



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

Managing Time...sounds like a plan!

When asked what they most need in order to care for a loved one with brain injury, many caregivers will say "more time".

Statements like, "there are never enough hours in the day" or "if only there were two of me, maybe I could get everything done", are common. To say that many family caregivers feel the pressure of too much to do and too little time in which to do it, is, by most accounts, an accurate statement.

Many full time caregivers encounter days filled with constant demands on their time and often these demands can vary from day to day and defy even the best laid out attempt to establish a manageable routine. It is the 'little things' that are unexpected and unplanned, that can cause a well organized caregiver to become a time strapped caregiver.

Caregivers who turn to the internet for help, and type in time management, can find all types of information on managing time. Even those sites that address caregiver stress and time management take into account that routines can vary due to situations that must be managed immediately, and often a time management plan can be difficult to adhere to, and in itself can even add stress.

What *CareNotes* found, while researching this topic, were many ideas that seem to make sense. No single website gave detailed alternatives to establishing standard time management schedules and routines. We did find, however, some practical suggestions that may help family caregivers save a few precious minutes.

Medication management is often time consuming. Some time saving tips for managing medications include working with doctors to try to make sure that all prescription renewals fall due at the same time. This will save time by streamlining the time it takes to phone in the prescriptions and making multiple trips to the drugstore. Presorting a full month of medications into pill sorters can also save time by streamlining the process of handling the medications and the organizing of dosages and medication combinations.

Meal preparation can take large blocks of time whether cooking for one person or a crowd. It is often difficult to find the time to prepare well-balanced meals for the family member being

cared for, let alone an entire family. One suggestion for saving time is the "bag a meal" method. When cooking, prepare double the amount of each menu item you are preparing. Take any extra, measure it into serving size portions, and place it into half pint plastic bags, then using quart or larger size bags sort the portions into prepared meals to use later. The meals can be refrigerated or frozen. By doing this each time you prepare a meal you will soon have a variety of meals on hand that can be quickly micro waved or heated by immersing the plastic bags in hot water. The time it takes to prepare a meal can be reduced by up to 90% by using this method consistently. This method works not only for small portions but is also a way of managing family sized meals.

Appointment management can be an effective way to save time. This may be done in several ways. First, prepare a list of the routine appointments (doctors, dentist, etc.) and the approximate date the visit should take place. If possible, schedule more than one appointment on a single day. This will save travel time and the time consumed by making preparations and arrangements, especially if special transportation or other supports are needed. While multiple appointments the same day may be tiring for both the caregiver and the person being cared for, the minimal disruption of the normal routine is a good dividend.

Basket Buddies can be a caregiver's best friend. Constant interruptions and the need to change directions on a moments notice can greatly affect the ability of a caregiver to complete task that they have started. Picking up the task where they left off can also be difficult. Keeping a basket at hand when doing chores can eliminate taking extra steps and losing track of what needs to be done next. Placing whatever is in hand into the basket anytime there is an interruption can eliminate extra steps. After taking care of the immediate need, check the basket, it's contents will serve as a cue to where the task was left off. One example of this strategy is to use the basket while doing housework. Rather than make multiple trips from room to room to place items in their proper location, place any out of place items in the basket until you reach the place they belong. A Basket Buddy can also be great for assembling caregiving supplies for the day so they are all in one place.

In short, thinking outside of the box is perhaps the most effective time management tool for caregivers.

From time to time CareNotes features agencies that may be of assistance to persons with brain injury and their families. This month we are featuring Vocational Rehabilitation Independent Living.

Agency Spotlight

Division of Vocational Rehabilitation - Independent Living Services



Supporting the Freedoms of Life

Assisting individuals with significant disabilities in achieving independence is the primary objective of VR's Independent Living Program.

That means providing services that enable these individuals to live and function in the homes and communities of their choice. Counselors and program participants jointly develop a plan that will provide a viable, cost-effective alternative to institutional living and in many cases help maintain or improve employment opportunities.

In addition to evaluation, counseling and coordination of resources, typical IL

services include:

- Independent living skills training
- Home and vehicle modifications
- Peer counseling and advocacy
- Rehabilitation engineering
- Adaptive aids, prosthetics, orthotics
- Consumer-managed personal assistance services
- Recreational therapy, leisure activities
- Communication/environmental control systems

Typically, participants' disabilities may include spinal cord and brain injury, muscular dystrophy, multiple sclerosis, cerebral palsy, amputations, sensory impairments and diabetes.

IL: FREQUENTLY ASKED QUESTIONS

How do Independent Living services help?

Independent Living assists eligible individuals with significant disabilities obtain services that :

- provide an alternative to institutionalization, when possible
- improve functioning in one's family, home and community
- help prepare a person for a vocational rehabilitation program

Who is eligible?

A person may be eligible for Independent Living services if all of the following apply:

- they have a significant disability
- the disabling condition severely limits their ability to live independently
- services will significantly improve a person's ability to live independently

A person's financial resources must be considered to determine if the agency should pay for many services. Some services are available to eligible individuals without regard to financial need.

What services are available?

The Independent Living Program will help eligible individuals develop objectives and identify services that will result in a plan of action. Services may include but are not limited to:

- guidance and counseling
- rehabilitation engineering
- home and vehicle modifications
- independent living skills training
- certain equipment purchases
- recreation therapy services
- assistance with leisure services
- personal assistance and personal assistant management training

Services may be provided directly, purchased, or coordinated through other community resources. For more information contact your local independent living office.

***** Information on this page is from the North Carolina Vocational Rehabilitation website www.dvr.dhhs.state.nc.us/DVR)**

CareNotes has presented Agency Spotlight which features information on agencies that may be helpful to persons with traumatic brain injury and their families in a variety of ways; by providing overviews of services, giving links to websites, and others. For the Summer 2008 edition, we did an e-mail interview with Donna Lovill, Manager of the Charlotte Vocational Rehabilitation Independent Living (VRIL) Office. We felt that reprinting this article would be a great addition to our Agency Spotlight on Vocational Rehabilitation Independent Living.

CareNotes: Could you give us a little bit of information about you and your role at VRIL?

Donna: *I have worked for Voc Rehab for 20 years and have been manager of the Charlotte Independent Living Rehabilitation (ILR) Program since 1999.*

CareNotes: Could you briefly give an overview of ILR and its purpose?

Donna: *The ILR Program is a program that assists eligible individuals with significant disabilities to transition from nursing facilities back into the community, prevent institutionalization or to increase or maintain independence in the home and community. The person who participates in our program must be able to work with the qualified rehabilitation counselor in planning of services and must be able to participate in that plan of services with a full understanding of what their needs are and communicate that to the counselor.*

CareNotes: How is the program funded?

Donna: *The Program is state funded and the amount of funding to the program is determined by the state legislature.*

CareNotes: Is eligibility for ILR services income driven, like many other services in North Carolina?

Donna: *There is a financial needs test that must be met, however, we can take into consideration disability related expenses that are paid out on a monthly basis which most of the time will help the person meet the financial needs test of the program.*

CareNotes: Are the ILR services offered consistent throughout the state, or do they vary from one area to another?

Donna: *The services ILRP provides are consistent throughout the 16 offices in the state. The 16 offices cover all 100 counties in NC.*

CareNotes: There is a variety of services listed on the NCDHHS website under Independent Living Services. Can you describe each of the following services, and what a consumer could expect to receive under each category if they qualify for the service?

- **Independent Living Skills Training**

Donna: *This service is provided to consumers who may need assistance with learning basic skills such a budgeting, planning, learning to access transportation in the community, etc. We also refer to other agencies when needed such as a Center for Independent Living or refer to an Occupational Therapist for other IL skills training with adaptive equipment if necessary.*

- **Home and Vehicle Modification**

Donna: *Home and vehicle modifications include an engineer assessment of the home or vehicle by working with the consumer to determine what modifications may be needed. These can include ramps, bathroom modifications, kitchen modifications, etc. to increase accessibility in the home. Vehicle modifications can include hand controls, car topplers for wheelchairs, lifts for vans, left foot accelerators, etc.*

- **Peer Counseling and Advocacy**

Donna: *Our staff work with consumers through guidance and counseling to assist them in Learning to advocate for themselves or may advocate with the consumer to meet their needs. Peer counseling is provided if there is a rehabilitation counselor on staff with a disability who can provide this service to a consumer. These services may also be provided through another agency if necessary for consumer to meet their goal of independence.*

- **Rehabilitative Engineering**

Donna: *This service is provided though our qualified rehabilitation engineers who can provide assessments of homes and vehicles for proposed modifications. They meet with consumer and counselor and discuss what modifications will work to meet the expressed needs of the consumer.*

- **Adaptive Aids, Prosthetics, Orthotics**

Donna: *The ILRP can provide, to eligible individuals, assistive aids and devices that will assist an individual to increase their independence in the home. This could include adaptive eating utensils, kitchen aids, toileting aids, etc. If the individual does not have Medicaid or Medicare, the ILRP can possibly assist with prosthetic and orthotics. (Must have a prescription from doctor for the latter.)*

- **Consumer-Managed Personal Assistance Services**

Donna: *The ILRP does have a Personal Assistance Services program. This program is totally consumer managed which means the consumer is responsible for all hiring of attendants, responsible for completing all paperwork and getting in prior to deadlines such as timesheets, reimbursement sheets, federal and state taxes, FICA, etc. The consumer must be able to direct their own care and manage the Personal Assistance Services Program independently.*

- **Recreational Therapy, Leisure Activities**

Donna: *The ILRP does have a Therapeutic Recreational Specialist on staff who can work with consumers on determining what their recreational and leisure interests are and assist the consumer in getting involved in those activities either in the community or in the home. These services include referrals to programs that provide certain activities such as Adaptive Sports, assisting with obtaining memberships to the local YMCA for activities or therapeutic classes or assistance with creating activities in the home.*

- **Communication/Environmental Control Systems**

Donna: *The ILRP can assist eligible individuals with obtaining communication devices to assist in communicating with others in the home or community. Environmental control systems can be provided for those who have significant limitations in mobility. This device can assist a person with opening doors, turning lights off and on as well as electronic devices such as TV's, computers, stereos, etc.*

CareNotes: Are there services not listed on the website that are offered in addition to those listed?

Donna: *Guidance and Counseling, Assistance with accessible housing placement, and Information and referral*

CareNotes: Does someone with a disability need to be referred by a physician or other professional or are self-referrals accepted?

Donna: *No, anyone can make a self referral or refer someone to our program. However, please be aware that the person referring themselves or the person being referred must have a significant disability that severely limits a person's ability to live independently and receipt of ILRP services will significantly improve the person's ability to live independently.*

CareNotes: What steps does a person need to take to apply to receive services through IL?

Donna: *Anyone who knows of someone who can benefit from ILRP services needs to make sure they discuss the referral to our program with the person first and foremost. However, the individual who needs the services would be the best person to call our office to refer themselves. Once the referral is received, it will be sent to the appropriate counselor, based on where the consumer lives. The counselor will call to set up an appointment and the counselor will either have the consumer come in to the office or will meet with them at their home or current place of residence. Once the application has been taken, the counselor then gathers medical information to determine eligibility. If the consumer does not have a significant disability based on our determination then no services can be provided. Referrals and information will be provided regarding other agencies that may be able to assist. If determined eligible, the counselor will discuss with the consumer what their independent living needs are and work together to develop a plan of services to meet their goals of independent living.*

CareNotes: A special thank you to Donna for explaining in greater detail the services provided by VRIL.

Assistive Technology

assistance that can make all the difference

Sometimes a little technology is all that is needed to enable persons to do things that were difficult or impossible before. The DHHS Assistive Technology Program provides assistive technology to people with disabilities.

The Assistive Technology Program is a broad program for all kinds of disabilities. It can assess for and provide equipment to assist with many facets of daily living. Below are some of the of services.

- **Vision** - Products designed to assist with vision; *Examples:* Magnifiers including CCTV systems; talking scales, blood pressure gauge, glucometer etc.; screen readers, screen magnifiers and Braille displays;
- **Hearing** - Products designed to assist with hearing; *Examples:* Personal amplification systems (Pocket Talker Pro); Personal amplification systems – wireless (FM); Group Assistive Listening Systems; smoke alarm with strobe flashers; door bell with flashing signal; vibrating baby monitor
- **Speech communication** - Products designed to assist with speaking and face-to-face communication for individuals with speech disabilities. *Examples:* Speech generating devices; Communication boards/books; Software with speech output; Artificial larynx; Devices that produce text but not voice output for face-to-face communication (e.g. Crespeaker); Voice clarifiers; Voice amplifiers; Stuttering aids
- **Learning, cognition, and developmental** - Products to provide people with disabilities with access to educational materials and instruction in school or other environments; products that assist with learning, and cognition. *Examples:* Calculators; Clocks/Timers/Wake-up Systems; General Personal Organization; Memory Aids; Money Management; Note taking/Recording Devices; Electronic Organizers/Personal Digital Assistants; Educational Software (spelling, math, reading, writing, science, history, etc)
- **Mobility, seating, and positioning** – Products whose main focus is on augmenting or replacing the functional limitations of an individual’s mobility. *Examples:* Ambulatory aids: low tech aids such as canes, walkers or crutches; also includes orthotics & prosthetics; Wheelchairs; Scooters and power chairs; Seating and positioning – considerations for postural control & deformity management, pressure & postural management, and/or comfort & postural accommodation.
- **Daily living** - Devices that enhance the capacity of people with disabilities to live independently, especially AT that assists with Instrumental and other Activities of Daily Living, (ADLs, IADLs) such as dressing, personal hygiene, bathing, home maintenance, cooking, eating, shopping and managing money. *Examples:* Writing guides, modified or large-handled tools and utensils, eating/feeding equipment, button hooks, zipper pulls, spiked cutting board, adapted writing implements, personal pager.
- **Environmental adaptations**- Environmental and structural adaptations to the built environment that remove or reduce barriers and promote access to and within the built home, employment and community facilities for individuals with disabilities. Environmental adaptations usually involve building construction, engineering, and architecture, but also include environmental controls and switches that can control a portion of or an entire living environment. *Examples:* Adapted playground equipment and structures; Alarm and Security Systems; Door/Gate Openers; Environmental controls and switches (i.e., electronic systems that enable people to control various appliances, lights, telephone and security systems in their room, home, or other surroundings) also known as electronic aids to daily living (EADLS)
- **Vehicle modification and transportation** - Products that give people with disabilities independence and enhance safety in transportation through adaptation of vehicles. *Examples:* Adaptive shoulder and seat safety belts; Tie downs and lock downs that secure the wheelchair to the vehicle floor; Hand controls; Extended directional mirrors; Vehicles and vans modified with lifts, ramps, raised roofs, etc.
- **Computers and related** - Hardware and software products that enable people with disabilities to access, interact with, and use computers at home, work, or school. Includes modified or alternate keyboards, switches activated by pressure, touch screens, special software, voice to text software. *Examples:* Standard software; Standard hardware; Computer accessories.
- **Recreation, sports, and leisure** - Products not already classified in other categories that help persons with disabilities to participate in sport, health, physical education, recreation, leisure, and dance events. *Examples:* Switch-adapted toys and games; tennis wheelchairs; skiing equipment; playing card shuffler; beach wheelchair; adapted camera and other photography equipment; adaptive exercise equipment (not used in a rehabilitation setting); adapted equipment for fishing, hunting, and camping.

Share Resources

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!

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.

www.bianc.net

The Brain Injury Association of North Carolina offers information and referral services to persons with brain injury and their families. There is a statewide resource directory on this website

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

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.

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