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Retreat draws caregivers seeking respite, rejuvenation

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CORRESPONDENT

Orrie Schulman certainly qualifies as an expert on caregiving.

She's been the recipient of disability services, takes care of an elderly relative with Parkinson's disease and operates a business aimed at assisting caregivers.

Plus, the Red Bank resident had a romantic relationship with a man who became paraplegic following a spinal cord injury. The relationship lasted for 19 months, until his death.

Schulman and about 150 other women from across the state met May 14 at the Robert Wood Johnson University Hospital's Hamilton Center for Health & Wellness in Mercerville for the fifth annual women's caregiver retreat.

They took in motivational talks, cooking demonstrations, health screenings, journal-writing exercises, financial and physical fitness education, lunch, some dance and yoga, and learned about support services.

The event was presented by the Family Support Center of New Jersey, various state offices of health, nutrition, fitness, and aging, and the American heart and stroke associations.

Participants included parents, siblings, children and other relatives of disabled family members. And while they shared the common ground of caregiving, their individual stories differed dramatically.

Schulman's disability awareness began in childhood when, at age 4, she contracted spinal meningitis, was comatose for 10 days and left with neurological impairments.

After many years of occupational and physical therapies, academic remediation services and a camp for children with neurological disorders, she was among the first special-education students to take high school honors courses.

"At that time, people thought you couldn't be gifted or intelligent and have a learning disability," she said.

Her experiences drew her to others dealing with disability issues.

"I was 33 and he was 67 when I fell in love" with disability advocate Steve Janick, she said. Janick's paralysis followed a diving accident when he was 35.

Schulman, now 36, is caregiver for her 84-year-old uncle, with whom she shares a home in Red Bank. "He's been a surrogate father for me since I was 2 weeks old," she said, so the arrangement is somewhat reciprocal.

She also operates Caring With Compassion, a Red Bank-based agency that provides respite and other services for those involved in home care for people with disabilities. Her mother and stepfather recently joined her to assist with the business side of the operation, she said.

After more than two decades devoted to raising six children -- one of them with developmental disabilities -- Sue DeTata of Brick is seeking time for herself, and particularly her health.

Her children, now ages 15 to 24, include a set of identical twins. "At one point, I had four in diapers," she said.

One of the twins has cerebral palsy and is deaf from a bout with spinal meningitis one week after birth. She requires constant care, and can't speak, bathe herself or walk without assistance, her mom said.

"Her identical twin is not handicapped, which is odd because you can see where she would be now," at age 23, DeTata said.

DeTata chose to attend the caregivers retreat -- her first -- following a health screening last December when her blood sugar tested a little high. "I'm 48 years old, 49 next month, and I feel like I have to live forever to take care of my daughter."

A retest put her blood levels back in an acceptable range, she said, but the scare motivated her to monitor her own health better, and exercise more. "I'm also learning to delegate, for self-preservation."

She already sports a healthy attitude. When people express sympathy about her daughter's condition, "I say, don't feel sad. She's happy, she has a wonderful life and she's a wonderful kid."

The annual retreat is free to caregivers; however, a \$20 deposit was required this year to hold a place for registrants.

Previously, about 15 to 30 women -- "repeat offenders," said Family Support Center of New Jersey's Executive Director Jacqueline Moskowitz -- would register and then not show up for the event, which effectively eliminated opportunities for others to attend.

Additional Facts

CAREGIVER RESOURCES

Caregiving with Compassion: (732) 450-1677

Caregivers of New Jersey: (800) 376-2345

Family Support Center of NJ, based in Wall Township: (800) 372-6510 (NJ only) or (732) 528-8080

National Family Caregivers Association: (800) 896-3650, (301) 942-6430

Well Spouse Association, Freehold area: (732) 577-8899