If I Look So Good, Why Do I Feel So Bad?
By Jeffrey Kreutzer, Ph.D.

Brain injury typically changes the way survivors think and the way they react to other people. Survivors sometimes feel really bad when another person gives them a compliment or tries to say something nice. How so?

Imagine yourself at church, at the mall, walking your dog in the street, or at a party - and a neighbor or friend says to you -

“You look great. When are you going back to work?”

or

“You look so good. When are you moving out of your parents’ house to live on your own?”

People who comment on how good you look are mostly trying to be nice. If others are trying to be nice, why do so many survivors feel so bad when they hear these phrases?

Many problems left over from brain injury cannot be seen by others. Sometimes even professionals have a difficult time understanding or seeing the problems you have. Common hard-to-see problems after brain injury include:

- Trouble following conversation
- Headaches and other kinds of pain
- Trouble thinking of the right word
- Getting tired easily
- Difficulty remembering people’s names and what has been said

Most likely, the reason you are not working or going to school, or living with your parents is because you have serious problems left over from your injury, problems that are hard to see or explain.

Questions from others about when your life is going to go back to normal are often a painful reminder that your life is different and difficult, and may never be the same. We know that the general public has little understanding of brain injury. Sadly, comments from others may leave you feeling misunderstood and alone. Others may be confused about your injury because you are pretending that everything is OK and telling people that you are perfectly fine. (contd. on page 2)
(contd. from page 1) You can explain to people in detail what your problems are. Most survivors prefer not to give a complete description of their injury and left over problems in public. Others don’t seem to care and won’t give you the time to listen.

What can you do if you are in public and someone says, “You look great, when are you going back to work (or school)? Let’s consider multiple-choice options. You can tell them:

A. “It’s none of your business when I’m going back.”
B. “Thank you for lying to me.”
C. “You don’t know it, but my life is a horrible mess and I have no idea when I’m going back.”
D. “Thank you. I’m doing okay.”

If you wish to avoid an argument or making a bad impression, choice “D.” would seem like the best choice. When someone in public tells you that you look good, we suggest that you simply thank them for trying to be kind. You will feel better if you save detailed explanations of how you feel for private discussions with family members and friends, the people who you trust and care about you.

This article is adapted from the upcoming 2nd edition of “Getting Better After Brain Injury: A Guide for Survivors,” a publication of the National Resource Center for Traumatic Brain Injury.

VCU’s Brain Injury Family Intervention Project

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

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

Families are welcome to 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 Emilie Godwin at (804) 828-3701 or toll free at (866) 296-6904.
Q: I often forget what I’m looking for when I enter a room. What can I do about this problem?

A: Forgetting what you are looking for is a common problem reported by persons who have had a brain injury. Here are some strategies for remembering what you are looking for:

- Avoid trying to do too many things at once. It is much easier to forget or get confused when you are trying to do different things at the same time.

- Repetition. Repeat the name of the object of your search over and over until you find it.

- Write down what you are looking for. Even just one word may be enough to trigger your recall. If paper is not handy, write on your hand. If a pen is not handy, “write” with your finger.

- Take something with you to remind you what you are looking for. For example, if you are looking for your checkbook, take the bill you intend to pay.

- “Retrace your steps.” For some, going back to the “scene of the crime” helps them recall what they are looking for.
  - Walk back to the last place you remember being. Look all around.
  - Try to form a picture in your mind of what you were doing. Were you sitting or standing? Were you alone or with someone?
  - Pantomime or “act out” what you were doing (e.g., writing something down, opening a drawer, leafing through a book).

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Survivor Stories Wanted!

Recovering from a brain injury can be very difficult. Sometimes, one of the most helpful and inspiring things is simply hearing from other survivors who have gone through recovery and faced the same challenges. Are you a survivor with a story you’d like to share? If so, then we’d like to hear it, and it might get into a future issue of TBI Today!

Submit to: jhmarwit@vcu.edu
or
TBI Today, VCU P.O. Box 980542
Richmond, VA 23298-0542
**CHAT WITH PAT**

*Pat answers your personal questions about brain injury with compassion and practical advice. However, advice from Pat's column should not be substituted for consultation with a doctor or rehabilitation specialist. The identity of individuals submitting questions to “Chat with Pat” is kept strictly confidential.*

**DEAR PAT:** It is after midnight and I can’t fall asleep so I decided to get out of the bed and write to you for help. I thought this problem would have gone away by now. It’s been six months since my accident! It drives me crazy that I’m not able to fall asleep like I used to. Nobody told me that this would be a problem after the accident.

So this is what happened...I was riding my bike one day in my neighborhood when a car came around the corner and hit me. He didn’t see me as he was turning the corner. Luckily, he wasn’t going very fast but the force still threw me off my bike. The helmet I was wearing was smashed in as it saved my life! I felt dizzy and out of it briefly while I lay on the ground. The man who hit me called the ambulance and waited with me.

When I got to the hospital, the doctor ran some tests on me and I had a brain scan. The results all came back normal so they let me go after a few hours. I felt fine when I got home except for a minor headache. But, it was a different story the next day. I can’t explain how I felt. I did not feel like myself. I felt nauseated, dizzy, and tired. I decided to go see a doctor about these problems. The doctor said I had a concussion and the symptoms would go away in a few days. Well, he was right, after a week, they all went away except for one problem. My sleep has been totally screwed up since then. I have trouble falling asleep every night. I tried going to sleep earlier. I tried going to sleep later. I tried drinking warm milk, taking a bath, reading a boring book, and the list goes on and on, but nothing worked. I just toss and turn all night until I fall asleep eventually for a few hours before I have to get up for work. Please help me Pat!

Lisa,  
Sleepless in Minneapolis

**PAT’S RESPONSE:** How frustrating it must be for you, Lisa! Having a good night’s sleep is so important to one’s sense of well-being because it impacts many aspects of our lives. You are not alone, though. Sleep disturbance is a common problem following a TBI. Injury to the brain often leads to changes in sleep. As such, people with a brain injury frequently complain of difficulty falling asleep or staying asleep, drowsiness during daytime and erratic sleep patterns. Several factors contribute to sleep problems: physical and chemical changes, changes in breathing control, medications, physical inactivity and daytime napping, pain, depression, alcohol, and caffeine and nicotine.

There are many things you can try to improve your sleep before talking to your doctor. Changing your behaviors and surrounding environment are often effective treatments for sleep difficulties.

Here are some suggestions for things you can do during the day: Set an alarm to try to wake up at the same time every day; Get off the couch and limit TV watching; Exercise every day; Do not nap more than 20 minutes during the day.

During nighttime: Try to go to bed at the same time every night; Follow a bedtime routine (e.g., Put out your clothes for morning, Brush your teeth and then read or listen to relaxing music for 10 minutes); Avoid eating prior to sleep to allow time to digest; Do not eat, read or watch TV while in bed; Create a restful atmosphere in the bedroom, protected from distractions, noise, extreme temperatures and light; and If you don’t fall asleep in 30 minutes, get out of bed and do something relaxing or boring until you feel sleepy.

Good luck restoring a restful night of sleep, Lisa! If your sleep problems persist, please talk to your doctor to explore safe and effective solutions.

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
See if you can solve this crossword puzzle! All of the words are taken from this issue. Clues which are in quotes are sentences taken from this issue with a key word missing. Other clues have synonyms. Answers on page 7!

**Across**

3. Doing this with your steps might help you remember.
5. "Please _____ me Pat!"
7. "It is after _______ and I can't fall asleep"
9. The only animal in this issue, he never forgets.
12. The newest staff addition. Have you met her?
13. Pat usually has a few of these for people who write in
14. "I often _____ what I'm looking for when I enter a room."

**Down**

1. dilemma, predicament, hardship
2. Special services or arrangements to help survivors overcome limitations.
4. Traumatic _____ Injury
6. "Several factors contribute to sleep _______"
8. News, Ideas, and _______ from the Virginia TBI Model System
10. Often, recurrently, habitually
11. A type of story you can submit to TBI Today

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Brittney Chappell, B.A., is a research specialist and psychometrist in the Department of Physical Medicine and Rehabilitation at VCU where she assists with neuropsychological evaluations. She is also involved with many research projects in the Department including the Brain Injury Inpatient Educational Intervention for Family and Caregivers, an intervention program designed to improve families' knowledge and understanding of life after brain injury. She also works with the Brain Injury Family Intervention program (BIIF), which aims to promote effective coping strategies for families experiencing significant emotional and behavioral changes post-injury. In addition, she is involved with the Bridge project, a pilot program designed to be part of multidisciplinary assessment of community readjustment in individuals diagnosed with HIV and recently released from incarceration.

Brittney lives with her husband in Carson, Virginia, where she enjoys staying active outdoors and spending time with friends and family. She graduated from the University of Virginia in 2010, where she received a B.A. in Psychology with a minor in English. She was involved in many aspects of research at UVA and even received an award for “Excellence in Research” for her work with the Human Dynamics Lab and the Center for the Advanced Studies of Teaching and Learning. Before her employment with the department, Brittney volunteered with the TBI Family Support Program and worked as a research assistant in the Massey Cancer Center studying health literacy. In the future, she aspires to obtain her PhD in Clinical Psychology, but for now she is thoroughly enjoying being able to interact with our patients and their families.
Accommodations Guide for Students with Brain Injury

Jeffrey S. Kreutzer, PhD, ABPP and Nancy Hsu, Psy.D.

The long-term effects of brain injury can be catastrophic for students at any level. Early on, students with the most severe injuries are unable to attend school. Some require home schooling until they recover enough to travel and attend classes with other students.

Research shows that brain injury often harms basic cognitive abilities such as memory, learning, attention and concentration, word finding, and visual perception. Injury can also harm important academic abilities such as reading, arithmetic reasoning, vocabulary, writing, and spelling. Parents and students often worry about falling grades and failure. Concerns about passing the school year, graduating high school, or graduating from college with a degree are often expressed.

Frequent complaints from students with brain injury include:

- I study for twice as long as I used to, but I’m doing much worse.
- I can’t remember anything I read no matter how many times I re-read the same thing.
- I study hard and feel like I know the material. Then I go into the test and can’t come up with the answers.
- Essay exams are murder. I need 20 minutes to think of what I want to say and then the time has run out.
- I get so tired I can barely get through the school day. At night, I’m just too tired to do my homework.
- I’m so distracted. I can pay attention for five minutes and then my mind wanders.
- I go to every class, but nothing sinks in.

Most of the time, school systems are very willing to provide accommodations to students with brain injury. “What are accommodations?” you might ask. Accommodations are special services or arrangements designed to help survivors overcome and offset injury related limitations.

Students and parents often don’t know that many kinds of accommodations are available to help students succeed. Many are also unaware of what accommodations are appropriate and reasonable for them. Having a thorough evaluation of academic and cognitive abilities is a first step toward understanding a student’s special needs. Evaluations can be performed by neuropsychologists, educational psychologists, and school psychologists. Students and parents are encouraged to seek an experienced brain injury professional who can thoroughly document academic strengths, limitations, and recommended accommodations. Nearly all schools require documentation of disability and recommendations in order to provide accommodations.

To help you understand what accommodations might be appropriate for you or your student, we have prepared a partial list of commonly recommended accommodations on the next page. Talk to the psychologist or educational specialist helping you to determine what is best for your situation.
Classroom Accomodations:

- allow additional time to complete in-class assignments
- allow for extra or extended breaks
- provide student with instructor’s notes or help student obtain quality notes from other students
- allow student to audio record lectures for later playback
- provide both oral and written instructions; clarify instructions
- for lectures, provide student with an outline or study guide when available
- allow use of a portable computer with spelling and grammar checks for assignments and note-taking
- in grading work, reduce emphasis on spelling and grammatical errors unless it is the purpose of the assignment
- permit referencing a dictionary or thesaurus for assignments
- provide preferential seating at or near the front of the classroom
- reduce quantity of work required, in favor of quality
- avoid placing student in high pressure situations (e.g., short time frames, extensive volume of work; highly competitive)
- exempt student from reading aloud in front of classmates because of impaired reading skills

Test Accommodations:

- allow additional time to complete tests
- provide for completion of tests in a quiet, individual environment with the goal of minimizing distractions
- administer long examinations in a series of shorter segments with breaks allowed between sections
- allow oral examinations and assist student in having responses scribed, as needed
- assess knowledge using multiple-choice instead of open-ended questions
- allow student to clarify and explain responses on exams (and assignments)
- permit student to keep a sheet with mathematic formulas for reference, unless memorizing the formulas is required
- permit student’s use of a calculator
- permit the student to utilize a dictionary and thesaurus in writing test responses
- if two exams are scheduled on the same day, allow student to reschedule one for another day

For a complete list of useful student accommodations, please call 804-828-3704, or write to us at VCU Post Office Box 980542, Richmond, VA 23298-0542.

About the Authors: Dr. Kreutzer and Dr. Hsu are specialists on staff at the Virginia Commonwealth Traumatic Brain Injury Model System of Care. They are both neuropsychologists in the Department of Physical Medicine and Rehabilitation which provides services to students within the VCU Health System.
Founded in 1983 by families and concerned professionals, the Brain Injury Association of Virginia is the only statewide non-profit organization in Virginia exclusively devoted to serving individuals with brain injury, their families, and those that care for and about them. Over 10,000 people find help from BIAV each year.

BIAV is a chartered state affiliate of the Brain Injury Association of America and exists to be the voice of brain injury through help, hope and healing for Virginians with brain injury and their families. We educate human service professionals and the community on the risks and impact of brain injury and advocate for improved medical and community-based services. Many of our staff members are Certified Brain Injury Specialists (CBIS Certified).

To find out more information about BIAV, contact us at 1-800-444-6443 or 804-355-5748. Or visit our website at www.biav.net.