



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

Stress and the Holidays...

timely tips for caregivers

It must be a serious issue! If you type “caregiver stress during the holidays” into Google on the internet, you will find about 278,000 sites that contain that phrase.

Caregivers are often stretched to the limit with just the day in and day out demands on their time and energy, without the added task associated with the holiday season when there are traditions to uphold, shopping and cooking to do, trees to decorate and visits to and from family and friends. Is it any wonder that the stress can become overwhelming?

The Washington State Department of Social and Health Services list some tips for managing caregiver stress during the holidays, such as;

Take care of your health

- **Eat nutritious meals.** Enjoy holiday treats, but don't give in to stress driven urges for lots of sweets.
- **Get enough sleep.** If you are awakened at night, try napping during the day to make up for your loss of sleep.
- **Exercise regularly.** Try to find someone to exercise with – it will keep you going.
- **Treat depression.** If you have symptoms of depression see a doctor right away. Depression is an illness and must be treated.

When considering those things that tend to stress you out during the holidays, it is important to remember that **you** are in charge. Taking a few minutes each day to set priorities can avoid the feeling of being sucked downstream by a raging river.

In order to have a low stress holiday season there are some simple things that may make a huge difference in how well you cope.

- Time management is important year round but especially during the holidays. The time you invest in planning is actually time saved in the long run.
- Setting boundaries or limits on what you can or cannot do, can make the difference in whether you enjoy the holiday season or just wait for it to end so that you can get your stress back to its normal level.

- **Take steps to control your expenditures.** Overspending can add to stress year-round. Set your budget within your comfort zone, make a list and stick to it. Resist impulse buying and keep track of what you have bought.
- **Don't overdo the decorating.** Consider the fact that everything you decorate must be undecorated after the holidays. Concentrate on the common rooms. Is that lighted tree in the powder room really necessary?
- **Cook some of the holiday menu items and treats ahead of time and freeze.** Many items store well and can be thawed and served on short notice.
- **Do not accept invitations just because they are extended.** Ask yourself, is this important to me and why is it important. Is it worth the time it will take and stress it will cause? If the answer to these questions is yes, then you should accept, but if the answer to one or more is no, then it is most likely not a wise expenditure of time.

There are many resources that offer tips for coping with the extra stress of the holidays, but it is important to remember that only **YOU** can control the amount of stress you create for yourself. Caregivers are often their own worst critics. Knowing your limits is often the key to managing the daily demands of the role of caregiver, and this becomes even more critical during the time of year when even those who do not carry the responsibility of caregiving often have difficulty managing the stress. Remember, **YOU** are in charge.

Holiday Stress Assessment for Caregivers

If you would like a helpful tool to assist with assessing the stress of the holidays, visit www.Caregiver.com, to find a helpful worksheet that will allow you to look at the things that create extra stress during the holiday season and evaluate their importance. This can help you decide what can be eliminated and what you must continue doing. You can find the assessment at http://www.caregiver.com/articles/holiday/holiday_stress-assess.htm

TRAUMATIC BRAIN INJURY ADVISORY COUNCIL MOVES AHEAD

On May 22, 2003 the North Carolina Senate bill S704R was ratified. This put into place a law that established the North Carolina Governors Advisory Council on Traumatic Brain Injury. The council consist of 29 members from various agencies and consumer groups and has five designated objectives.

1. Review how the term 'traumatic brain injury' is defined by state and federal regulations and to determine whether changes should be made to the State definition to include 'acquired brain injury' or other appropriate conditions.
2. Promote interagency coordination among state agencies responsible for services and support of individuals that have sustained traumatic brain injuries.
3. Study the needs of individuals with TBI and their families.
4. Make recommendations to the Governor, the General Assembly, and the Secretary of Health and Human Services regarding the planning, development, funding, and implementation of a comprehensive statewide service delivery system.
5. Promote and implement injury prevention strategies across the State.

The work of the Advisory Council continues, and we have asked Marilyn Lash, former Chairman of the Brain Injury Association of North Carolina Board of Directors, who now serves on the Advisory Council to keep CareNotes updated on what is happening with the TBI Advisory Council.

Update from the Advisory Council on Traumatic Brain Injury

By Marilyn Lash, Vice Chair

At the Council's recent meeting on September 20th, we came up with a 7 step plan for the Council for what we aim to accomplish in 2007.

1. *Increase public awareness about TBI by fact sheets using statewide data*
2. *Train groups of individuals and families for legislative advocacy*
3. *Prepare presentations of personal and Factual materials for legislators*
4. *Analyze costs of services for persons with TBI in NC*
5. *Develop interagency agreements for the state plan of TBI services*
6. *Support effective programs for brain injury prevention*

7. *Support related legislation such as gun locks, helmets, seatbelts, speed limits, etc.*

There is a saying that...

data drives policy

policy drives funding, and

funding drives services.

It is a complicated process but it begins with all of us – and each one of us has a role to play. I will be asking for your help.

We have to start with the numbers. The first question usually asked is, How many people are there in NC with a TBI? How big a problem is this?"

I will be spending time over the next few months with the Surveillance, Prevention and Awareness Committee as we sift through the data from the Injury Prevention and Violence Branch in the NC Department of Public Health. There is excellent data from 1999-2004 on the deaths, emergency department visits, and hospitalizations of individuals with traumatic brain injuries. We will be putting together single page fact sheets to help legislators and the public understand the scope and depth of traumatic brain injury in North Carolina.

However, we need to put personal faces and stories with the data. So we will be asking you to share your personal experiences to help us drive home our message. You can be the most effective advocate for improving the services available to families and individuals in your community. We look forward to working with you closely over the next year as we try to raise awareness and educate legislators and the public about the needs of persons with TBI and their families in NC.



Brain Injury Association of NC

Walk & Roll-a-thon

March 31, 2007

Five Locations across North Carolina

Locations: Raleigh: Lake Crabtree Park,

High Point: Creekside Park,

Asheville: To be announced

Greenville Area: Location to be announced

Fayetteville: Location to be announced

For Information Contact: Susan Fewell at The

Brain Injury Association of NC

1-800-377-1464

Caring for Family in the Home

CAP- Waivers may be the answer

In North Carolina, The Department of Health and Human Services provides services for eligible persons with traumatic brain injury through the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DHHS/MH/DD/SAS). The Department of Social Services (DSS) also provides services for eligible individuals with disabilities.

There are four types of CAP (Community Alternative Programs) programs, through which adults and children with disabilities can receive community-based services if they are determined eligible for the services. These programs are offered through either DSS or DHHS/MH/DD/SAS

- CAP/DA (Community Alternatives Program for Disabled Adults) provides a package of services to allow adults (18 and older) who qualify for nursing facility care to remain in their private residences. This program is administered through Department of Social Services/ Medicaid.
- CAP-MR/DD (Community Alternatives Program for persons with Mental Retardation or Developmental Disabilities) provides community services to individuals of any age who qualify. Services within this program are managed by DHHS/MH/DD/SAS. Individuals who have a TBI may be eligible for CAP-MR/DD since TBI is defined as a developmental disability through DHHS/MH./SAS.
- CAP-C (Community Alternative Program for Children) provides services to medically fragile children who would otherwise require long term hospital care.
- CAP-Aids services persons of any age with Aids and children who have tested HIV positive.

Determining what type of services best fit the needs of the individual with TBI and what programs they can qualify for can be confusing. Consider the following information. Many persons with TBI who need a higher level of nursing care may qualify for and benefit from services through CAP-DA. The CAP-MR-DD the Home Community Support (HCS) program can offer assistance for individuals to accomplish tasks that involve daily living activities. North Carolina Division of MH/DD/SAS defines Home Community Support (HCS) program as: "Assistances to individuals for acquiring, retraining and improving self-help, socialization and adaptive skills necessary to reside successfully in home and community-based settings. Habilitation (to develop skills), training and instruction are coupled with

elements of support, supervision and engaging consumer participation to reflect the natural flow of training, practice of skills and other activities as they occur during the course of the consumer's day." When discussing CAP-MR/DD services, request information about this program to determine if it could be beneficial for the individual applying for services.

To address eligibility questions for CAP-MR/DD, CAP-C, or CAP-Aids contact your Local Management Entity (LME) through Area Mental Health. This information is available by county on the DHHS/MH/DD/SAS website at www.dhhs.state.nc.us.mhddsas/tbi. To address eligibility questions regarding CAP-DA contact your local Department of Social Services. The local phone number can be obtained in the government pages of your phone book.

MARCH IS BRAIN INJURY AWARENESS MONTH

It is not too early to begin plans for Brain Injury Awareness Month. Individuals and support groups across the nation can use this designation to educate their communities about brain injury.

There are many ways individuals who provide care of a loved one with brain injury can become involved.

Local Support Group Activities: If you participate in a local support group, urge the group to organize events that would spotlight brain injury and educate the community.

Legislative Advocacy: Contact your local and state elected officials and ask if you can speak with them about brain injury and how it affects families who experience it. Be prepared with fact sheets and specific ways the legislator can help.

Public Bulletin Boards: Use bulletin boards at locations such as grocery stores and other public locations to post fact sheets and other information about brain injury. Fact sheets and other information are available at <http://www.biausa.org/biam.htm>

Health Fairs and Community Forums: Contact local healthcare agencies who may hold health fairs and ask if they can offer information on brain injury as part of their focus.

Speak about your experiences: Churches and other organizations may allow you to speak about your experiences as a caregiver of a person with brain injury.

Securing the Future ... Exploring the options

Contributed By: Ryan Platt, MBA SPC

As a caretaker, you have sacrificed willingly for your loved one, and as time marches on your concern becomes how you can continue to care for your loved one long term. There comes a point where you realize that someday you may no longer be able to care for them, and it is important to ensure they are taken care of in the manner you see fit.

It is understandable that as you search out answers you can become overwhelmed and frustrated because solutions are hard to find, and then of course are difficult to fund. Depending on your individual situation, there are numerous ways you can accomplish your goal and provide the life to your loved one that they deserve. For instance, there are certain trusts that you can set up and fund on an on-going basis that will protect government benefits (like Medicaid and SSI), but still provide for care beyond the government's scope. You can use simple savings vehicles within the trusts to fund these. I have included four vehicles below:

1. ***Money Market Account****– This account will normally provide a better rate of return than a regular savings account in the bank
2. ***Mutual Funds****– This type of an account is a security that gives small investors access to a well-diversified portfolio of equities, bonds and other securities. Each shareholder participates in the gain or loss of the fund. Shares are issued and can be redeemed as needed.
3. ***Annuities**** – This type of vehicle can be used to accumulate money, but also is designed to provide a guaranteed income stream for life
4. ***Life Insurance****– There are many types. Certain types afford you a death benefit plus a build of value inside called cash value that you can use for any purpose

These trusts can also be funded after death. Typically, life insurance is used to accomplish this:

1. ***Permanent Life Insurance****– This type will provide you a death benefit, but can also be used as a savings vehicles. (See above)
2. ***Term Life Insurance****– This type will provide a death benefit for a fixed period of time. For instance, a 10-year term life insurance policy will provide you a death benefit for 10 years. If you do not die within the 10 years, your cost will either increase or your policy will expire and you will no longer have any life insurance

Obviously, there are numerous ways for you to ensure proper care for your loved one. It truly is an individual decision that is based on your specific situation.

These are very general category topics for complex financial tools. All these vehicles are taxed differently and that should be considered when you are selecting the best one to use for your situation. All information contained in this article is of a general nature and should not be taken as specific legal, tax or financial advice. Before making any financial decisions it is best to consult your legal, tax and financial advisors to ensure decisions you make fit within your specific situation.

Ryan Platt is a Special Needs Care Planner with the Hinrichs Flanagan Financial, Personal Strategy Group. In this role he assist families of persons with special needs with planning for the future of their loved one.

Want to know more?

Have you ever wondered what would happen if you were no longer able to care for your family member, or what will happen to them when you are gone? While many families are able to arrange for the continued in-home care of their loved one, care is not the only consideration that needs to be addressed. Insuring the continuation of government benefits and other factors can greatly impact the future of the person being cared for.

Project STAR at Carolinas Rehabilitation will host a workshop to help families learn the steps necessary to plan for the future of their loved one with brain injury on March 9, 2007. Watch for additional information on how you can register to attend this workshop.

Information in contributed articles is solely the views and opinions of the person contributing the article and does not necessarily reflect the views of Project STAR or Carolinas Rehabilitation. Source information for all articles in CareNotes is on file at Project STAR. For additional information, contact Project STAR at 1-877-962-7246

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.headinjury.com

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

<http://birf.info>

Brain Injury Resource Foundation offers general information as well as information on healthcare services and advocacy issues.

www.aapd-dc.org

Justice for All - a site maintained by American Association of People with Disabilities

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

STORIES NEEDED

CareNotes would like to have personal stories from family caregivers to share with our readers. Your experiences as a caregiver of a family member with TBI could serve as an inspiration for others who are also filling the role of family caregiver. If you would like to share your story with others please contact Project STAR at 704-355-1502

BOOKS TO READ

Brain Injury-It's a Journey

This is a practical user-friendly manual to help families understand the consequences of brain injury. Edited by Flora Hammond, MD and Tami Guerrier, B.S.,C.T.R.S. with the Brain Injury Program at Carolinas Rehabilitation and published by Lash and Associates the book offers detailed descriptions of how a brain injury can affect physical abilities, cognition, behavior, emotions and communications.

Available at www.lapublishing.com

A Change of Mind

Written by Janelle Breese Biagioni, the wife of a brain injury survivor, this book offers a look into the emotional rollercoaster of family life and relationship issues that she experienced after her husband was injured in a work accident.

Available at www.lapublishing.com

The Poem Book

Reflections of a Brain Injury Survivor

This book of insightful poems by brain injury survivor, Daniel Windheim. In his poetry he expresses all of the emotions that accompany his journey through the world as a person with a brain injury. It is available for purchase online from Daniel's web site at TBI Life or from book stores. The *TBI Life* web site also publishes poems from other people with a brain injury.



Brain Injury Association Of North Carolina

Toll-free Helpline 1-800-277-1464
Triangle Family and Community Support Office
Raleigh, North Carolina
800-377-1464 or 919-833-9634
Family and Community Support Office
at Carolinas Rehabilitation
Charlotte, North Carolina
877-962-7246 or 704-355-1502
Eastern Family and Community Support Office
Greenville, North Carolina
1-800-697-3115 or 252-439-1900
Western Family and Community Support Office
Asheville, NC
828-277-4868



Project STAR at Carolinas Rehabilitation at 704-355-1502

For Information Contact:

Wesley Chapel, NC

6301 Weddington – Monroe Road

Siler Presbyterian Church

8:30 AM – 4:30PM

March 9, 2007

This workshop is to help caregivers who are providing care for a loved one with brain injury plan for the time when they are no longer able to provide care for their loved one. The workshop features speakers and displays to help families determine the steps they need to take to insure that their family member continues to receive the type of care they deserve, long after the family caregiver is out of the picture. Often when the primary caregiver dies or becomes disabled it can spell disaster for the person for whom they were providing care. The preservation of benefits and the continuation of quality care are important and this workshop offers information that can help people get the planning process started.

Beyond Tomorrow
Planning for the future

Project STAR
Carolinas Rehabilitation
1100 Blythe Boulevard
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