

Spousal support: Caregivers need care too

BY DEBORAH BRESLOW
Correspondent

Anita Bluestone, of Teaneck, was 41 when her husband, Barry, was diagnosed with Parkinson's

disease. Her young daughters, Marissa and Erica, were 12 and 14. Within 15 years, Barry's symptoms became chronically debilitating. Weeks and months passed while Bluestone's world revolved around

transport to medical appointments, communication with medical professionals and, as the family's primary source of income, working full time. Money was pored into medical expenses that insurance

did not cover. Responsible for the needs of the household; coupled with no reprieve from care giving, she grew weary.

Reluctant to be away for any period of time, she attended a hospital-based caregiver support group. Unfortunately, it was not for her. "The participants were much older than me," she recalls. "My kids were young - their children were grown. I was a vibrant forty-something - they were retired, getting on in years." But the most significant difference was that those in attendance had elderly parents who were ill; not spouses.

"The telephone support groups I located were generic," Bluestone remembers. "I couldn't make connections." As the Internet became easier to navigate, she searched for some person, some group to validate her feelings of sadness, anger, boredom and guilt. Her prayers were answered when she located

a posting for Well Spouse Association.

Founded in 1988, this unique spousal support program began in response to a book by Maggie Strong titled "Mainstay." Strong was a caregiver for her husband who suffered with multiple sclerosis. Desperate to overcome the loneliness, fear and exhaustion she'd come to experience with regularity, Bluestone made arrangements to attend a national Well Spouse conference in Rhode Island.

Topics such as marriage and family, financial burdens, legal and insurance issues and the importance of self-nurturing were discussed. Bluestone was immediately inspired. "I felt instant chemistry with the others," she reflected.

"Despite the fact that each spouse was combating a different illness, we were linked by the col-

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lective level of expertise we'd gained in areas we'd never have chosen to master."

After 13 years running on automatic pilot, Bluestone admits she was truly depressed. It was at the conference that she finally saw some light.

A trained social worker, Bluestone was eager to help others. Since Well Spouse Association's headquarters was located in Freehold, Bluestone partnered with Barbara Marder, a New York resident, to start a group for tri-state area spouses in Manhattan. Beginning in 2004, well spouses from Westchester, Rockland, Bergen County and areas south drove into the city to share their common experiences with one another. After a year, she became the Bergen County Support Group Leader, offering monthly meetings in Teaneck and Paramus. An active volunteer, Bluestone was

appointed Well Spouse's National Support Group Leader Coordinator.

"Our members attend meetings for different reasons," Bluestone explains. "Some crave social stimulation, some need a sounding board and others require help with completing insurance claims and applications for state aid." Members need a safe venue to express the resentment they carry con-

cerning their ill spouse. "Some just can't tolerate watching their spouses stare off into space."

Well Spouse aims to reach spouses of patients with a variety of chronic illnesses. "We support full-time caregivers and those whose partners have only moderately disabling illnesses." The nominal \$25 membership fee includes a subscription to the monthly Mainstay newsletter.

Spouses are provided with information on funding for respite weekends, memorial scholarships and enjoyable "get-away" activities. "Our members and leaders are all volunteers.

We hope to make health care professionals and the general public aware of the great difficulties caregivers face everyday."

Sadly, Bluestone's husband, Barry passed away this year. But

she remains connected with her Well Spouse friends. "I wouldn't wish what I went through on anyone," Bluestone admits, "but my involvement with Well Spouse has made me a better person. I have a new lease on life."

For more information about Well Spouse Association, call 800-838-0879 or visit www.wellspouse.org.

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