and that is why it is taking me so long to recover. It has been over a year now, and I still cannot do the normal daily activities I was doing before the accident. I used to run marathons and 1/2 marathons which I loved doing as well as mountain biking and road biking. I was extremely active. Now I have a hard time remembering to go for a walk. I have gained close to 40 pounds. Now I sort of forget the point of my question, but I guess it is: am I going to be back to my normal self soon? What do you think my problem is and what should I do to get better?

PAT'S RESPONSE: How frustrating it is not to be able to do the things you used to do! It is normal to want to go back to the way you were before the accident. You are probably feeling discouraged by the rate of recovery.

The symptoms you have described sound like you sustained a traumatic brain injury (TBI) in the accident. The memory difficulty, fatigue, sleep disturbance, anxiety, and trouble getting through the day are common problems people with TBI often have. Many of the problems typically resolve over time on their own. At the same time, some problems persist and you have to learn to cope with the difficulty. The recovery period varies individually, depending on severity of injury, type of injury, age, and other factors. Therefore, it is difficult to predict the course of your recovery. It is important to follow the recommendations of your treating physician. Attending rehabilitation therapies to improve functioning and getting plenty of rest to combat fatigue are some of the things you can do.

It sounds like you have a counselor to discuss your frustrations and challenges. You may also want to consider finding someone who specializes in treating persons with TBI and has experience working with cognitive problems following a TBI. It is important to discuss losses and changes following the accident. You have described some changes, particularly functional abilities, which have affected your mood and self-perception. Ways to help yourself include: asking for help, taking one step at a time and setting goals for each day, being kind to yourself and allowing yourself time to adjust, and focusing on what you can do instead of what you can’t.

Finally, I would suggest that you ask your treating physician about a referral for a comprehensive neuropsychological evaluation. The evaluation could give you a better overall picture of your cognitive difficulties and make recommendations to help you get better.

If you wish to get involved with your local support group to share your experience, Brain Injury Association of America has a list of support groups you and your family may attend. To contact BIAA, you can call their family helpline (1-800-444-6443) or send them an e-mail at family-helpline@biausa.org. The website for BIAA (www.biausa.org) provides links to state chapters and additional brain injury resources. You may also write BIAA for more information at 8201 Greensboro Drive, Suite 611, McLean, VA 22102.

Questions for Pat or the FAQ column are welcomed. Send them to: “ASK PAT” OR “FAQ” P.O. BOX 980542. RICHMOND, VA 23298-0542 or e-mail: jhmarwit@vcu.edu
Title: In an Instant
Author: Lee & Bob Woodruff
Publisher: Random House Publishing Group, 2007
ISBN: 9781400066674
Price: $17.13
Description: 288 pages

In an Instant is a candid and heartening account of Bob and Lee Woodruff’s life together, highlighting Bob’s TBI sustained after an improvised explosive device exploded near the tank he was riding in while covering a news story about the war in Iraq in January 2006. It is a great read for anyone, the survivor, caregiver, and health professional alike.

This narrative is given by Lee and Bob. Revealing details of their life together before the injury and drawing from the journals she wrote during Bob’s recovery, Lee provides the reader with an intimate portrait of survival following tragedy. While some of her accounts leave the reader teary-eyed, in other moments her wit and humorous observations bring about laughter.

In her description of their earlier days of marriage, she tells of their moves from city to city as Bob was receiving promotions and chasing his dream of world journalism. She shares her frustrations and feelings as Bob went on long assignments in other parts of the world while she raised four children in his absence. Later, her personal glimpses into their lives reveal Lee’s feelings as she stands by Bob while he undergoes surgeries, remains in a coma, and receives therapy.

Bob gives his account of his earlier life and what he remembers from the blast in a true “facts only” style far removed from Lee’s more emotional approach. He also describes his challenges that are typical after a brain injury such as memory problems and some different emotions he experienced. Through his optimistic view he reflects that because of the injury he has learned to appreciate his friends and family more. He also shares his hopes and dreams for his and his family’s future.

This story is a testament to the power of hope, love, family, trust, and generosity. It also brings attention to the growing need for rehabilitation services for civilians and servicemen and women returning from Iraq with a TBI. I would strongly suggest this book to TBI survivors, family members of survivors, TBI caregivers, and anyone else interested in witnessing a truly remarkable journey.

Lee and Bob continue to give a voice to TBI survivors. They actively speak at TBI conferences and engagements. They have established the Bob Woodruff Family Fund for Traumatic Brain Injury to help meet the needs of those with TBI, combat stress, and other combat-related injuries. The fund aids in ensuring that TBI survivors and survivors of other injuries have access to state-of-the art treatment options, education, and employment opportunities. To learn more about the fund visit www.bobwoodrufffamilyfund.org.

By: Mari Rawlings, B.S.

VCU’s Brain Injury Family Intervention Project

Virginia Commonwealth University has developed the Brain Injury Family Intervention (BIFI) program directed toward both brain injury survivors and their family members. This program is available to families regardless of how long it has been since the brain injury. The purpose of the program is to strengthen families and promote long-term recovery after brain injury.

Many families have described the program as very helpful. A decrease in depression symptoms and an increase in independence of the brain injury survivor are just a couple of the positive outcomes some participants in the BIFI program have experienced.

Several types of families can participate in the BIFI program, and the program is free. If you would like to participate in the BIFI program or learn more, please contact Taryn Dezfulian at (804) 828-3701 or toll free at (866) 296-6904.

A New Development to Help Those with TBI Manage Their Health Information

Many of those with TBI have trouble remembering doctor appointments, medication refills, and other important things related to their health. There is a new website to help individuals with such problems. HealthOrganizer.org has been developed as a confidential health management site for people with memory difficulties and other thinking problems related to TBI. The website is free and can be used to maintain your own medical history, track your medications, track your health care providers, keep a list of problems to discuss with your doctors, receive reminders of medical appointments and medication refills, get information about TBI, and receive other health tips. If you have internet access and are interested in using the site, visit http://healthorganizer.org or call 1-888-622-1375.
Juan Carlos Arango, Ph.D., obtained his doctoral degree in Clinical Psychology with a concentration in neuropsychology from Complutense University of Madrid, Spain in 2002. He then completed a post-doctoral fellowship in the Neuropsychology and Neuroscience Lab at the Kessler Medical and Rehabilitation Research. Dr. Arango became an Assistant Professor in the Department of Physical Medicine and Rehabilitation (PM&R) at the University of Medicine and Dentistry of New Jersey and currently is an Assistant Professor in the Department of PM&R at VCU.

Dr. Arango has an extensive background in the area of assessment and diagnosis of individuals with neurological disorders. He has authored over 40 peer-reviewed scientific and review articles in both English and Spanish in the areas of neuropsychology, TBI, health disparities, and rehabilitation.

Dr. Arango has also written 15 chapters and has edited two Spanish-language textbooks on dementia and neuropsychological rehabilitation. He was a guest editor of the Journal of Head Trauma Rehabilitation and is a guest editor for a special issue on cultural issues of the journal NeuroRehabilitation.

Dr. Arango is well-known in his areas of expertise, both in the US and abroad. He is the cultural competency coordinator for the National Institute on Disability and Rehabilitation Research’s (NIDRR) Traumatic Brain Injury Model Systems and co-director for the NIDRR-funded Advanced Rehabilitation Research Training Program.

Dr. Arango travels frequently to lecture at conferences and in seminars across the nation, in Latin America, and in Europe. He has extensive research experience working with Spanish-speaking individuals with brain injury and family members/caregivers. Over the past six years, Dr. Arango has conducted numerous research studies in Spain, Mexico, Colombia, Argentina, Peru, and the U.S. focused on understanding and addressing the psychological, emotional, and family needs of individuals with brain injury. He and his work have been recognized nationally and internationally. He received the American Psychological Association Presidential Latino Leadership Early Career Award in 2005, the Brain Injury Association of New Jersey Founder’s Award, and the Colombian Psychological Society Award of Excellence in Research Award in 2006.
Alicia’s Journey: A Survivor’s Story

I was your average active 16-year-old. I was a junior in high school who was involved in 7 school clubs, in my 13th year of dance, and working as a lifeguard and swimming instructor. I was planning to become a professional ballerina and dance teacher. On November 22, 1997 I was driving home and was hit by another vehicle at 60 mph on my left side. I suffered fractured ribs and a severe TBI.

I was in a coma for a month. My doctors predicted that if I ever came out of the coma I would still be severely impaired cognitively and dependent on someone all of the time. The tests that they did supported their predictions as well. I came out of my coma three days before Christmas and was then transferred to a rehabilitation unit. Once I was out of my coma I began recovering at a fast rate. I met all of my therapists’ goals set for me as well as some they had not. They attributed my quick recovery to the physical strength and abilities that I had developed through dance. I made a goal to be out of the hospital by February 27 and achieved that goal.

Following my discharge, I completed summer school, participated in outpatient therapy, and performed in my 13th year recital. When my senior year started I was pumped and ready to go. I returned to dance for my 14th year and was involved in the Future Homemakers of America, National Honor Society, Band, Colorguard, and Students Against Drunk Driving at school. I continued to receive physical therapy and speech therapy at school. My two most memorable moments are being the first pediatric patient at Jim Thorpe Rehabilitation Hospital to receive the Jim Thorpe Courage Award, and performing with my class in my 14th dance recital with a solo performance.

I went on to attend college and receive my Associate’s in Science from Rose State College where I majored in Physical Education and Recreation. But, my greatest achievement from my college years was not just earning a degree but starting TBI Raiders Volunteer Organization. The purpose of TBI Raiders is to see that students who have sustained a TBI succeed in school and life. It is an on-line club and a volunteer service which is very close to becoming a non-profit organization.

TBI Raiders is not only for students and young adults with TBI, but also students with other disabilities in middle and high school as well as college. Through the organization, each group can understand each other and see the capabilities in one another.

One major part of the TBI Raiders Volunteer Services is “Survived to Vote.” The purpose of Survived to Vote is to give Americans living with a TBI and other disabilities a voice in this election and in future elections. Its goals are to help see that better representation in the government is achieved and that those elected hear our issues and what is important to us as TBI survivors.

Through TBI Raiders becoming a non-profit, I’m hoping to establish a link between the state, medical community, and the school systems. One of the trustees is a current state legislator and the other is running for a house seat. Also incorporated in the TBI Raiders are my neuropsychologist, physical therapist, and a K-12 school. This organization very much is what I would call my baby. I was recognized through a House Resolution Bill in May of 2006 for the work I do to help those living with a TBI.

TBI Raiders provides an opportunity for TBI survivors and others with disabilities to form a network, share information about resources, and help improve the lives of those with TBI through awareness and education.

Alicia Payne is the co-founder and director of TBI Raiders. She can be reached by email at tbiraiders@sbcglobal.net. You can learn more about Ms. Payne and TBI Raiders by visiting the website, www.angelfire.com/ok5/tbiraiderok/.

“This is an opportunity for administrators and students with and without a TBI to work together and gain an understanding of each other. It is a chance for students with a TBI to be able to see they are capable of doing so much in their life. Also, it is an opportunity for those without a TBI to increase their knowledge about the disability.”

Want to share your survivor story? If so, please e-mail it to jhmarwit@vcu.edu or send by mail:

TBI Today
P.O. Box 980542
Richmond, Virginia 23298
Betty’s husband asked her how her day had been when he got home from work that evening. Betty told him about the last few minutes of the day when she was opening some cans of beef stew for dinner. Her anxiety rose when she was unable to remember anything else that she had done or experienced. How could the day float by without her awareness? Surely she must have done something. She felt out of control.

Many persons with brain injury notice they quickly forget the day’s happenings. Forgetting what you did the other day, yesterday, or this morning soon becomes frustrating, especially when you find yourself doing the same things over and over again. You may worry that you’re not getting things done and wonder how you’ve been spending your time. Forgetting to do things you need to do, such as going to appointments or mailing letters is also frustrating. The best way to manage concerns over how you spend your time is using a “memory log book,” also known as a daily planner or organizer.

WHAT SHOULD I PUT IN MY MEMORY LOG BOOK?

- Yearly Calendar
- Schedule with time blocks (Daily, monthly, or weekly)
- Note paper
- Address book with phone numbers
- Tabs to separate each section
- Pen or pencil
- Business cards
- Pouch/pocket for storing loose items
- Other important information you want to keep track of, such as:
  - Medications list and schedule
  - Grocery lists
  - Exercise schedule

WHERE DO I FIND A MEMORY LOG BOOK THAT’S RIGHT FOR ME?

- Browse office supply or discount stores (e.g., Wal-Mart, Kmart, Target)
- On-line resources include:
  - Daytimer: www.daytimer.com
  - Franklin: www.franklincovey.com

WHERE DO I KEEP MY MEMORY LOG BOOK?

- At home, decide on one special place where you’re most likely to see it and remember to write in your book (e.g., kitchen table, next to favorite chair, next to telephone, on top of the TV)
- Always keep your book in the same place every time you use it

This article was taken from the book, Memory Matters: Strategies for Managing Everyday Memory Problems by Deborah West and Jan Niemeier. For more information about this book and other helpful resources, visit the National Resource Center for TBI website at www.nrc.pmr.vcu.edu or call (804) 828-9055 to request a catalog.