



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

Planning for the Future Now...

Never is not an option

After a family member sustains a brain injury, many families choose to care for their injured family member in the home, while others, who are unable to provide the needed level of care, opt for residential placement. Regardless of the living situation or the amount of hands on care needed, family caregivers play a vital role in the wellbeing of the individual with the injury.

Frequently, the primary caregiver is a parent caring for an adult child, or a spouse who is caring for their spouse, but regardless of the situation, caregivers often have little or no backup in case they encounter a problem and cannot fill the caregiver role. The responsibility then falls to other family members, or professionals, who must step in and assume the caregiving role, often with little or no knowledge of what is involved in the caregiving process.

In 2007, the spring and summer issues of CareNotes, focused on planning for the future care of persons with brain injury who are currently being cared for by family members.

Project STAR feels it is time to revisit this topic. This issue will reprint some articles from those editions, plus other information on putting a plan in place to insure that the family member with brain injury continues to receive quality care, even after the current caregiver can no longer provide that care.

It is human nature to avoid thinking about a time when we are unable to do things we do today, or that time when we are no longer here, but avoidance is not an option for those who provide care for a family member with brain injury. The future of the person with brain injury depends upon a good plan for continued care.

Project STAR would like to thank those who contributed articles for this edition of CareNotes and allowed us to reprint articles from previous CareNotes.

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!

Medicine Cost- A tough pill to swallow



When talking with persons with brain injury and their caregivers, one of the things we often hear is that paying for needed medications is difficult if not impossible.

Internet sites can offer a wealth of information on programs designed to assist those who qualify with getting help with medications. Here are a few.

NeedyMeds.com

www.needymeds.com

NeedyMeds.com list 410 companies, many of whom offer medication assistance programs to those who qualify. The site is easy to navigate and offers information in a easy to understand format. In most cases eligibility guidelines are included in the program information and applications can be downloaded or faxed to the applicant or their physician. Other links allow visitors to the site to look at state and federal programs as well as other useful links. When you visit this site you may want to pack a lunch, the information and links are seemingly endless, and it may take a while.

RxAssist

www.rxassist.org

RxAssist requires registering for a free account to access the information. There is a patient information registration as well as one for prescribing professionals. The site is easy to navigate. The program offers about 125 generic medications used to treat a variety of conditions and is available to individuals and families with incomes of up to 300 percent of the federal poverty level. For a family of four, this figure is about \$63,600 per year. Through this program, people who qualify financially can get more than 125 generic medications.

Partnership for Prescription Assistance

www.pparrx.org

The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them.

Do not hesitate to ask your physician about programs that offer free or reduced cost medications. Do your homework by researching what several different programs offer, and go prepared to present information on available programs if your physician is unaware of them. Remember, it never hurts to ask!



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.

Below we have identified some of the information that could be invaluable to persons who find they must step into caregiver roles. Whether it is done by a filing system using a file cabinet, or by using notebooks or other organizational methods clean, precise and thorough record keeping can be the difference between a good caregiver transition or a poor one.

Personal Information: Biographical information such as name, birth date, place of birth, social security number, address, etc., should be included. 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.

Emergency Information: Emergency contact information for the primary contact, along with the preferred backup, if the primary emergency contact is unavailable, should be readily available. It is important to make sure the emergency contacts are aware of their responsibilities if an emergency occurs. They should be aware of the existence of the healthcare and other information 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 easy to access. 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.

Healthcare Providers: Records should include information on all medical personnel involved in the care of the individual. Keeping the information for each provider is important in order to establishing treatment history. Information should include dates of visits in order to create a historical record of treatment. New providers can be added as they become involved.

Physician Clinic Notes: It is important to keep copies Doctors notes and reports for all visits to any physician regardless of the reason. Most 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: Developing a log sheet to track medication history can avoid complications at a later date. If there are allergic reactions or other issues such as behavior changes, etc., these should be documented.

History and Physical: Hospital admit and discharge notes that describe the injury, assessment and treatments as well as discharge plans can be important in seeking medical attention or appropriate residential placement. These records should include reports for all hospitals, rehabilitation and other treatment facilities and should include each hospitalization, no matter what the reason.

Insurance/Financial: Information on insurance and other financial information can be important to securing services. Copies of insurance cards, Social Security card, Medicare or Medicaid card, military discharge papers, VA benefits card or any other applicable entitlement information are best kept together and accessible to those who may need to act as a caregiver. If a card or document is two sided it is important that the copy is of both sides.

Community Information: Information on any community programs and/or agencies associated with the individual can be important to document. These may include Area Mental Health, Social Services, vocational programs, support groups or others. Include information on the name of the contact for each agency and the role of that the agency or group. Making frequent updates insures that the contacts are accurate.

Personal History Notes: A diary of personal information can be useful 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.

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.

Contributed Article

BIG SHOES TO FILL By Perry Fisher, Attorney at Law

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.

Perry is an attorney that specializes in representing individuals with traumatic brain injury..

You may reach Perry at 1-800-220-0550 or through his website at www.braininjurync.com

Safety Strategy

New technology can often offer innovative methods of enhancing the care of persons with brain injury. There is a new and innovative product called the "Wellness Wizard" that is an easy to use caregiver's assistant. The device, which retails for around \$150.00, can be programmed as a medication reminder, to call up to six numbers on a rotational basis in an emergency, as a daily planner to maintain schedules or keep appointments, and has many other uses. It can also call the caregivers cell phone with reminders. You can get more information on the "Wellness Wizard by visiting their website at www.safetyandwellness.com

Contributed Article

THE WORST CASE SCENARIO ...Good Intentions are not always good! By Ryan Platt

A Story.

As the Caregiver, you have thought ahead, met with a SpecialCare Planner and have developed a plan that will take care of your loved one with special needs in just about any situation, especially in the event you are no longer able.

As you developed your plan you considered Living Arrangements, Medical Care, Education / Training, Employment, Social Life, Necessary Equipment, Needed Income and then projected the Lifetime Costs of these items. You then examined the benefits your loved one would receive from the government and realized not all those items would be covered and the items that are covered were not covered to your satisfaction. It has always been your goal to provide your loved one a Life, not merely an existence.

You and your SpecialCare Planner determine that a Special Needs Trust would certainly be necessary in this situation. This type of trust will provide for those things that government benefits will not, and it moves assets out of the name of your loved one so that they can qualify for these government benefits. You design your trust, fund it based upon your estimation of Lifetime Costs subtracting the expenses that government benefits will pay, choose a guardian and select a trustee. You feel good that you have taken the time to secure the future of your loved one.

And Then YOU DIE.

Your sister, Mary, feels awful and she wants to help. She does not have a great deal of money, but she starts an account in the name of your loved one with \$8,000 and sends it as a gift. Unfortunately, this one act of benevolence just undid all your work to secure your loved one's future. This small amount of money is now an asset of your loved one, and will cause them to forfeit many of the government benefits you were trying to protect. Now, your calculations of lifetime costs minus expenses paid by government benefits is disastrously incorrect, because the government benefits will be drastically reduced if not totally eliminated. This means that your loved one only has the money that you provided in the Special Needs Trust to last the rest of their life, which based on the plan will not be enough and your vision, your hopes and your dreams for your special needs loved one are lost.

How can this situation be averted?

It is all about taking the last step. The final step in your process is to always communicate the plan to immediate and extended family so that everyone is on the same page and that your wishes are carried out in the manner in which you determine!

What is at stake?

For individuals and families in a special needs situation, benefits are vital. Benefits can range from resources to answer questions, to medical insurance, and can even include income. For many people, these benefits will be subsidized by the government. Unfortunately, there is great confusion about these benefits, especially how to utilize them effectively, and how to ensure they are not forfeited.

Government Benefits that might be affected by Mary's gift.

- *Medicaid is a program that is paid for by the federal government and by the states. Medicaid covers the cost of certain medical care and procedures for low-income individuals. You must qualify based on income and assets. For children with special needs who are under 18, those income levels are based on their parents, but for those over the age of majority the qualification changes and is based on his or her income. For this reason it is important to understand the implications of any assets or any earned income that will be considered in the individual's name.*
- *Medicare is a government health insurance program and is available to children and adults with certain disabilities. For a child, eligibility will be based on the parent receiving Social Security or the parent working long enough to be covered by Social Security Disability Insurance.*
- *State Children's Health Insurance program (SCHIP) is a program specifically for children in low-income situations that are ineligible for Medicaid and are uninsured.*
- *State-Mandated Insurance Programs are for those who have been refused health insurance, offered health insurance at a higher-than-standard premium or have been offered health insurance with a rider that reduces the coverage.*

THE WORST CASE SCENARIO *continued...*

- *Social Security Income (SSI) is available for persons under the age of 18, who's disability will last for more than 12 months or result in death, and who's parents' income and resources are limited. After the age of 18, the individual becomes eligible for SSI based on his or her own income and assets.*
- *Social Security Disability Insurance (SSDI) is based on qualifications for Social Security Retirement of Disability benefits. Children under the age of 18 may also be eligible based on the parent's eligibility and can continue to receive benefits in adulthood, if disabled before the age of 22.*

Obviously, every situation differs; however, it is important to understand how government benefits can play a role in your life. You may be able to utilize them in order to minimize the personal burden. It is important to structure your assets and income correctly in order to be eligible and to not forfeit these invaluable services and benefits.

Ryan Platt, as a Special Needs Care Planner with the Personal Strategy Group of Hinrichs Flanagan Financial in Charlotte, NC. Ryan works with families of children and adults with disabilities to effectively plan for the future..

www.hinrichsflanagan.com or 704-557-9630

IN CASE OF EMERGENCY...

In a recent article, Caregiver.com addressed in home emergency escape planning for persons with mobility challenges.

This thought provoking article brought safety concerns front and center to Project STAR, especially in light of the number of persons with brain injury who might have both physical and cognitive difficulty that could impact safety in an emergency situation in their home.

By considering the types of emergencies you might encounter and what would be required to make sure the family member with brain injury could be evacuated safely, you will be able to put a plan in place to handle the situation, should it arise.

The article points out many things that can be done to create a emergency preparedness plan, including some home maintenance suggestions and other steps such as rehearsal of what you should do in case of various situations, should they arise.

Not all brain injury survivors have physical limitations, but cognitive issues could also affect the safety of a person with brain injury. Having a plan and making sure everyone who may be involved is well rehearsed could be the difference between getting by unscathed, or possible injury or death.

You can find this article as well as other informative articles for caregivers from CAREGIVER.COM on line at

http://www.caregiver.com/channels/mobility/articles/safety_begins_at_home.htm

Upcoming Events

- October 3-5** Camp Carefree Brain Injury Survivors Camp
Stokesdale, NC
To Register: 1-800-377-1464
Or visit www.bianc.net for application
- October 10** Beyond Tomorrow-Planning for the Future
Pathways Auditorium
Gastonia, North Carolina
For information or to register
704-355-1502
- December 6** Christmas Celebration 2008
Siler Presbyterian Church
Fellowship Hall
Wesley Chapel, NC 28104
For Information: 704-355-4354
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

peaav.philbrick@carolinashealthcare.org

BIANC AND SUPPORT GROUP OPENS A NEW BRAIN INJURY RESOURCE CENTER IN THE TRIAD AREA

A new brain injury resource center is now open. For information please contact Triad Brain Injury Resource Center
Peggy Nelson, Office Manager
336-687-4702
1911 N. Centennial Ave. Ste. 138
High Point, NC 27262
peggy.nelson@bianc.net

Project STAR at Carolinas Rehabilitation
And
Pathways Local Management Entity

Presents

Beyond Tomorrow-Planning for the Future

A workshop designed to help family caregivers of persons with brain injury begin to plan for the time when the family caregiver can no longer provide care

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. If this is a concern for you and your loved one, this workshop is for YOU.

Professionals will address topics such as:

- Protecting government benefits
- Record keeping/communication,
- Guardianship,
- Financial planning, Making long range plans
- Agencies and Service Providers will be available to share information

When: Friday, October 10, 2008

8:30 AM – 4:00 PM

Pathways Auditorium

901 South New Hope Road

Gastonia, NC 28054

There is no charge for attending this workshop but registration is necessary in order to plan for lunch and handouts. Please register no later than October 2, 2008.

For additional information, or to register, please contact Project STAR at 704-355-1502
or Toll free at 1-877-962-7246

Project STAR at Carolinas Rehabilitation is funded in part by the North Carolina Department of Health and Human Services through the Department of Mental Health/Developmental Disabilities and Substance Abuse Services Division.



Carolinas Rehabilitation