



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

SPOTLIGHT on TBI Survivors that require total care ...

- Tips for caregivers
- What are survivors' unique needs?
- What are specific issues regarding care?
- Resources that target these individuals

An estimated 5.3 million Americans require long-term assistance with activities of daily living (ADLs) due to a TBI. Most often family members or other individuals close to the TBI survivor are responsible for providing ADL assistance.

Statistics show that caregivers responsible for the ongoing physical and emotional health of their loved one are less likely to take time to manage their own health and well-being. Reports show that individuals caring for a loved one after TBI often experience sleep deprivation, unhealthy eating habits, and missed routine medical check-ups; furthermore caregivers are less likely to seek out healthcare services when ill. Family caregivers are also at increased risk for excessive alcohol, tobacco use, and drugs use. Studies reveal that over 46% of family caregivers may use substances to cope.

As a caregiver, you may find it challenging to focus on yourself given the demands of assisting a dependent TBI survivor. However, one of the most rewarding things you can do for your loved one is to ensure that your own physical and emotional needs are being met. Both you and your loved one will receive benefits in the long term.

So take a minute and begin to focus on YOU! Don't wait! Now is the time to start taking care of the caregiver!!

1 Thurman DJ, Alverson C, Dunn KA, et al; Traumatic brain injury in the United States: A public health perspective. J Head Trauma Rehabil 1999; 14 (6): 602-15

Tips for Caregivers ...

- * Exercise regularly
- * Get proper rest and nutrition
- * Schedule regular doctor visits for yourself
- * Schedule time away from your loved one
- * Participate in pleasurable, nurturing activities (i.e., gardening, meditation, music, yoga) as often as you can
- * Accept the help of others when they offer – suggest specific things they can do
- * Have a support team (i.e., a trusted friend, clergy, family member) in place for yourself when you need it
- * Seek support from community programs/ support groups - there is strength in knowing you are not alone
- * Be open to ideas that promote your loved one's independence as much as possible
- * Stand up for your rights as a caregiver !

GREAT NEWS ...

Bill # H 1309 has been signed by the Governor! The purpose of the bill is to direct the commission for mental health, developmental disabilities, and substance abuse services to adopt rules providing for the licensure and accreditation of residential treatment facilities for persons with traumatic brain injury (TBI) and to make changes to the NC Traumatic Brain Injury (TBI) Advisory Council.

Websites for Caregivers

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| Full Circle of Care | www.fullcirclecare.org |
| C.A.R.E.-PRO | www.asaging.org |
| Caregiver Handbook ADSA | www.aasa.dshs.wa.gov |
| Caring Connections | www.caringinfo.org |
| Care Central | www.carecentral.com |
| Net of Care | www.netofcare.org |
| National Family Caregiver's Association | www.nfcacares.org |
| Family Caregiver Alliance | www.caregiver.org |
| Caregiver Message Board | www.thefamilycaregiver.org |
| Family Caregiver Support Program | www.charmeck.org |
| Well Spouse Association | www.wellspouse.org |
| Next Step in Care | www.nextstepincare.org |
| Joni and Friends Ministries | www.joniandfriends.org |
| TBINET | tbinet.org |
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CONTRACTURES – Reasons & Remedies...

Are contractures an issue for your loved one? When a person is immobile for a long time, the use of their muscles, tendons, and ligaments is reduced and soft tissues, vessels, and nerves can shorten. It is possible for these changes to lead to permanent limb difficulties.

To minimize the risk of contractures, doctors may apply splints or casts that keep limbs extended, and will start moving a survivor as soon as is medically appropriate. Splints may be especially useful at night as sleeping postures frequently encourage the development of contractures.

The most important way to deal with contractures is to prevent them, if possible. Contractures are sometimes prevented by active, daily exercise that moves the muscles and joints through their range of motion. If the individual is unable to engage in independent exercise due to muscle weakness, a family member or caretaker can do gentle passive range of motion exercises under the guidance of the physician, the physical therapist, or the occupational therapist.

Once contractures develop they are often difficult to correct. However, if contractures do occur, physical and occupational therapists, along with family members and caretakers can help in stretching out the limbs.

If you feel that your loved one would benefit from further intervention regarding contractures, contact the provider responsible for your loved one's primary care.

New and Exciting ...

... Learn more about traumatic brain injury from our Online Course

We are very excited to inform you about the newest TBI training program available in North Carolina. www.nctbitraining.org is an online orientation and training program available at no-cost to anyone interested in learning more about traumatic brain injury. The website contains basic information about TBI, as well as resources available in North Carolina and across the country for individuals and their families living with the effects of TBI. The training was specifically designed for healthcare professionals and service providers; however it could be helpful to individuals with TBI and their families. The training consists of five educational modules. Each module is followed by a brief quiz to maximize the effectiveness of the training.

At some point, caregivers may need to locate legal representation for themselves or their loved one. The following are legal resources that specialize in areas relevant to TBI survivors such as estate planning, personal injury, and workers' compensation.

Legal Referral Directory

| Firm Name | City | Phone | Website | Practice Areas |
|--|---------------|------------------------------|--|---|
| Law Offices of Sema E. Lederman | Chapel Hill | 888-529-3678 | www.benefitsforveterans.com | Veterans Benefits |
| Legal Aid of NC | Raleigh | 919-294-4171 | www.legalaidnc.org | Nonprofit, free legal services for civil matters to low-income families |
| Legal Services of Southern Piedmont | Charlotte | 704-376-1600 | www.lssp.org | Legal assistance for civil matters to low-income persons |
| Maynard & Harris Attorneys at Law, PLLC | Winston-Salem | 866-912-8731 336-793-1758 | www.maynardharris.com | Personal injury Workers' compensation |
| Pulley, Watson, King & Lischer, P.A. | Durham | 800-844-4529 919-682-9691 | www.pwkl.com | Personal injury medical malpractice workers' compensation |
| The Sumwalt Law Firm | Charlotte | 704-377-3770 | www.sumwaltlaw.com | Workers' compensation |
| White & Stradley, LLP | Raleigh | 919-844-0400 | www.injurednc.com | Personal injury Medical malpractice Workers' compensation |
| Charles G. Monnett III & Associates | Charlotte | 800-977-3077 704-376-1911 | www.carolinlaw.com | Personal Injury specializing in Brain Injury Medical malpractice |
| Caviness Law Firm, PLLC | Charlotte | 704-332-0881 | www.cavinesslaw.com | Estate Planning |
| Kincaid & Associates, LLC | Charlotte | 866-435-5971 | www.kincaidandassociates.com | Estate Planning |
| Robert L. Armstrong, Esq. | Wilmington | 910-256-1233 | www.rlaattorney.com | Personal Injury medical malpractice wrongful death |
| Riddle & Brantley, LLP | Greensboro | 866-777-5878 | www.justicecounts.com | Personal Injury |
| Crumley & Roberts, LLP | Greensboro | 866-336-4547 | www.crumbleyroberts.com | Personal Injury |
| Law Offices of Michael A. DeMayo | Charlotte | 877-529-1222 | www.DeMayoLaw.com | Personal Injury |
| Disability Rights North Carolina | Raleigh | 919-856-2195 | www.disabilityrightsncc.org | Council on behalf of disabled citizens |
| Perry Fisher, P.A. | Asheville | 828-505-4300 | www.perryfisherlaw.com | Personal Injury specializing in Traumatic Brain Injury |
| Higgins, Frankstone, Graves & Morris, P.A. | Raleigh | 919-968-4717 | | Estate Planning |
| Ted A. Greve & Associates, P.A. | Charlotte | 800-375-9190 | www.mydrted.com | Personal Injury |
| Kirk, Kirk, Howell, Cutler & Thomas, LLP | Wendell | 919-365-6000 | www.kirkkirklaw.com | Estate Planning Personal Injury Workers' Compensation |

Website information sources are intended to be used at the reader's discretion and are not intended as an endorsement or recommendation by Project STAR or Carolinas Rehabilitation.

Brain Injury: From the Athletic Field to the Battlefield

October 22, 2009 An Evening with Lee Woodruff
A fundraiser to benefit the Brain Injury Association of North Carolina
Reception at NC State Alumni Club

BIANC Conference October 23, 2009

For information on how to purchase tickets for the Evening with Lee Woodruff
or to register for the conference
Call 919-833-9634
or visit www.bianc.net

Getting and Staying Organized

Keeping track of caregiving responsibilities can be daunting. Staying organized can help you care for your loved one or friend and can maximize the amount of quality time you and your loved one spend together.

Making lists of important information can be an easy way to help keep organized and can be very useful in case of an emergency. These lists should contain important information about caring for your loved one. For example, you might make a list of all the things you need for morning and bedtime routines such as bathing items, medications, and clothing. These lists can be put into a clearly marked notebook and kept where others can easily find them. This notebook should contain enough information so that someone filling in for you will know exactly what is needed and what to do.

Consider making a list for each of the topics below:

- The name, specialty, phone number, and address of each key medical provider
- The phone numbers for healthcare agencies you commonly interact with
- The names and phone numbers for friends, family members, and community supports
- Lawyers and financial advisors that you are connected with
- Where needed items are kept, such as thermometers and blood pressure monitors
- Medications, when they are to be taken, and where they are stored
- Exercise schedules and directions
- Emergency contacts in addition to 911

National Hospice and Palliative Care Organization

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 reader's discretion and inclusion in this publication is not intended as an endorsement or recommendation.

ABOUT CARE NOTES . . .

Care Notes is a newsletter for family caregivers of persons with brain injury. It is published quarterly by Project STAR at Carolinas Rehabilitation. Project STAR also houses one of three Family and Community Support Offices for the Brain Injury Association of North Carolinas (BIANC). The focus of Care Notes is to provide caregivers with useful information on services, opportunities and general items of interest.

Sources are provided for articles included in Care Notes. This allows readers to gather more complete information by accessing the sources referenced in Care Notes.

We welcome your thoughts and suggestions. Please feel free to contact Project STAR and let us know what you would like to see included in Care Notes. You can contact us at 704-355-1502 or by email at mary.ruckart@carolinas.org.

Project STAR



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