

Family Caregivers Take Charge

(Editors Note: This article was compiled by Irene Selver from material provided by the National Family Caregivers Association.)

“Anyone can become a caregiver at a moment’s notice” says Cindy Fowler, co-founder of the National Family Caregivers Association (NFCA). Though the circumstances are different for each individual caregiver, many share the same concerns, questions, fears and sense of isolation. “We all hurt the same way, feel the same guilt,” says Suzanne Mintz, NFCA’s other co-founder. “We all want our loved ones to be well, we all want a miracle. We all experience frustration more than other people do and we all start to feel invisible and isolated. We rarely get the help we need. What we have in common are our emotions.” Angry at being so isolated and ignored in their challenging role as caregivers, these two friends channeled their frustration and began the National Family Caregivers Association in 1993.

NFCA is a not-for-profit membership organization whose mission is to improve the overall quality of life of America’s more than 25 million family caregivers. As family caregivers focus on their loved one’s needs, NFCA focuses on family caregivers. It is the only national organization serving all family caregivers, regardless of their relationship to the person receiving care or the specifics of the medical situations they confront.

Membership to NFCA is open to family caregivers, their friends, and the professionals and institutions supporting them. Through its services in the areas of education and information, support and valida-

tion, public awareness and advocacy, NFCA strives to minimize the disparity between a caregiver’s quality of life and that of mainstream Americans.

Family caregivers are known to provide approximately 80% of all the home care in this country. Three-fourths of all caregivers are women. According to surveys conducted by NFCA and backed by other studies, caregivers tend to neglect their own health, developing what Suzanne Mintz refers to as “Caregiver Disorder”. She points out

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that as family caregiving is about chronic, long-term care, occurring mostly in the home behind closed doors, it goes unnoticed in our current health care system. As caregivers struggle to create as good a quality of life for the family as possible, there is a loss of normalcy that needs to be recognized and addressed. “‘Caregiver Disorder’ needs to be recognized as a very real syndrome — one that is treatable with education, proper psychosocial and medical attention, and an appropriate level of help and support from others. But it can’t be treated until caregivers, the health care community, policy makers and the general public recognize its existence. Caregiving

needs to lose its cloak of invisibility.”

Quoting the founders of NFCA, “Taking care of yourself as a Caregiver is not a selfish act, it is a selfless act”, the organization provides a variety of services which include: a quarterly page newsletter, TAKE CARE! Self Care for the Family Caregiver; a Caregiver to Caregiver Support Network; the NFCA Speaker’s Bureau; the NFCA Caregiver Member Survey Report; a new Bereavement Program for former family caregivers; Cards for Caregivers; and the National Family Caregivers Week Celebration, to raise public awareness and caregiver consciousness. Also available is NFCA’s resource guide, *The Resourceful Caregiver: Helping Family Caregivers Help Themselves*.

From their own personal experiences as family caregivers, Suzanne Mintz and Cynthia Fowler co-founded the National Family Caregivers Association around the following Principles of Caregiver Self Advocacy:

- Choose to take charge of your life.
- Honor, value and love yourself.
- Seek, accept and at times demand help.
- Stand up and be counted.

For additional information or to receive a membership packet, please contact: National Family Caregivers Association

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benefits and services through both government and private programs.

- **Traumatic Brain Injury Services:** Information, referral, and services are provided to individuals with traumatic brain injury and their families. In addition to assisting consumers with TBI with relocation opportunities, this program helps to identify and address the gaps that exist in the continuum of care for TBI in the region — from coma to re-entry into the community.
- **Minority Outreach & Integration Project:** This project seeks to build lasting bridges to the African-

American and Hispanic communities in Westchester by ensuring that minority consumers have full-range access to the resources available for people with disabilities and equal opportunity to participate in all aspects of community life.

- **Social Integration Program for Visually Impaired Elderly:** Community specialist and older adult volunteers assist visually impaired clients, 55 and older, with activities linked to maintaining or re-establishing social integration.
- **Mentoring Program for Individuals who are Legally Blind:** The Mentoring Program provides individuals who are legally blind with peer assistance to challenge and inspire them to pursue a realistic goal and to strive for a new level of personal satisfaction.

Westchester County is home to approximately 150,000 persons with varying disabilities. WILC’s Systems Advocacy Services will take necessary actions to make systematic changes on community issues that effect people with disabilities as a group. “We need to collectively work toward changing our communities in order to positively affect the quality of disabled individual’s lives,” affirms Joe Bravo. For more information about what you can do to get involved and/or participate in any of the services that WILC offers, contact The Center at: 914-682-3926.

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