



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

Caregiving and the Economy

Family Caregiving can be one of life's most rewarding experiences. It can be a testimony to love, and family values, with rewards that overshadow any stresses or difficulty encountered by the caregiver. In many cases, the choice to care for a loved one with brain injury in the home is a decision that was easily made, however the decision often requires lifestyle changes that have an impact on the entire family unit.

Often the primary caregiver leaves the work force and stays at home to provide care, thereby reducing the family income. Households accustomed to more than one pay check can find themselves having to adjust to getting by on less income.

The decision to leave the public work arena in order to provide in-home care is usually based on sound decision making and planning. No one could have predicted the economic downturns, high gas prices and other factors that are increasingly affecting American families, especially those who have chosen to live on a reduced income in order to become full time caregivers. The question then becomes; "How do we manage financially?"

Resources that can help families survive crisis situations vary by location. What is available in some areas of the state may not be available in others, thus, it can be challenging to track down needed help. There are often local resources that can help, but finding them can present a challenge.

One main focus of Project STAR is to provide resource information to persons with brain injury and their families and assist them in locating resources within their own communities. The following suggestions may be helpful for those who find they need assistance.

- Contact your local **United Way Office** to get referrals to member agencies that can provide assistance. You can locate the United Way office that serves your area by going to the North Carolina United Way website and clicking on the location of the office nearest you. Many offices are regional and serve several counties. <http://www.liveunited.org/myuw/local.cfm>
- Contact your local **Department of Social Services (DHHS)** to check for eligibility for

programs that offer aid to those who qualify. It is important not to assume you will not qualify. The process for determining eligibility is complicated and includes many different factors. Let the DSS office make the determination of eligibility. Local office contact information can be found at <http://www.ncdhs.gov/dss/local/index.htm>

- Check with local **Churches** to inquire about available community assistance programs. Many churches have programs that provide community outreach and will assist with food, heating cost and other necessities. While not all churches have such programs, a large number do. For example; Presbyterian (PCUSA) Churches often offer this type of help through their Local Missions programs and Catholic Charities operates throughout North Carolina. Other denominations also have community assistance programs.
- Contact your **Local Brain Injury Support Group**. The local support group is often one of the best sources for resource information. In many cases someone in the group has encountered a similar situation and is aware of where to go for assistance. Support groups can offer not only information, but emotional support through difficult times. Information on local support groups can be found on the Brain Injury Association of North Carolina website at www.bianc.net

It is often difficult for families who have always been self sufficient to find them selves in a position where outside help and support is necessary. For many, asking for help goes against the grain, but it is important to remember that programs designed to help during difficult times are there for the purpose of providing support for those who need it.

LET US HEAR FROM YOU!

Do you know of a resource that you would like to share with other caregivers?

If you do, please contact Project STAR at 704-355-1503 or 1-877-962-7246

or you can email us at

peggy.philbrick@carolinashealthcare.org

We appreciate input from our readers!



The Case for Revisiting Rehab

Participation in a support group can have many benefits. The groups offer a wide variety of support, such as information on community resources and emotional support and empathy, but perhaps the most important aspect of the group is the understanding and the sincere concern for the wellbeing of fellow survivors exhibited by group members.

A common scenario at brain injury support groups is a new visitor who is several years post injury and has come to the meeting seeking information or looking for solutions to lingering problems resulting from their brain injury. They may be experiencing cognitive difficulty, behavioral or emotional challenges or other injury related issues that are negatively affecting their lives. For this individual the decision to approach the support group is often the first step toward getting back into the rehabilitation mode of thinking.

Once inpatient and outpatient rehabilitation is completed, the person with brain injury often returns to their everyday life, assuming that any difficulty encountered is only temporary. For many, this is the case, but for others the difficulties do not resolve. It is often after months, or years, of struggle that they reach a point where they start to seek answers to, and solutions for, brain injury related difficulties.

The first support group meeting can be eye opening. The discovery that they are not alone, and that there are others who are coping with the same issues, can be key to understanding and managing the frustrations of living with brain injury. Another discussion that can quickly occur is the case for revisiting rehab. This is possibly the most important information that the new attendee will receive. The points made by group members, while articulated in various ways, often convey the following argument for initiating a new rehab evaluation.

One discussion that invariably comes up is *Physiatrist vs. Family Physician vs. Neurologist*. The points made in the argument for going back to rehabilitation is that *most* general practitioners have limited experience with brain injury. While a person with brain injury needs a family physician to treat the everyday maladies such as colds and other illnesses, they should also visit a physiatrist, (a physician who specializes in rehabilitation medicine) who specializes in brain injury at least once a year. A Physiatrist specializing in brain injury treats the results of the injury with a goal of addressing medical issues resulting from the brain injury (such as: headaches, seizures, weakness, pain, irritability, depression, sleep disturbances, etc.), maximizing functional ability, and enhancing the quality of life for individuals who have sustained brain injuries. The Physiatrist can help identify areas that can be improved, and work with the other specialists that might be needed for the particular issues at hand. Sometime a Neurologist is needed to help manage recurrent seizure episodes.

Medications used in the treatment and management of brain injury are constantly evolving. As new medications come on the market or older existing medications are found to be effective, there are more medication interventions available to help manage the wide range of issues that can affect the lives persons with brain injury. This adds another point to the case for revisiting rehab.

Neuropsychological testing to determine where and what compensatory strategies may be helpful and vocational rehabilitation options are frequently parts of the discussion. Many persons with brain injury have never had a neuropsychological evaluation, so they have little information on the level of impact the injury is having on their cognitive functioning, behaviors, motor skills and other areas of their lives, including the ability to find and hold a job. A physiatrist can determine if neuropsychological testing is needed and implement a treatment program based on the results.

Many brain injury survivors mistakenly assume that once they are discharged from outpatient rehabilitation it is the end of the line as far as rehabilitation is concerned. The status quo is accepted as being all there is, until the person with the brain injury, or a family member, stumbles upon a support group and hears the potent arguments made by those who have stayed connected, or reconnected to rehabilitation treatment options. A point well made at a recent support group meeting during a discussion about going back for a rehab visit is that "help won't come looking for you- you have to go look for it".

Revisiting rehabilitation to visit the Physiatrist is a good place to start.

Family caregiver needs are often overlooked by family members who are busy with their own lives and have little understanding of how consuming caring for a loved one with brain injury can be. This poem says a lot about the sacrifices made by those who choose to be family caregivers.

A Caregivers Wish List

The Holidays season is nearly here,
and I am far from eager.
I know that even at the very best,
my efforts will be meager.

You asked me what I want for my gift,
so I have given it some thought.
The things I would most like to have,
can't be bartered or bought.

I want a nap in the middle of the day,
preferably on a rainy afternoon.
I want to snuggle in my ragged old quilt,
and dream that I am visiting the moon.

I want to go over to the Shopping Mall,
and just have time to roam.
I don't want to stress over the time,
or hurry to get back home.

I want to telephone a friend,
and talk until I'm totally winded.
I want to have a complete conversation,
not one that is abruptly ended.

I want to take a long hot leisurely bath,
with lots of candles and bubbles.
I want lots of chocolate and a glass of good wine,
preferably a double.

I want to sit down and read a thick book,
and the time to absorb the whole plot.
I want to discuss the book and the story I read,
and whether I liked it or not.

I want my back rubbed and my feet massaged,
at the end of a long hard day.
I want to watch "My Name is Earl",
to see karma make him pay.

I want my whole family gathered close,
during this special season.
I want to see all conflicts put to rest,
no matter what their reason.

To answer your question about that gift,
the one I want from you,
Just an understanding hug
and a little of your time will do.

Anonymous

HAVE YOU HUGGED A CAREGIVER TODAY?

Books to Read

to LOVE WHAT is:

A Marriage Transformed

by: Alix Kates Shulman

In July 2004, the life of writer Alix Kates Shulman changed irrevocably after her husband, Scott York, fell from the sleeping loft in their remote Maine cabin and sustained a traumatic brain injury. After the accident, she became his full time caregiver. This book is the story of their life after his injury. This book is available at most book stores and on line at www.amazon.com

In Search of Wings

by: Beverly Bryant

Beverley Bryant describes her journey back from brain injury with humor, determination and courage. She helps survivors, families and rehabilitation staff understand the emotional and cognitive impact of a brain injury. This book is available through Lash and Associates Publishing at www.lapublishing.com

If you have read a good book and would like to share the information with other caregivers, please contact CareNotes at 704-355-4354 or email Peggy at peggy.philbrick@carolinashhealthcare.org

Brain Injury Family and Community Support Offices

Asheville 1-866-890-7801

Charlotte
Project STAR 1-877-962-7246

Greenville 1-800-697-3115

Raleigh 1-800-377-1464

TRIAD Resource office
Highpoint 336-687-4702

You can contact the Family and Community Support Office nearest you for resource information, or visit the BIANC website at www.bianc.net

Contributed Article

By Craig Sharp

This article contributed by Craig Sharp gives a unique insight into how brain injury can affect the life of an ordinary person, and reiterates how life can be changed in the blink of an eye. Craig is a member of the Union County Brain Injury Support Network.

Watching Life Go By

It's been eight years and twenty two days since my life changed. In a matter of milliseconds, I changed from a forward moving, happy, engaged in life individual, to someone who watches life go by. It was a "minor" automobile accident, in which the only visible evidence of injury was a massive bruise that ran the entire length of the left side of my body. That faded with time. Although I was "dazed" immediately after the collision, I never lost consciousness. To all observers, I was a little banged up, but otherwise, just fine. I believed them. I thought that after the insurance fixed my car, life would be good again. It took quite awhile for me to actually believe something was permanently wrong. It is, to this day, almost impossible to get others to believe that there is anything wrong at all. To many, I'm "lazy," or "not motivated," or "unfocused," or any of a number of other descriptive terms that imply I'm just not "willing" to pull my weight. If only they could know how much of a struggle it is just to keep up with the basic necessities of life, (which I'm failing miserably to do.)

I remember before the accident, I was driven to advance in my career, learning every new thing that I could, in my field or not. I have always been able to observe the connections between things, so as I learned my trade, my interest grew in the supporting areas around it. I could see the connections between data networking and telephony long before the public even thought it was a possibility, and pursued voice over IP before it was commonly known. I was changing jobs. My income was climbing. Life was good!

In the years after the accident, I have continued to learn. Life-long learning had become a habit that would not stop, thankfully. So what's different? I now have difficulty convincing people that my knowledge can be useful to them. The amount of time that I stop on any individual subject long enough to do anything with it is short. I watch life go by. I have difficulty engaging in life. I observe. I learn. I enjoy the sensations of life. I have a hard time worrying about things. So what's so bad about that? At some level, worry is what drives us. Will I make enough money to pay the bills? Will I make it to my appointment on time? Will I get fired if I'm late again? Try as I may, I just can't connect worry to action. I can't worry long enough for that to happen.

Many people with brain injuries are fortunate enough to have a "caretaker;" that person who assumes the role of helping the injured get through the difficulties in life; an advocate for their loved one or friend. I learned a statistic. If a marriage is going to fail as a result of a brain injury, it will happen within the first two years. Mine fell into that statistic: eighteen months. Some people just aren't equipped, for what ever reason, to be caretakers. Although I needed a caretaker for myself, it fell upon me to be a full-time single father. I was now responsible to guide my 14 year old daughter and 10 year old son to adulthood, alone.

The beautiful thing about children is that they are intuitive and reflective. While I managed to cling to what ever work I could now get, bringing home the slowly declining income, my children rose to the occasion, helping me help them. They were my motivation in life. Caring for them helped me find what little focus I had. They have become fine young adults, and now I find the nest empty. I no longer have a driving force that helps me grasp the realities of the working world.

I perform my best for those who really need my help. I have not lost my technical knowledge, and, in fact, it is as strong as ever. I find myself sharing my knowledge with those who need it, but I have yet to figure out how to earn a living at it. I need structure. I need someone to say "This is what I need," and then leave me to do it. Without structure, I just watch life go by.

Lately, having become aware of it, I have been watching myself watching life go by. I am now aware that there are times, (many times!) that I just observe what's happening around me. There is usually little emotional involvement. There is usually little involvement of any kind. It's almost like I am hyper-aware, yet without direction or coaching, I just watch, taking it all in. Any movement, any conversation, any wild train of thought, anything can capture my brief attention, I know intellectually,

that there are many things I need to be doing, yet I am unable to stop on any of them long enough to initiate action.

I am “interrupt driven.” In computers, any input that needs to be handled NOW interrupts the processor, saying, in effect, “Handle my needs now. I’m more important! Do your stuff later.” I have always been that way to some degree, but for the last eight years and twenty two days, my interrupts seem to be the only thing that can make me take action. I remember to pay the power bill (plus reconnect fees) after they turn it off! I remember to pay the phone bill when my call is routed to the billing department instead of the person I have called. I remember to prepare and send my invoices after the ATM spits out the “insufficient funds” receipt. I remember to work when someone calls me for help. I remember to apply for jobs when I notice that it’s been awhile since I’ve worked. I remember to apply for disability when... Oh, yea, I can’t seem to remember that one long enough to get it done!

Over the years, I have been fortunate enough to meet people who truly understand what has happened to me. They share ideas that have been helpful. I merge the techniques of others with the technologies that I know so well, and somehow still have faith that all will be OK. I have learned that, in spite of the lack of understanding by the majority, there is a steadily growing, yet relatively unknown community who know what it’s like. There are those who live through it and share the feelings. There are the medical professionals, caring by nature, who, for whatever motivation, have decided to get involved; to understand and help.

I have learned that there exists an alarmingly large number of people whose lives have been indelibly changed by a single event of physics. Automobile accidents, falls, sports injuries, and the horrors of war; all leave behind a trail of crumbling lives. Broken homes, strained relationships, loneliness, failure at school, failure at work, poverty, and homelessness; situations that can be traced to a single moment in time by those willing to look.

While most people are engaged in life, aware of their plans and their paths in life, they fail to understand those of us who are just watching life go by. We are the lazy ones “living off the system,” taking their hard earned money. We are the invisible people living on the street, known only to the workers paid by taxes. We are the soldiers, whose wounds sent us home to a life that will never be the same. We are the people whose lives were changed in an instant. We are the people just watching life go by.

Information shared in contributed articles does not necessarily reflect the opinions of Project STAR or Carolinas Rehabilitation. Websites and other information sources are intended to be used at the readers discretion and inclusion in this publication is not intended as an endorsement or recommendation.

WEBSITES TO VISIT

<http://www.dhhs.state.nc.us/mhddsas/>

The North Carolina Department of Health and Human Services/ Developmental Disabilities and Substance Abuse Service Website provides links to state service information including Medicaid and Community Support Services

www.carolinasrehabilitation.org

Carolinas Rehabilitation –Information on the inpatient and outpatient Brain Injury Rehabilitation Programs

www.familiesusa.org

Families USA - a site that offers information on healthcare services and advocacy issues

www.tbi.org

The Perspectives Network- Information for families and survivors including current articles of interest

www.caregiver.org/caregiver/jsp/home.jsp

Family Caregiver Alliance offers information, fact sheets, a newsletter and other information for family caregivers. It also provides links to other informational websites.

www.state.sc.us/ddsn/pubs/head/toc.htm

Making Life Work after Head Injury

A practical guide to making life work at home after head injury. This publication offers strategies and information for family caregivers and other family members.

www.icdi.wvu.edu/others.htm

Untangling the Web is a site that has links to hundreds of topics related to disability and caregiving.

www.headinjury.com

Head Injury Hotline- a site that offers links to many information sites and other resources.

If you find a website you would like to share please contact CareNotes and share the information

Researchers at Carolinas Rehabilitation are looking for persons with a traumatic brain injury (TBI) who have trouble with emotions and cognition (thinking) to participate in a research study.

The purpose of the study is to see if certain treatments are effective at improving emotional and cognitive problems after TBI.

Persons interested must:

1. Have had a moderate to severe TBI.
2. Had a TBI at least one year ago.
3. Be between 18 and 65 years old.

What's involved in this study?

1. Those who are interested will come to Carolinas Rehabilitation to review details about the study. Persons who decide they would like to participate will be asked to complete several activities that will determine if they are further eligible for the study. (Declining to participate will not in any way harm relations with your doctors or with Carolinas HealthCare System).
2. Next, participants who are found eligible will be asked to return 3 weeks later for more tests and will be randomly assigned to one of the study's three treatment programs.
3. Participants will begin their assigned treatment program. Each of the programs is free and consists of 9 one hour sessions with a therapist on the computer 3 times a week, for 3 weeks.
4. After treatment ends, there will be 3 more testing sessions: 1) within 5 days after treatment ends; 2) 3 months after treatment; and 3) six months after treatment.

Things to consider:

- Participants will be paid for their time.
- Someone who knows you best will need to complete some questionnaires on 5 occasions.
- You should have access to reliable transportation.

Call Dawn Neumann at 704-355-4211 to learn more about this unique opportunity.



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