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. If you need to furnish them to others, make copies from the originals. Request copies of all medical records;

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TBI Today is published by Virginia Commonwealth University’s Department of Physical Medicine and Rehabilitation’s Neuropsychology Service. This newsletter, is a project of the Virginia Model System, which is funded by the US Department of Education’s National Institute on Disability and Rehabilitation Research (NIDRR). The views, opinions, and information presented herein are those of the publisher and are not necessarily endorsed by the US Dept of Education.
(Continued from page 1) 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
RESOURCES TO THE RESCUE

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 its 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

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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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 receive educational materials and referral information. Participants are also asked to complete surveys and questionnaires before and after they complete the program. Participants will be paid up to $50 for being in this study. For more information, call Laura Taylor at 804-828-3703 or toll free at 866-286-6904 or email taylorla@vcu.edu.

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Degree was granted by Ohio State University in Columbus, Ohio where she majored in psychology. Areas of interest other than TBI include severe mental illness, medication management of psychiatric problems, family support and education, and community mental health. She also enjoys going to the beach, reading good books, and throwing Frisbee with her dog, Dakota.
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. 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.
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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 FAMILIARIZE 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.
SURVIVOR TIP:
CHALLENGES TO WORKING AFTER BRAIN INJURY AND HOW TO OVERCOME THEM

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.

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!

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).
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.

ACROSS
1. Color associated with anger
4. Take it easy
7. Scholastic Aptitude Test (abbr.)
9. Affirmative vote
10. Opposite of west
12. Holds onto
14. Goes into, as a door
15. Gathered up the leaves
16. "Say it isn't __"
18. Compound used in soap
19. "May the ____ be with you."
22. Mystery writer Edgar A. ___
24. Told a fib
26. Advertisement (abbrev.)
27. Wager, as on a horse
28. Moves the car left or right
29. Unwelcome picnic guest
30. Opposite of "from", as in "I sent a letter ___ my friend."
32. TV horse Mr. ___
34. "Make a call on the tele__"
37. Narrow band of color
40. To stare at
42. Auto help club (abbrev.)
43. Hostility
44. Female poet ___ Dickinson
46. Get older
47. Heavy beer
50. "____ as pie." - Not difficult
51. Approaching old age

DOWN
1. Gathers leaves
2. Used for seeing
3. Timid animals
4. Dangerous
5. Plant offspring
6. Sun darkened
7. Turn a car right or left
8. Ate a small amount
11. Holy person (abbrev.)
13. Very lightly colored
19. Payment
20. Special poem
21. Broken leg wear
22. Mystery writer Edgar A. ___
23. Water-loving weasel family member
25. Irritant you want to scratch
27. Blind flying mammals
31. Not under
33. Use the telephone
34. Green pod vegetable
35. Not any at all
36. Hen’s offspring, initially
38. Actor ____ Selleck (played Magnum, PI)
41. It’s between your hip and your foot
43. Got older
44. Female sheep
45. It is (abbrev.)
46. TV show “___ in the Family”
47. First 2 vowels in alphabet
48. “Either this ___ that”
49. Next to, beside, as in “___ the side of the road”

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
(Continued from page 3)

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?