

***Practitioner's Brief* Brain Injury Association of Tennessee Caregiver Support Network**

Pam Bryan, CBIS

Executive Director

Brain Injury Association of Tennessee

Abstract

Caregivers are best able to care for others when they themselves are nurtured – when they find a community of others who know, understand and care about each other.

The Brain Injury Association of Tennessee, with a grant from the Tennessee Disability Coalition, developed the curriculum for their Caregiver Support Network program. The program addresses caregiver needs through information and education regarding various aspects of caregiving. In addition, numerous opportunities are provided for caregivers to share their personal “stories” and experiences. These vital sharing opportunities allow caregivers to gain and give much needed support.

Keywords

caregiver, support, brain injury

Caregivers are best able to care for others when they themselves are nurtured - when they find a community of others who know, understand, and care about each other.

As a caregiver for 15 years for my son, I know personally the need and importance of having support and understanding as we travel the journey of living with a brain injury. The role of caregiving for me involves providing emotional support, physical care, advocacy, and so much more. As a caregiver, it is beneficial to set realistic goals, trust your instincts, love and believe in yourself, maintain your health, keep your life in balance, take a break/respite, accept help, and know that you are not alone. Caregiving has been very rewarding and meaningful and has given me self-confidence and a sense of pride. I have also experienced fatigue, stress, and the feelings

of being overwhelmed. This is all part of caregiving and caring for yourself is one of the most often forgotten aspects of being a caregiver. When your needs are taken care of, the person you care for will benefit too.

Brain injury is unpredictable in its consequences. Brain injury affects who we are, the way we think, act, and feel. It can change everything about us in a matter of seconds. In Tennessee, approximately 8,000 people per year are admitted to the hospital with a traumatic brain injury. The responsibility for caring for individuals with a brain injury falls largely on families who struggle with these new and unanticipated responsibilities. Recovery from brain injury is measured in weeks, months and years; however, the effects can be life-long.

The mission of the Brain Injury Association of Tennessee (BIAT) is to ensure hope and support by providing brain injury prevention, awareness, education, and advocacy to survivors and their families. In keeping with this mission, BIAT's Caregiver Support Network program's primary goal is to create a helping process in which the physical and psychological well-being of all caregivers of brain injury survivors is maintained while they provide assistance to their loved ones. The need for long-term care can touch any family at any time, and the task of providing such care can be overwhelming.

The Brain Injury Association of Tennessee, with a grant from the Tennessee Disability Coalition, developed the curriculum for their Caregiver Support Network program. The program addresses caregiver needs through information and education regarding various aspects of caregiving. In addition, numerous opportunities are provided for caregivers to share their personal "stories" and experiences. These vital sharing opportunities allow caregivers to gain and give much-needed support and to help them realize that they are not alone. The program gives caregivers the opportunity to learn from each other as well.

As part of the education piece of this program, Caregiver Support Workshops are being offered across the state. The curriculum for the workshops is based on the text *Caring for You, Caring for Me: Education and Support for Family & Professional Caregivers*, Second Edition, developed by the Rosalyn Carter Institute for Caregiving. (<http://www.rosalyncarter.org/product/2/>) It has been modified to address the specific concerns and challenges of brain injury survivors and their caregivers/family members. These workshops are also for professionals/service providers for individuals with brain injuries.

The workshops consist of four modules:

- What it means to be a caregiver – Telling your story
- Taking care of yourself – Managing caregiver stress

- Preventing and solving problems – Hope and healing
- Advocating – Resources and services

Three groups are targeted:

- Group 1: Family members whose loved one is still in a rehabilitation facility
- Group 2: Family members who are caring for their loved one with a brain injury in the home – long-term caregiving
- Group 3: Service providers who provide care to individuals with brain injury

Currently, we conduct caregiver support meetings at Stallworth Rehabilitation Hospital in Nashville. Once a month, before our regular brain injury support group meeting, I meet with families who they and/or their loved one(s) are just starting their journey of learning to live with a brain injury. This gives family members the opportunity to ask questions, express their concerns and fears about going home, and to receive the answers and support they need.

As funding allows in the future, the Caregiver Support Network program will offer caregiver support groups across the state of Tennessee, fun outings for caregivers, and resource fairs with information about resources and services available to caregivers of brain injury survivors in their area.

With each husband, wife, son, daughter, sister, brother, mother, father, significant other, or friend who becomes injured, there are many lives also seriously altered. Regardless of the seriousness of the injury, the impact on families can be substantial. This includes our returning wounded warriors/heroes with brain injuries and their families.

With knowledge, all caregivers can experience the rewards of giving care – the fulfillment that comes from helping those they love.