



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

What about the Future?

Project STAR at Carolinas Rehabilitation has long held the desire to support those who are in the role of caregiver to persons with brain injury.

In past editions of CareNotes, we have touched on the role of family caregivers in the care of loved ones with brain injury, and have featured contributed articles on preserving benefits, and planning for the future. While all family caregivers hope to be around forever and to continue to provide the needed care for their family member, the reality is that at sometime in the future, they may have to relinquish the responsibility to someone else.

This issue of CareNotes continues the focus on planning for the future, and offers some tips on record keeping and communication that can greatly impact the future of the person being cared for.

Project STAR recently hosted a one day workshop that offered families the opportunity to learn about preparing for the time when they can no longer provide the hands on care that they now provide. The information shared by the professionals at this workshop included, record keeping and communication, guardianship, residential options, financial planning, advocacy and legal options for special needs trust and other financial considerations.

It is the goal of Project STAR to share some of the information from this workshop in this, and future editions, of CareNotes. It is hoped that you will find this information useful.

If you have comments or suggestions, please contact Project STAR at 704-355-1502 at toll free at 1-877-962-7246 or by email at peggy.philbrick@carolinashealthcare.org

AGENCY SPOTLIGHT...

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North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) oversees the state's public system of services to persons with Traumatic Brain Injury.

North Carolina general statute includes traumatic brain injury (TBI) in the definition of developmental disability. A developmental disability is defined as a severe, chronic disability of a person which:

- Is caused by a mental or physical impairment or a combination of mental and physical impairments.
- Occurs before the person is 22 years of age, unless the disability is caused by a TBI and is sustained after the age of 22.* (**Traumatic Brain Injury services fall into this designation regardless of the age of the individual at the time of onset.*)
- Is likely to continue indefinitely.
- Results in difficulties in three or more areas of major life activities such as self-care, language/communication, living independently, learning, mobility and working.

In North Carolina support is available for eligible individuals of all ages with TBI.

The first step in determining eligibility for services is to contact your Local Management Entity (LME) referral and information line. Intake coordinators will ask questions to, assess needs and the urgency. They may also ask for medical records which document the TBI. This will help determine eligibility for services.

Once eligibility is determined those eligible will be assisted with choosing a service provider in their community who can provide services to meet the needs of the person with TBI. This provider will then work with the individual and family members to determine a personalized service plan.

Person Centered Planning explores what an individuals needs are and ways to address these needs. Some examples of services include in-home support, residential services and assistance with finding a job.

Services may vary in some areas due to the limited services and service provider options available. The local LME will work with eligible individuals to reach the best service options available.

To locate the Local Management Entity or area program that serves your community visit www.dhhs.state.nc.us/mhddsas/tbi or call 919-715-5989.



Good Caregiver Advice

"Worri'n' is like a rockin' chair...
...It gives you something to do...
... but it doesn't get you
Anywhere."

Tom Wilson as "Ziggy"



Record Keeping...

for now and in the future

Record keeping may be one of the most important functions of the primary care-giver. While there is no substitute for the information stores and knowledge a caregiver can gain over the years, good record keeping can help bridge the gap. Good documentation can significantly improve the learning curve of whoever assumes the responsibility when the primary long-term caregiver is not available to provide care.

Setting up a flexible, and easy to maintain, system to help keep information organized is essential. While no single method will work for everyone, many caregivers have successfully used a system of keeping records organized by category. This method requires little or no copying unless a service provider needs a copy of a specific document. It provides portability and can accompany the person with brain injury to doctor appointments and other places where access to current and past information may prove invaluable.

Outlined below is a basic guide to one of many effective methods of record keeping:

Supplies Needed:

- 1 or more Loose-leaf Binders (this will depend upon the amount of information to store)
- A 3-Hole Punch set to match rings in the loose-leaf binder
- A package (12 minimum) of Page Dividers with insert tabs
- 1 Three-hole Composition Book
- Loose Leaf Notebook Paper
- Zipper containers that fit a loose-leaf notebooks or 1-gallon size zip-lock bags. (The bags can be hole punched in the bottom and used instead of the zipper containers.)

Suggested Divider Titles and Content:

Personal Information: Biographical information such as name, birth date, place of birth, social security number, address, etc., should be included in this section. It can also include educational history, preferences in food, likes and dislikes or any other information of a personal nature. A list of immediate family members, contact information and relationship to each may also be included.

Healthcare Providers: This section should include information on all medical personnel involved in the care of the individual. It is best to have a sheet for each provider in order to add information or make changes. Dates of visits should be listed in order to create a historical record for the provider. New providers should be added as they become involved and information for providers no longer involved should be removed and placed in a plastic container at the back of the section.

Physician Clinic Notes: This section should include the Doctors notes and reports for all visits to any physician regardless of the reason. These can be organized by physician or in chronological order. Physicians will supply copies of the notes when requested. A written and signed request for a copy of the notes should be presented at the time of the visit.

Medication History: Develop a log sheet to track medications. It is also important to keep copies of the drug information sheets for prescription medications as well as an ongoing log of medications. If there are allergic reactions or other issues such as behavior changes, etc., these should be documented in this section. The least work intensive method is to hole punch the information sheets for easy filing. If the information sheet does not include the prescription information, a copy of the medication label can be stapled to the sheet. In order to keep this section from becoming cumbersome, replace the sheets for current medications each time a prescription is refilled and discard the old sheets.

- *When a medication is discontinued, the information sheet can be placed in a plastic container and be kept for future reference.*
- *The log sheet should be a record of all medications prescribed and notations on refills, etc. It is important to indicate dates when medications are discontinued as well as when prescribed.*

History and Physical: This section should contain hospital admit and discharge notes that describe the injury, assessment and treatments as well as discharge plans. These should include reports for all hospitals, rehabilitation and other treatment facilities and should include each hospitalization.

Insurance/Financial: Information on insurance and other financial information can be important in securing services. Copies of insurance cards, Social Security card, Medicare or Medicaid card, VA benefits card or any other applicable entitlement information should be kept together in this section. If a card or document is two sided it is important that the copy is of both sides.

Community Information: This section should contain information on any community programs and/or agencies associated with the individual. These may include Area Mental Health, Social Services, and Vocational Programs, Support Groups or others. Information should include the name of the contact for each agency and the role of that the agency or group. Frequent updates are important to insure that the contacts are accurate. Information on agencies and programs not currently involved can be placed in a storage bag.

Family and Friends: Include a list of family members along with mailing addresses and telephone numbers. A notation of relationship should accompany each listing.

Emergency Information: Emergency contact information should be included in this section along with preferred backup if the primary emergency contact is unavailable. It is important to keep this list current and to make sure the emergency contacts are aware of their responsibilities if an emergency occurs. They should be aware of the existence of the Record Book and have access to it. If there is a medical power of attorney, a living will or other legal documents that may be needed during an emergency copies of these documents should be included in the book. The persons likely to handle an emergency in the absence of the primary caregiver must know where the original notarized documents are stored in case they are needed.

Personal History Notes: This section serves as a diary of information that can be used for various purposes. One such use is to document events and situations that affect the individual. It may also be used as a tool to communicate with other caregivers when the care giving is a shared role. Information can be reviewed before doctor visits in order to address any noted concerns. A 3-hole composition book that can be replaced when full works well for this purpose. Completed books should be stored for future reference.

While each caregiver must develop his/her own method of tracking and storing information, it is important to keep it simple. Records should be kept in such a way that anyone who may need to draw from the information can locate the facts they need with minimal effort. Good record keeping can insure appropriate and speedy treatment in emergencies and avoid mistakes that could have a negative impact on the person with brain injury.

www. HELP! finding information to help family caregivers

Family caregivers often struggle to find the support and information they need. With the volume of information available on the internet, there are more resources and information available than ever before. Many of the websites are interactive and allow family caregivers the opportunity to communicate and share ideas with other caregivers. These websites offer a wealth of information to benefit, not only the person receiving care, but also the family member who is providing care.

The websites listed below are some examples of the type of interactive web support that is available.

Caregiver.Com Magazine Website <http://www.thefamilycaregiver.org>

The National Family Caregiving Association (NFCA) <http://www.familycaregiving101.org>

National Alliance for Caregiving <http://www.caregiving.org>

The National Caregivers Library <http://www.caregiverslibrary.org>

TBI Help Desk for Caregivers <http://www.tbihelp.org>

NC Family Caregiver Support Program <http://www.dhhs.state.nc.us/aging/fcaregr/fchome.htm>

If you are aware of other websites that offer support to family caregivers, please let us know so that the information can be shared with other caregivers. Please send us the link. You can email us at peggy.philbrick@carolinashealthcare.org or contact us by phone at 704-355-1502 or 1-877-962-7246.

Contributed Article

BIG SHOES TO FILL By Perry Fisher

Many issues arise when we are asked to represent someone who is not fully able to look after himself or herself. Representing someone incapacitated through a brain injury brings an additional set of issues. Disability checks, tax returns, contracts, motor vehicle titles, and medical treatment directives all require the signature of the person affected or someone officially designated as their legal representative. Being the primary caregiver is not enough to establish legal authority. The first thing to determine is whether the person is capable of making legal decisions. If they just need guidance or assistance that can be provided without more formal paper work. If the person has enough capacity to make legal decisions, but that capacity may not be consistent or is expected to diminish, then more formal paper work is needed.

The most typical representative designating paperwork is a Power of Attorney. A Power of Attorney is simply a legal document by which one person authorizes another to act on their behalf. In order to execute a Power of Attorney, the person needs only "legal capacity". Everyone is presumed to have legal capacity. Legal capacity is defined as the capacity to understand the nature, scope and effect of the act in which the person is engaged, to understand what they are contracting to do or refrain from doing, to know with whom they are transacting, and to understand the purposes for which they are contracting and the consequences of their act. A party may have sufficient legal capacity although he does not act wisely or discreetly or drive a good bargain. Furthermore, a party may also have sufficient mental capacity even if they are suffering from a mental weakness or infirmity. *Caudill v. Smith*, 117 N.C. App. 64(1994).

Once the decision is made to execute a Power of Attorney, the first step is to select a representative. This person needs to be able to look after the legal and personal affairs of the injured person with a focus solely on what is best for the injured person. The person selected must not have a conflict of interest. Once the person is selected, (selecting alternate representatives is always a good idea), the scope of that representation needs to be determined. It is important for the person designated as the attorney in fact to know and follow the injured person's wishes, not those of others.

Generally speaking, Powers of Attorney in North Carolina can be either Durable or Limited. A Limited Power of Attorney is for a specific event, act or time. A Durable Power of Attorney continues until the death of the brain injured person.

Limited Powers of Attorney ends upon a person's mental incapacity. Durable Powers of Attorney are typically used for the brain injured.

The scope of the powers granted by a Power of Attorney document can include some or all of the following: The business affairs, legal transactions, and all manner of healthcare decisions. Healthcare decisions include changing doctors or hospitals to also the treatments given or used by those doctors.

If a person who is brain injured lacks the legal capacity to sign a Power of Attorney document then a proceeding before the Clerk has to be started in order to appoint someone as legal guardian. In a future article we will talk about the steps involved in getting appointed legal guardian. Those steps are complicated and can rarely be done without the assistance of an attorney. The brain injured need compassionate people looking after their interests. A good Power of Attorney is the best way to designate a representative. Those who act in representative capacity are truly special people.

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RESOURCES



Finding resources and information can be frustrating to caregivers and persons with brain injury, and while there are many agencies and resources that can help meet the needs of persons with brain injury and their caregivers, locating the right service can at times be challenging and frustrating. Some communities offer services that are unavailable in others,

but state and federal agencies serve all areas.

The Brain Injury Association of North Carolina has created a Brain Injury Resource Guide to help persons with brain injury in North Carolina locate resources that may meet their needs.

The resource guide that list state and local services that serve persons with TBI is available on the Brain Injury Association of North Carolina's web site at www.bianc.net or you can receive a copy by becoming a member of The Brain Injury Association of North Carolina. For information on how to join please contact the Triangle Family and Community Support office at the number below.

1-800-377-1464

The benefits of Support Groups...

People attend support groups for many different reasons. Some go for the fellowship, some to give or receive emotional support and empathy, and some just go for somewhere to go and something to do, but information is the one thing that everyone gains from being involved in a support group. Sharing information and experiences with others in like situations can allow participants of support groups to find resources of which they are unaware.

North Carolina has a network of support groups that meet around the state. These groups receive information and support from the Brain Injury Association of North Carolina through the Family and Community Support Offices. Project STAR at Carolinas Rehabilitation maintains contact through e-mail with support group leaders to insure that all groups have access to information. Each community support group is unique as determined by the needs and interest of those who attend. As this network grows to include new groups, communities that do not currently have a support group are encouraged to start one. Below is a list of current support groups. For additional information on the group nearest you can contact the number listed.

Asheville Karen Harrington 1-866-890-7801	Durham Shani Cohen 919-529-1241	High Point Diane Rankin 336-889-7922	Greensboro Lucy Hoyle 336-382-7450	Monroe Project STAR 704-355-1502	Statesville Kim Munroe 704-528-0399
Cary Leslie Johnson 919-336-2576	Fayetteville Ellen Morales 910-486-1101	Jefferson Wylene Taylor 336-246-4542	Greenville Darlene Wetzel 1-800-697-3115	New Bern Amy Davis 252-514-2918	Wilmington Vance Williams 910-815-5618
Chapel Hill Karla Thompson 919-966-8813	Gastonia Shirley Moore 704-884-2500	Lake Norman Sylvia Whitmire 704-224-6069	Henderson Mike Scott 252-738-0707	Raleigh Monica McGrath 1-800-377-1464	Winston Salem Robin Alexander 336-718-3407
Charlotte Project STAR 704-355-1502	Gastonia Traci Iradi 704-671-5738	Lenoir Pam Gilbert 882-758-0463	Hickory Crystal Podger 828-304-9096	Rocky Mount Emily Ellis 252-451-3704	
Concord Gayle Pittman 704-888-4110	Goldsboro Pier Tarrant 919-689-3268	Lincolnton Melody Thompson 704-736-2625	High Point John Peeler 336-887-0745	Stanly County Margaret Owen 704-485-2483	

If there is not a support group that meets near your home, you can contact the closest Regional Family and Community Support Office of the Brain Injury Association of North Carolina for assistance with starting one.

Raleigh 1-800-377-1464 Charlotte 1-877-962-7246 Asheville 1-866-890-7801 Greenville 1-800-697-3115

Tips and Tidbits

WHAT ARE YOU LOOKING FOR...???

Medication information: Sometimes it is difficult to locate information on the usage and side effects of medications. The Medco Health Pharmacy website offers detailed information on many medications, including those frequently used to treat persons with TBI. The website also offers information on non-prescription and over the counter medications.

www.medcohealth.com

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.

Upcoming Events

March 31 BIANC Walk & Roll-a-thon
Five locations across NC
1-800-377-1464

April 27-29 Camp Carefree Brain Injury
Survivors Camp
Stokesdale, NC
To Register: 1-800-377-1464

May 2007 Certified Brain Injury Specialist
Training
For Information: 1-800-377-1464

May 19 Fun at Hinds' Feet Farm
For Information 704-355-1502

June 9 Annual Water Ski and Picnic Event
For Information: 704-355-1502

If you know of events that may be of interest to other caregivers please contact Project STAR at 704-355-1502 or by email at peggy.philbrick@carolinashealthcare.org

Carolinas Rehabilitation



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