A PROACTIVE APPROACH TO LIFE AFTER BRAIN INJURY

Traumatic brain injury (TBI) is an event that interrupts life in unprecedented ways. No family is ever prepared to understand how their lives and the lives of other family members may change over an unpredictable period of time. It is difficult at the onset, when life hangs in the balance, to consider the need to do more than maintain a bedside vigil; however, proactive planning better prepares the family for managing their caregiving role once the individual returns to the community.

Information is the key to better understanding how injury to the brain can affect your family member’s ability to conduct his/her life in a manner consistent with the pre-injury lifestyle. In many cases, effects of the injury will create persistent deficits that impact on the individual’s ability to regain independence. While cognitive and behavioral issues often create the greatest family disharmony, most of the problems subsequent to TBI can be managed in home settings.

Family members inevitably become “quasi” case managers once available funding sources, i.e., insurance, state or federal programs and/or workers compensation are limited or exhausted.

Some suggested ways to proactively prepare for your caregiving/case management role are as follows:

1. Contact your state brain injury association for printed information about the nature and consequences of TBI. The Brain Injury Association of America’s Family Help line can provide information about access to your state association (1-800-444-6443) or web site (www.biausa.org). Join a local brain injury support group where you can share information and resources with others experiencing TBI.

2. Purchase and use spiral notebooks to record names of physicians, therapists, procedures performed (include dates) and file or pocket folders to file correspondence with insurance carriers or other funding sources. Keep originals of all bills, medical records or other important documents.

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Lee Livingston, Psy.D. has been a post-doctoral fellow in the Department of Physical Medicine and Rehabilitation at Virginia Commonwealth University Health System (VCUHS) since September 2002. In this position, she conducts neuropsychological assessments and provides psychotherapy to TBI survivors and their families. Dr. Livingston is also a research associate for the TBIMS, conducting psychological assessment of persons with TBI. She participates in a study investigating ways in which clinicians evaluate the emotional functioning of people post-injury. Dr. Livingston has co-authored a book chapter and assisted with revisions to the Neuropsychological Assessment Kit-3rd edition. She is a regular contributor of articles to the TBI Today newsletter.

Dr. Livingston obtained her Psy.D. in clinical psychology from Nova Southeastern University in Ft. Lauderdale, Florida. Prior to her fellowship at VCUHS, Dr. Livingston completed a pre-doctoral internship at Vanderbilt University in Nashville, Tennessee. Her undergraduate degree...
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you will need complete medical information should you seek second opinions or as your family member moves through a succession of rehabilitation services.

3. Gather all the information you can about resources. Most areas have programs for general disability populations and, although they may not be specialized for TBI, they may provide services appropriate to your needs, e.g., adult day care, case management, mental health, epilepsy services, and information about state-provided supplemental funds and waivers for certain populations.

4. Participate to the fullest extent possible in your family member’s rehabilitation program. Ask questions; make sure you understand what will be expected of you once your family member returns to the community. There is no better way to understand the impact of residual deficits than as an observer in the rehabilitation setting.

5. Family conferences are vitally important and every effort should be made to attend. The survivor, family and members of the treatment team generally meet periodically to discuss progress, share treatment goals, and help the family toward a more realistic expectation for restoration of function. Ask if these conferences can be taped or bring your own tape recorder as it is often difficult to absorb all the information presented at a time that may be stressful for the family. An additional benefit of taping conferences is sharing the information with other family members who were unable to be present.

6. A neuropsychological assessment is usually performed during the rehabilitation phase of recovery. This assessment is used primarily to develop a treatment plan. However, it provides valuable information about the individual’s strengths and weaknesses and should be explained, in detail, for the survivor and family.

7. Gather information about entitlement programs, such as, Social Security Disability Insurance and Supplemental Security Income as well as subsequent benefits that accompany these programs. For example, Medicare becomes available automatically twenty-four months after Social Security Disability begins. Medicaid, funded through a mix of state and federal dollars, is a medical-assistance program, which often becomes available within weeks of injury.

8. Appoint one family member to be responsible for managing insurance claims, paying bills, and other financial matters.

9. Seek legal counsel regarding the need for guardianship, conservatorships, or when considering litigation. Legal advice can be very helpful, even in the absence of litigation, in assisting with insurance issues, setting up trusts or other vehicles to protect the individual.

Most importantly, take care of yourself. Caregiving can be a rewarding experience but often exhausting, particularly when cognitive and behavioral issues create the need for twenty-four hour a day monitoring for safety. Learning better ways to manage these problems results in a more harmonious environment. Sometimes it makes no difference what activities you engage in as long as the activity is accompanied by enthusiasm and a cheerful attitude on the part of the caregiver. How you do what you do matters greatly and this will maximize the results.

Carolyn Rocchio
Brain Injury Services, Inc. (BIS) serves survivors and their families in the Northern Virginia area. In 1988 a Head Injury work study group was established in response to advocacy by survivors and their parents for services to assist them after formal rehabilitation had stopped. Through this study emerged Brain Injury Services with Case Management as it’s core service.

Over the last 14 years, BIS has grown to meet the needs of survivors and their families by providing Consumer-Directed Case Management to both adults and children out of our Springfield office. Individuals in Fairfax, Loudoun, Arlington, Alexandria and Prince William Counties as well as in the City of Alexandria and Fairfax are served through advocacy and education. A Clubhouse program is offered in Fredericksburg and Fairfax Counties, while Case Management and Life Skills training is offered in Loudon County.

BIS also provides education about brain injury through individual sessions and through workshops and a Case Management Conference. We partner with Northern Virginia Brain Injury Association (NVBIA) to offer support groups and to host events spotlighting prevention and celebrating the many accomplishments of survivors. We offer a Volunteer Program and multiple social events to facilitate community involvement.

Over the last few years, BIS has partnered with State and Local Representatives to advocate for the many services survivors need to remain active members within their communities. Through these efforts, we have helped other areas of the state start programs similar to ours. BIS, Inc relies on state and local funds as well as donations to provide services. For more information or to make a referral to BIS, please call 703-451-8881.

Susan Rudolph, RN

RESEARCH TO HELP FAMILIES AFTER BRAIN INJURY

Brain injury affects survivors and their family members and friends. Like survivors, families often have a hard time adjusting to life after brain injury. Researchers at the TBI Model System want to look at ways to help and support families during the recovery period. We are conducting a study to see if a support and education program for survivors and their families is helpful. Volunteers are needed for the study. People with TBI and an adult family member (or friend) can enroll in the program.

Participants meet regularly with rehabilitation professionals to participate in discussions and through workshops and a Case Management Conference. We partner with Northern Virginia Brain Injury Association (NVBIA) to offer support groups and to host events spotlighting prevention and celebrating the many accomplishments of survivors. We offer a Volunteer Program and multiple social events to facilitate community involvement.

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Susan Rudolph, RN

MEMORY-WISE

REMEMBERING NAMES PART I

When you meet someone for the first time, say the person’s name several times during the conversation. For example, you could say:

- “It was so nice to meet you, Mary.”
- “Mary, isn’t this beautiful weather we’re having?”
- “Mary, how long have you been waiting in this line?”
- “How kind of you to notice, Mary.”

Ask the person how they spell their name, for example: “is that Mary ‘M-a-r-y’ or is it ‘M-e-r-r-i-e’?

Ask if they can give you a business card—write on the back of the card any distinguishing physical characteristics (for example, hair color, facial hair, eye color, height) that could help you remember what the person looks like.

Try to associate the person’s name with someone who is familiar to you (such as “Aunt Mary” or “Cousin Fred”)

Or associate their name with a physical characteristic or a rhyme (examples: “Mary, Mary quite contrary”; Fred has red hair; “Shaun likes to yawn”)

See part II for more ideas on remembering names...

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QUESTION: Can a person have problems resulting from a closed head injury? What if you didn’t lose consciousness or if the CT scan doesn’t show a problem?

ANSWER: Some people who sustain closed head injuries also sustain mild brain injury or brain damage. It’s possible to have brain damage even if there are no visible signs of damage to your head and there was no loss of consciousness. It’s also possible even if the CT scan doesn’t show any problems. Believe it or not, CT scans often DO NOT detect mild brain injuries.

Brain damage in closed head injuries occurs when the brain bounces around inside the skull. Nerves inside the brain may be stretched and broken. Brain tissue may be bruised and torn by hitting against the hard surface of the skull.

QUESTION: After an accident where you hit your head, what problems should you watch out for? How do you know if you should go to the doctor?

ANSWER: It’s often very difficult to tell if someone with a closed head injury has had a brain injury. It’s usually better to be “safe than sorry” and go to the hospital immediately.

Here are some problems to look for during the first 24 hours after the injury -

1. Weakness in one arm or leg.
2. Vomiting.
3. Continuing or worsening headache.
4. Neck stiffness or pain.
5. Unequal pupil size.
6. Vision changes (e.g., seeing double).
7. Clear or bloody drainage from the ear.
8. Convulsions ("fits" or seizures).
9. Difficulty swallowing or speaking.
10. Difficulty in arousing or waking.
11. Loss of consciousness.
13. Failure to improve.

In children, also look for:

1. Restlessness or fussiness.
2. Difficulty paying attention.
3. Forgetfulness.
5. Lethargy (takes longer to do things).
6. Tiring easily or wanting to sleep more than usual.
7. Does not act the same; personality or mood changes.
8. Impulsivity; acting before thinking.
9. Dropping things a lot.
10. Difficulty in arousing or waking.
11. Loss of consciousness.
13. Failure to improve.

Any time someone has new symptoms following an accident, it’s a good idea to go back to the doctor and ask him or her to evaluate the cause and recommend treatment. The doctor might suggest more tests or make a referral to another specialist, like a neurologist, a psychiatrist, a psychologist, or a psychiatrist, as well.

If any of these problems occur, you may have had a brain injury and should see a doctor or go to the hospital right away.

QUESTION: Is it possible for someone to develop problems later after a closed head injury even though they seemed okay afterward?

ANSWER: Many people who’ve had a head injury are seen in the Emergency Room, without being admitted to the hospital. They may have been examined by a doctor, given a CT scan, and been told that they were well enough to go home. Most mildly injured people experience no further problems. However, sometimes doctors don’t find anything obviously wrong right away after the injury.

Any time someone has new symptoms following an accident, it’s a good idea to go back to the doctor and ask him or her to evaluate the cause and recommend treatment. The doctor might suggest more tests or make a referral to another specialist, like a neurologist, a psychiatrist, a psychologist, or a psychiatrist, as well.

DEAR PAT: I’m in a real bind. I have a hard time saying “No” to people—mostly my friends and family. I tend to help others too much and try to solve their problems. Whenever one of my children (all adults), ex-boyfriend, friends, or roommate needs help, I’m the first one to lend a hand (and a foot, and a leg…you get the picture). If my son loses his job, I’ll find him a new one. When my roommate gets into a fight with her boyfriend, I stay up with her half the night handing her Kleenex, one after another. If my friends are short on cash, I pull out my checkbook. I can’t help but feel like I brought this on myself in a way. As long as they’ve known me, my friends and family have always counted on me to help them out of life’s jams.

My situation has changed a lot since I had a brain injury, though. I can’t handle a lot of stress in my life now. I tend to worry a lot and get really stressed out when things aren’t going right. My worries spiral out of control pretty quickly. It’s hard

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enough managing day-to-day living without trying to solve everyone else’s problems! It’s not that I don’t care about their troubles anymore. I truly don’t want to see people I love suffer. I wish I could help them out like I always have. But, keeping my own fears and worries in check takes most of my energy. How can I keep myself from getting so involved in their problems while letting them know I still care?  

Hapless Helper

PAT’S RESPONSE: You are obviously a kind-hearted soul. Helping people out from time to time is a quality others have come to expect from you. Our lives are often intertwined with many people—friends, family, neighbors, co-workers, and the like. It’s natural to worry about people you care about. You can still provide them with help, show your concern, and keep their problems from weighing on your mind. Try some of these ideas; hopefully, you’ll see the gauge on your “stress meter” decline.

- Communicate your needs.
- Tell close friends and family about your limits in helping them.
- Reassure them that you still care about their well-being.
- Seek out support to learn how others manage stress and set limits on helping others (Try out a support group for brain injury survivors and their families and friends!).
- Develop a low-stress lifestyle.
- Take good care of yourself mentally, physically, and emotionally. Remember you can’t take care of others if you’re over-stressed yourself!
- Avoid taking on too many responsibilities at once (that includes trying to fix others’ problems).
- Work on only 1 or 2 problems at a time, starting with your own.
- Practice relaxation – breathe slowly and deeply, visualize a comfortable place you enjoy, take a walk outside.
- Set reasonable goals for yourself.
- Offer less direct ways you can help others out. For example, you could...
  - Show your son how to find his next job by himself (looking through the classifieds, networking with others, and filling out job applications).
  - Help your friend work out a budget instead of handing over your spare cash.
  - Listen to your roommate’s latest tale of heartbreak for no more than one hour (or one box of Kleenex, which ever comes first).

Be patient with yourself and your loved ones. It may take some time to break the “helping habit.”

Remember, to help others you must first help yourself. — Pat

THE INFORMATION PROVIDED IN THE FAQ AND CHAT WITH PAT IS INTENDED TO FAMILARIZE THE PUBLIC WITH ISSUES RELATED TO TRAUMATIC BRAIN INJURY. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEUTIC ADVICE OR AS A SUBSTITUTE FOR CONSULTATION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

REGIONAL RESOURCE CENTERS
(Project START: Building Bridges with Information)

The Brain Injury Association of Virginia, a chartered affiliate of the Brain Injury Association of America, is the recipient of 2 grants that have allowed the organization to open 5 Regional Resource Centers in Duffield, Fishersville, Fredericksburg, Hampton Roads and Roanoke, Virginia. These regional offices improve the ability of the Brain Injury Association of Virginia to serve as a catalyst for increasing services, education and public awareness at local levels. These centers are funded through grants from the Virginia Commonwealth Neurotrauma Initiative and the federal TBI Act.

The goals of these grant-funded programs are to improve public awareness of brain injury, conduct outreach and educational activities, and develop, expand and enhance local services and supports. Advocacy for the brain injury community is central to the duties of these offices. In addition, presentations and materials specific to the needs of state agencies, hospitals, nursing homes, community-based programs and primary and secondary schools are being developed and distributed.

Feel free to call the Regional Resource Coordinators to learn more about ways they can help you advocate for services, for information on local resources, or provide education to service providers. The staff and locations of the Regional Resource Centers are as follows:

Sandy Bradley-Cannon  
Junction Center for Independent Living  
P.O. Box 408  
Duffield, VA 24244  
276-431-7213

Keith Burt  
WWRC  
Brain Injury Services, Suite 1500  
Box W125  
Fishersville, VA 22939  
540-332-7035

Marylin Copeland  
Commonwealth Support Systems, Inc.  
349 Southport Circle, Suite 107  
VA Beach, VA 23452  
757-816-1857

Lorraine Justice  
Westwood Clubhouse  
507 Westwood Office Park  
Fredericksburg, VA 22401  
540-372-7700

Juanita Thornton  
Blue Ridge Independent Living Center  
1502-B Williamson Road  
Roanoke, VA 24012  
540-342-1231 X3015

For more information, contact Anne McDonnell, Special Projects Director for the Brain Injury Association of Virginia at 804-355-5748 or 800-334-8443.
After TBI, many people have trouble going back to their old jobs or finding new jobs. Fatigue and slowness are two common problems that prevent people from successfully returning to work and carrying out responsibilities.

Sleep problems are common after brain injury. Some people have trouble getting to sleep. Others have trouble staying asleep. Lack of sleep is known to cause irritability and inefficiency. Tasks previously accomplished easily are now hard to do. You may find yourself feeling frustrated because you accomplish little during the day. Here are some tips for managing fatigue:

Most people with brain injury try to take on too much and end up feeling frustrated. Recognize your limitations and plan accordingly. Take credit for doing the best you can.

If you feel like you don't get much done, that's a sign you're planning too much each day. Set smaller goals and realize that great accomplishments are often the result of many small successes.

Talk to your boss about your schedule. It may be possible to work shorter days.

Schedule regular breaks during the day. Breaks will give you a chance to recharge your batteries, so you can think more clearly.

Schedule mentally challenging tasks, such as work and balancing the checkbook, during peak periods of energy.

Promote sleep hygiene. Stick to a schedule — try to go to bed and wake up at the same time every day. Avoid caffeine and exercise in the evening. If you can't fall asleep within 20 minutes of getting in bed, get up and do something quiet for a while before trying again.

Talk to your doctor about medications for sleep and fatigue.

We recently did some research to find out where people with brain injuries are working. This list may give you some ideas about what kinds of jobs with which you are likely to be successful.

- Computer data entry
- Typing & word processing
- Filing
- Food preparation
- Phone answering
- Collating & stapling documents
- Light cleaning
- Photocopying
- Pricing
- Packaging & unpacking materials
- Microfilming
- Mail preparation
- Light assembly
- Delivery

If you have other ideas about places people with brain injuries may be able to work successfully, send us your suggestions (ddwest@vcu.edu).

After injury, many survivors notice problems with mental and physical slowness. You may feel like you just can't think or do things as fast as you used to be able to. Often, family, friends, coworkers, and employers may not understand that slowness is a result of your injury. You may feel frustrated when you can't get as many things done in a day and other people don't understand. There are some things you can do to help. Read this list and try some of these ideas -

- Recognize that you are trying hard. Give yourself permission to take a little longer to get things done.
- Organize your work environment for efficiency. Be sure that everything you need is close by, so you do not have to move to get what you need.
- Be sure you give yourself enough time to do things. Avoid rushing yourself.
- Plan small breaks between tasks, so you have time to get your energy back.
- Develop a list of tasks you need to accomplish, and then rank order the list in order of importance. Make sure you work on the most important tasks first.
- Make a schedule of when you'll complete each task and stick to it. Be sure your timelines are realistic, so you don't put too much pressure on yourself.
- Reward yourself when you finish each task — take a walk, call a friend, play a game, take a short nap. You deserve it!

Remember to be kind to yourself! You are trying your hardest to get better.
JUST FOR FUN!

Working word puzzles can help keep you sharp. Just for fun, see how many squares you can fill up. If you need a hand, answers are on the back page. Try to peek only when you’re stumped.

BRAIN INJURY MEDICAID WAIVER

Combining federal and state funds, Medicaid covers the medical insurance needs of eligible persons. Typically, long-term care needs are met through institutional care, such as in a nursing home. On the other hand, community-based services – many of which are non-medical in nature – allow a person to return to or remain in their homes.

In 1981, the Social Security Act was amended to allow each state to create “waivers,” which would fund community-based services. Medicaid waivers allow a state to provide a wider range of services, not otherwise covered by Medicaid, to a selected target population, thus providing an alternative to institutional care.

While Virginia does not have a brain injury waiver, many people with brain injury are being served under other waivers (Virginia currently has six waivers). However, the services provided through these other waivers are not specifically designed to meet the needs of people with brain injury.

In November 2002, the Disability Commission (chaired by Lt. Governor Tim Kaine) instructed the Department of Medical Assistance Services – DMAS – (Virginia’s Medicaid agency) to work with the Department of Rehabilitative Services and the Brain Injury Association of Virginia in preparing an application to the federal government for a Brain Injury Waiver for Virginia.

In a perfect world, everyone who needs services would receive every service they need; however, the reality is that some difficult choices will need to be made. A waiver will not be a “cure-all” for all the problems that arise from a brain injury. A workgroup has been formed to begin to hash out many of the difficult decisions that will need to be made for the application. These issues include whether there will be a lower and/or upper age limit regarding eligibility, how broad the definition of “brain injury” will be, what services will be provided and other questions.

Although there are not currently funds available for a brain injury waiver, by starting the work now on the application, a structure will be in place when funds are appropriated.

Christine Baggini, MSW
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If you get "stuck" trying to recall someone's name don't keep asking yourself "what is their name? What is their name?" Chances are good you "filed" their name somewhere besides the "name" drawer in your memory. You may have filed it under "people I knew from school" or "people with children under 10." What to do?

Play detective! See if you can find the "drawer" where you actually put the name. Here are some examples of different questions you might ask yourself to retrieve the name you're looking for:

- What is their first name? Last name? Nickname?
- What letter does the name start with?
- Is it a common name or is it unusual?
- Do I know this person from work? From school? From the dentist's office?
- What is their wife's/husband's/kid's name?
- When was the last time I saw this person? Was it inside or outside? Day or night?
- Do I have their name written down anywhere? Where would I have written down their name?
- How often do I see this person?

IMAGINE...
TBI TODAY UPDATES E-MAILED TO YOUR COMPUTER!

Sign up for our List Serve and receive the latest information and findings from the TBIMS. Contact TBI Today editor, Debbie West at ddwest@hsc.vcu.edu (804-828-8797) for information.