
❖ Brain Waves ❖

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The Community Skills Program® Newsletter

Fall 2011

Once More With Feeling...Fatigue

The fall and winter holidays can bring excitement and exhilaration—and also fatigue. While we know that fatigue is a common symptom of traumatic brain injury, it can be particularly severe during the holidays, when there are frequent disruptions to usual routines and over-stimulation. Fatigue can have an impact on an individual's cognitive functions and ability to initiate and carry out activities of daily living. Fatigue can also have a negative effect on mood and can be particularly problematic when it interacts with pain and chronic sleep disturbances. In their chapter entitled "Fatigue: Assessment and Treatment," in *Brain Injury Medicine: Principles and Practice* (Demos, 2007, 545-555), Jonathan L. Fellus, M.D., and Elie P. Elovic, M.D., pointed out that it has been difficult to define and operationalize post-traumatic fatigue in relation to traumatic brain injury (TBI) because TBI is a "heterogeneous collection of injuries to the brain that can result in physical, behavioral, cognitive or emotional dysfunction." That fact, they added, makes it hard to determine the incidence of fatigue, but the range has been estimated to be between 21% and 73%. In an article in 2001 in *Brain Injury*, Kreutzer, Seel, and Gourley reported an incidence of 46% among persons attending an outpatient TBI clinic.

Some of the general recommendations for managing fatigue include routine performance of a home exercise program, energy conservation through adequate pacing when carrying out tasks/activities, good nutrition and weight management, and establishment of priorities so that the most meaningful tasks/activities are more likely to be accomplished.

It is important to recognize that, in addition to the individuals with the brain injuries, caretakers, significant others, and treatment providers without brain injuries also experience fatigue. Although for most caregivers, significant others, and treatment providers the cause is not the underlying pathophysiology of post-traumatic fatigue, the effects can be similar.

There are many reasons why caregivers and significant others may experience high levels of fatigue. The challenges of daily living are profound following traumatic brain injury, which, as we know, is a "family matter." There is often just too much to do, and the hectic pace can exceed one's reserve of energy. This is particularly true around the holidays.

The impact on treatment providers is being given more attention recently, as evidenced by the increase in advertisements for continuing education programs on what is being called "compassion fatigue." It is distinguished from stress and burnout, although some ways of managing it may be the same or similar.

The bottom line is that all of us need to adhere to the general recommendations for managing fatigue, and also discover our own specific, effective solutions to reduce fatigue and achieve a better quality of life.

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Update

- Welcome to our new clients—Andrew, Byonte, Carolyn, Crawford, Deborah, Gabriel, Hugo, Jeanne, John, Jon, Joseph, Joy, Latoya, Mark, Mary, Megan, Nanette, Paul, Robert, Sharleen, Thomas, Veronica, and William.

Our clients and staff continue to be involved in many interesting, varied activities. As usual, in each issue, we mention some of them; more will be mentioned in the next issue of *BrainWaves*.

- In his first semester in a culinary arts program, Gus not only earned a perfect 4.0 grade point average, but also was recognized as the best student of the semester and received a "Best in Quarter" award. Congratulations, Gus!
- Fernando continues to volunteer at three different work sites. In September, Fernando and his family adopted a cat and he has assumed the responsibility of pet care tasks. In addition, Fernando has been preparing dinner for his family on occasion; one evening, he made spaghetti with meatballs and garlic bread, and on another occasion, he made two pepperoni pizzas.
- In October, William resumed working on his model railroad; with the assistance of his neurorehabilitation specialist, he organized the workspace in his basement, took inventory of all of his model supplies, and created a shopping list of needed items.
- Congratulations to Charlie, who recently obtained employment as an inventory clerk at Walmart!

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Update continued (from page 1)

- Michelle and her neurorehabilitation specialist, April Moser, B.S., CBIS, recently took a jewelry-making class and are enjoying making jewelry.
- Elizabeth recently subscribed to a professional nursing journal, *Nursing 2011*, and plans to read the articles in it. Also, she recently cooked a surprise fish dinner for her husband, using a recipe she found during a visit to her local library.
- Anju continues to enjoy crocheting as a leisure activity. In October, she began co-leading, along with her neurorehabilitation specialist, another crochet class, held every Wednesday.
- Tom recently became a member of a photography website (www.dpchallenge.com), on which he has viewed, rated, and commented on photographs submitted by other members; he will also be able to submit his own photographs on the website. In September, with the assistance of his neurorehabilitation specialist, Tom used *Photoshop* computer software to create a photo album of his vacation to Boston in August.
- Marissa King, M.S.W., and Kim Schlaline, M.S.W., recently passed the exam for licensure as a social worker (LSW). Congratulations to both of you!
- Our congratulations to Carrie Ocheskey, B.A. (formerly Carrie Hayes), one of our neurorehabilitation specialists, who married Joseph Ocheskey on September 3, 2011.
- On November 29, 2011, Daniel Giovanni Puglisi (seven pounds, eight ounces, 20.5 inches long) was born to Renéé and Mike Puglisi. Renéé Puglisi, B.S., CTRS, CBIS, is our client services liaison for northern New Jersey. Congratulations, Renéé and Mike!

Tips On...

Using Your Medication Safely*

If you take medications, you know that all the information about each one can be confusing (for example, why you take it, when to take it, how much to take, whether or not you can take the medication with food or drink, possible side effects). So, we have provided you with some tips to help you make sure that you are taking your medications safely and effectively and to help prevent medication errors.

- √ **Make a list of all the medications you take**, and update the list every time you get a new medication. Be sure to include all prescription and over-the-counter medications, vitamins, and herbal supplements you use. It is also a good idea to include on the list any medications that you *cannot* take due to allergic reactions. Take the list, or a bag with all your medications, with you when you go to your doctor's office, the pharmacy, or the hospital. If your doctor prescribes a new medication, ask if it is safe to take it with your other medications. (We found a website, www.safe-medication.com/safemed/mymedicinelist, that provides a link to download a copy of the "My Medicine List" document to your computer. You can create your own personalized medication list by filling out each line electronically and printing out a copy. The document provides simple, easy-to-understand instructions on how to fill out the form.)
- √ **Ask questions about your medications.** Ask questions and make sure you understand the answers. Choose a pharmacist and doctor you feel comfortable talking with about your health and medications. You may want to take a relative or friend with you to ask questions and remind you about the answers later. Write down the answers. Use only one drugstore or pharmacy, if possible. If you fill prescriptions at more than one pharmacy, make sure that each of them has the same information about your medications.
- √ **Make sure your medication is what the doctor ordered.** Question anything you do not understand or that does not seem right. Be especially alert to unexpected changes, such as receiving a prescription refill that seems to have a different strength or appearance from your original prescription. If something seems wrong, ask the pharmacist to double-check it. Most errors are first found by patients.
- √ **Ask how to use the medication correctly.** Read the directions on the label and other information you get with your medication. Have the pharmacist or doctor explain anything you do not understand. Be sure you know how much to take, when to take it, and whether or not you can take the medication with food or drink. Ask if there are any foods or activities (e.g., driving) you should avoid while taking the medication. Also, be sure you know what to do if you miss a dose. Ask if you need lab tests to find out how the medication is working or to make sure it does not cause harmful side effects.
- √ **Ask about possible side effects.** Side effects can occur with many medications. Ask your doctor or pharmacist what side effects to expect and which ones are serious. Some side effects may bother you but will subside after you have been using the medication for a while. Call your doctor right away if you have a serious side effect or if a side effect does not subside. A change in the medication or the dose may be needed.

*[Note: This information was obtained from the following websites: www.fda.gov, www.ahrq.gov, www.safemedication.com, and www.webmd.com. The key words, "Using Medication Safely" were used to search for the information.]

For another "Tips On..." article, turn to page 7.

Spotlight: Adam Wertz



Adam Wertz

Spotlight: Please tell us a little bit about yourself.

Adam: My name is Adam Wertz. I am 28 years old. I live in Mohrsville, PA, with my parents. I graduated from Hamburg High School in 2002. I ran track and field in high school. I like basketball, baseball, and going to Penn State football games.

Spotlight: Tell us about your family.

Adam: My parents are Gerry and Sue; they have been married a long time.

Spotlight: You also have a few brothers and nephews. What are their names?

Adam: I have three brothers: Matt, Greg, and Jeff. Matt is married to Annie, and their son, Dylan, just turned a year old. I recently visited them in Florida. Greg has a son, Brady. Jeff is engaged to marry Heather.

Spotlight: Tell us how you got injured.

Adam: I got injured at work on January 7, 2008 at 9:00 p.m., close to the end of my shift. I was doing 22-inch round ingots, grinding the defects on the outside. I had to put a new ingot on. *[Editor's Note: At this point in the interview, Adam asked his father, Gerry Wertz, to provide more details in response to some of the questions.]*

Gerry: I got the call around 9:30 p.m. Adam was on a ballister and changing the ingots. He was taking one off to put in his station to grind. Co-workers brought a crane over, and Adam hooked the chain up to the end of the ingot. Adam made a motion to the crane operator to tell him to lift up the ingot. Once the ingot is in the air, a three-foot long spacer made of iron is to slide under the ingot. As Adam was putting the spacer under it and the ingot was in the air, the chain slipped off the ingot. The ingot is about 3,000 pounds. When the ingot fell, it landed on the end of the spacer and created a seesaw effect, which caused the other end to hit Adam in the chin and puncture him next to his neck, near the carotid artery. He fell back about five feet, and the back of his head hit the cement floor. His brain was jarred two times—first when the spacer hit him and second when his head hit the cement. A co-worker acted quickly and saved his life.

Spotlight: What hospital did you go to after your accident?

Adam: I was sent by ambulance to The Reading Hospital [referring to The Reading Hospital and Medical Center in West Reading, PA]. I was there for a month. I was unconscious for 11 days. I was very confused when I woke up. I remember thinking I was late for work and didn't know where I was.

Spotlight: Where were you transferred to?

Adam: I was sent to Kessler Rehab in New Jersey [referring to Kessler Institute for Rehabilitation in West Orange, NJ] for about three months. I had to relearn everything...how to walk, talk, eat, and swallow. My memory was also affected, and they worked with me on improving my short-term memory. My long-term memory is good.

Gerry: Many of the facilities that were recommended were in Pennsylvania, but someone had told me about Kessler

and we chose Kessler. It was a great place to go and all of the people there were great.

Spotlight: Did you receive occupational, physical, and speech therapies at Kessler?

Adam: Yes, all three.

Spotlight: Do you remember when you were discharged to come home?

Adam: I think it was the end of April.

Gerry: Adam came home on April 30, 2008.

Adam: It was awesome to come home. When I left Kessler, I told them I could walk out myself, and I did.

Spotlight: Were there any accommodations or modifications needed at your home?

Adam: When I came home, I stayed in a hospital bed on the first floor instead of upstairs in my room, because I was not ready to walk up and down stairs. I slept a lot at first. It was difficult for me to do anything.

Spotlight: Where did you go for outpatient therapy?

Adam: Good Shepherd [referring to Good Shepherd Rehabilitation Hospital in Allentown, PA].

Spotlight: Did you have any other physical problems as a result of the accident and your brain injury?

Adam: My leg, my arm, and my breathing.

Gerry: Adam saw Dr. Esquenazi for a gait analysis. [Gerry is referring to Albert Esquenazi, M.D., of MossRehab Physical Medicine Associates in Elkins Park, PA.] He had a hitch to his walk. His right heel wasn't going down all the way when he walked.

Adam: I had botox injections in my calf—six injections that day.

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Spotlight continued (from page 3)

Gerry: He was given stretching exercises. Three months later, he got another set of shots and six months later he got another set. About a year later, he got another set of shots. Dr. Esquenazi only sees him once a year now.

Dr. Mayer worked with Adam's upper extremities. [Gerry is referring to Nathaniel Mayer, M.D., of MossRehab Physical Medicine Associates.] Adam had problems with his right arm; his arm would just come up. Dr. Mayer said it would get better on its own. Adam had an appointment in June of this year. His arm did get better and he has control over his right arm.

Adam had a hard time breathing. Originally, everyone thought it was asthma. Christine Kosinski [Adam's nurse case manager from Paradigm], got us an appointment with Dr. Santarelli, who found Adam's windpipe was closed 60 to 65 percent. [Gerry is referring to Rocco Santarelli, D.O., in Wyomissing, PA.] We then went to see Dr. Mirza from the University of Pennsylvania. [Gerry is referring to Natasha Mirza, M.D., of The Hospital of the University of Pennsylvania.] Dr. Mirza said the problem was scar tissue from where the trach tube was. She did an evaluation of Adam and determined that laser surgery would be the best option to open up his windpipe. It was actually more than just scar tissue; it was also cartilage. Adam's windpipe is now opened about 70 percent.

Spotlight: You see Dr. Weiss for your medications. Correct? [The interviewer is referring to Burton Weiss, M.D., neuropsychiatrist in Philadelphia, PA.]

Adam: Yes. I go every other month for my prescriptions.

Gerry: The first doctor to prescribe medications and stimulate his brain was Dr. Fellus [referring to Jonathan

L. Fellus, M.D., director, Brain Injury Services, Kessler Institute for Rehabilitation].

Spotlight: Do you receive any other counseling?

Adam: I see Dr. Diorio every other Friday [referring to Martin Diorio, Ph.D., neuropsychologist, Good Shepherd Rehabilitation Hospital].

Spotlight: Are there any other doctors you would like to mention?

Gerry: Dr. Daniel Yeager at Good Shepherd Rehabilitation Hospital oversees everything related to Adam's brain injury, as Dr. Fellus did. Also, Dr. Jaxheimer monitors Adam's carotid artery. [Gerry is referring to Eric Jaxheimer, M.D., in West Reading, PA.] Adam will have a checkup in the beginning of 2012.

Spotlight: How did you hear about Community Skills Program?

Adam: I heard about Community Skills Program from my case manager, Chris Kosinski.

Spotlight: How long have you been with Community Skill Program?

Adam: About three years.

Spotlight: What types of activities has Community Skills Program helped you with?

Adam: First, Megan helped me. [Adam is referring to Megan Rohrbach, M.S.S., LSW, CBIS, his former neuro-rehabilitation specialist with Community Skills Program.] I relearned how to do my wash, review my checking account and statements, clean my room, clean my car, and clean my bathroom. I was put on a schedule, which I still follow today.

Spotlight: Can you tell us a little about your schedule?

Adam: On Mondays, I volunteer at United Way, or wherever they send me. I go to the gym and I do my wash. On Tuesdays, I try to go to the gym and cut the grass when it's not raining. On Wednesdays, I volunteer at the American

Cancer Society, then I go to the gym to see my personal trainer, and I clean my bathroom. Thursdays, I try to clean my room. Fridays, I have Dr. Diorio and I sometimes go to the gym. I take a nap every day in the afternoon for two hours. I go to church on Sundays.

Spotlight: You mentioned volunteering. Can you tell us a little about that?

Adam: On Mondays, I volunteer through United Way from 9:30 a.m. to 11:30 a.m. They send me to other places, like the Salvation Army, Easter Seals, and Junior Achievement, or to the United Way office in Reading.

Spotlight: What are some of your volunteer responsibilities?

Adam: It depends on where I am and what they want me to do. I do mailings, tri-fold flyers, put packets together, file, clean, and organize closets.

Spotlight: Do you have any assistance?

Adam: Suzy used to pick me up at home and take me, but I meet her at Body Zone now and she drives me from there. She helps me when I get confused. She is cool. [Adam is referring to Suzy Timins, program assistant with Community Skills Program.]

Spotlight: In 2010, you participated in United Way's week-long camp called Live United, a camp for teenagers. Did you enjoy that?

Adam: Yes, I remember I got tired a lot and you drove me home. [Adam is referring to Megan Dissinger, B.A., CBIS, neurorehabilitation specialist with Community Skills Program, who accompanied him to the camp at Reading Area Community College in Reading, PA. Due to Adam's fatigue, Megan helped him choose, by looking at the activities, what part of the day he wanted to attend. Megan conducted this interview.] I got to tell my story

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Spotlight continued *(from page 4)*

of how my life changed. The kids were cool.

Spotlight: I know you really enjoy the Salvation Army. What do you do there?

Adam: For November, I help sort food, like canned goods for needy families for Thanksgiving. In December, I sort toys for kids. They give me a paper that says what the kids want for Christmas, and I find the gifts and put them in a pile.

Spotlight: You volunteer on Wednesdays, too. Tell us about that.

Adam: On Wednesdays, I volunteer at the American Cancer Society in Temple, PA, from 9:00 a.m. to 11:30 a.m. I meet Suzy there.

Spotlight: What are some of the activities you do there?

Adam: I file, shred paper, change the sign, wash the van, and do bulk mailings.

Spotlight: How long have you been volunteering?

Adam: Almost three years at both places.

Spotlight: What do you like most about volunteering?

Adam: I like volunteering because I get bored at home and it's something for me to look forward to doing each week.

Spotlight: Prior to your accident, you worked out a lot. How has that changed?

Adam: I used to work out every day at Body Works in Temple. After my accident, I had to do exercises at Kessler and then Good Shepherd.

Spotlight: What exercises did you do at Kessler?

Adam: First, I was in the rehab room...I had to walk, bend over, balance, and lift small weights. At

Good Shepherd, I did bicep curls, bikes, elliptical, treadmill...basic stuff. I did some bench presses.

Spotlight: After Good Shepherd, it was recommended that you join a gym.

Adam: My insurance company got me a membership at Body Zone in Wyomissing, because it was local and had everything I needed. I started in September 2010 with a personal trainer, Nate Seager, three times a week, for the first eight or nine months. Now I go for personal training one time a week, on Wednesday, for an hour (12:00 p.m. to 1:00 p.m.). I started out slow, with the treadmill, bike, elliptical, and stretchy bands. Now I can bench 185 pounds. I benched it 10 times. Before my accident, I could bench up to 225 pounds. I can do more by myself. I am able to jump and run now. I have lost 22 pounds and I feel good. I went from 198 pounds to 176 pounds.

Spotlight: You mentioned you only have the personal trainer once a week now. Do you also exercise independently?

Adam: I go on my own two to three times a week, now that I can drive. I go for an hour each time. Nate gave me routines I can do when I am by myself.

Spotlight: You mentioned you drive now. When did you start driving?

Adam: I had a driving evaluation at Good Shepherd and passed, with flying colors! But I had to buy a new car since my car was stick shift. It was recommended that I drive automatic. It was also recommended that, at first, I have a parent with me while I drive. It was so I could relearn the roads, how to get places, and for safety.

Spotlight: When did you start driving independently?

Adam: About a year ago. I started with small trips, about 10 minutes, to the pharmacy, to the bank, and to church. I also went to Hamburg to the grocery store or to get some food.

Spotlight: Your parents bought you a GPS. Right?

Adam: They bought me a GPS last Christmas (2010) so I could go places and find my way home. I like it and I can use it myself. I drive almost daily and I now meet Suzy at my volunteer places. I can go to most places within Berks County. For farther trips, to Allentown, to Penn State, and to Philadelphia for my doctors' appointments, I go with my dad or mom. I usually drive one way and my dad drives the other.

Spotlight: What other groups or community activities are you involved in?

Adam: I bowl with my dad on a league team on Wednesday evenings at Berks Lanes in Sinking Spring, April through August.

Spotlight: Do you participate in any brain injury support groups?

Adam: I go to two support groups. One is in Pottsville; the other is in Wyomissing. I like going to the support groups. It is very informative for my parents to see other people like me. I feel good about going. *[Editor's Note: Adam attends the brain injury support group at Schuylkill Rehabilitation Center in Pottsville, PA, held on the second Wednesday of every month at 6:00 p.m. Adam also attends the support group at The Reading Hospital for Post-Acute Rehabilitation in Wyomissing, PA, held on the third Wednesday of every month at 6:00 p.m.]*

I also go to the "Out & About Group." It is cool to be around people like me. I like the social part of it and the friends. *[Editor's Note: Formed by Community Skills Program, the "Out & About Group" is an activities group in Berks County, PA, for individuals with cognitive disabilities and their interested family members or friends. The goal is to find friends who share*

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Spotlight continued (from page 5)

similar experiences. The group meets monthly in various locations in Berks County. Members decide which events they are interested in and help plan low-cost activities and the agendas.]

Spotlight: What are some challenges you still face?

Adam: I am still very forgetful. My memory stinks. I use my cellphone and put all important dates and appointments in it. I also have it set to remind me to take my medicine.

Spotlight: What are some of the goals you would like to reach in the future?

Adam: I hope to one day move out of my parents' house to my own place. I would also like to get married.

Spotlight: How has having a brain injury changed your perspective on life?

Adam: I am more respectful to people now than I was before, to my parents and peers. I used to drink a lot and make bad decisions. I appreciate life more—just being alive—even though some days I am depressed, just because some days are more difficult than others. I also go to church, at Saint Mary's (in Hamburg, PA), every Sunday, at 8:00 a.m. I didn't go to church a lot before.

Spotlight: Do you have any advice for others who may be recovering from a brain injury?

Adam: Make the best of every day. Listen to your doctors and your family and friends.

Spotlight: Gerry, do you have any advice for family members or caregivers?

Gerry: It has been an experience. You learn as you go. We dealt with problems along the way as they came up. The biggest thing is having the family be there for him. He is still Adam, but a new Adam, and we had to accept and understand that. It was very difficult to understand why he lost all his friends. It was explained to us by

Dr. Diorio that, when people are uncomfortable, they tend to stay away, because it is easier than being uncomfortable. Be there for the person, no matter what.

Spotlight: Adam, is there anything else you would like to say?

Adam: Brain injuries are a life-changing experience. My life changed. I have lost a lot of friends because they didn't understand what I am going through.

I would like to thank my parents and the rest of my family for being there for me through this whole thing. They are trying to understand and help me the best they can. My brother Matt came to visit me five times when I was in the hospital at Kessler. I'd also like to thank all the doctors and the various organizations that I am involved with for helping me through this as best as they can. Thanks.

Gerry: All the facilities he has been in and the people he has worked with, and still work with, have been excellent to us. I have only good things to say about everyone involved.

[Editor's Note: It is evident when reading this interview that many people have been, and still are, a part of Adam's rehabilitation process. The sharing of information and collaboration between providers (facility-based and community-based), Adam, and his parents have been essential to Adam's progress. Also essential to his progress have been the opportunities provided by organizations for Adam to challenge himself and gain more independence in natural community settings, like Body Zone and the sites for his volunteer activities. Chris Kosinski, RN, CCM, network case manager for Paradigm, was actively involved in every step along the way while serving as Adam's case manager for Paradigm. She was thorough and skillful in assessing his needs. We are grateful for her support while Paradigm was involved and want to thank both Paradigm and Travelers for the allocation of funds for services that have enabled Adam to make such noteworthy progress.]



Changing the lettering on the sign is one of Adam's work tasks at the American Cancer Society where he volunteers.

Tips On...

Free Income Tax Return Preparation

The Internal Revenue Service (IRS) sponsors two programs that offer free tax help for taxpayers who qualify. The Volunteer Income Tax Assistance (VITA) Program offers free tax help to low- to moderate-income individuals who are unable to prepare their own income tax returns. Trained community volunteers offer help with special tax credits, such as tax credits for persons who are elderly or disabled. VITA sites are typically located at community centers, libraries, schools, shopping malls and other convenient neighborhood locations. Most locations also offer free electronic filing (e-filing). For more information on VITA or to locate the nearest VITA site, call 1-800-906-9887.

The Tax Counseling for the Elderly (TCE) Program offers free help to individuals aged 60 and older. Trained volunteers, often from non-profit organizations such as the American Association of Retired Persons (AARP), provide free income tax counseling and basic income tax return preparation to senior citizens. For more information on TCE or to locate the nearest TCE site, call 1-800-829-1040.

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