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Caring for the caregivers

Group meetings help those coping with dementia in a loved one

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WORCESTER— You came to the right place, the group told the silver-haired woman who had just joined them.

She took her seat on one of the 14 armchairs fanning out from the fireplace at Dodge Park Rest Home. Twice a month, people caring for loved ones with Alzheimer's disease meet to share supper, stories, strategies and support. Across the hall, their relatives can have a meal and take part in an activity while the two-hour session unfolds.

The new arrival, who didn't want her name used in the newspaper, told the group why she came.

"I don't think I know how to handle the situation with dementia," she said about her husband's disease, diagnosed 10 years ago. "I lose my temper a lot and I get exasperated. I know I'm not handling things well, not for him and not for myself."

Everyone in the room struggles with anger, frustration, fear and sorrow, said Deanne Weissflog, who was sitting next to her. While the men and women were all caring for relatives in different stages of dementia or Alzheimer's, they all know the difficult road they are traveling.

And that includes Nafie Saba-Shapazian, executive director of Dodge Park and its Day Club, and Don Kemp, who helps her lead the sessions for caregivers.

Ms. Saba-Shapazian, a registered nurse, is responsible for Dodge Park's 60 residents. Mr. Kemp, a rehabilitation counselor, took care of his father when he had Alzheimer's.

They all know dementia and Alzheimer's are insidious diseases, stealing up on people and their families. Only after the fact do bizarre behaviors and odd lapses make sense, sometimes after working lives and financial security are in a shambles. Alzheimer's affects about 4.5 million Americans. There are some medications that stall the chronic, progressive disease, but there is no cure.

At the meeting, Betty Belevick read from an article in a business magazine about drugs in the pipeline. It might be too late for their loved ones in the grips of Alzheimer's, but maybe it could help their children, Donna Haran said. There has been progress, not just in medications, Jeanette Rosa-Brady, support group coordinator of the Alzheimer's Association's Massachusetts chapter, said in an interview. She is not involved with the Dodge Park group. When she started training support group leaders in 1992, not as much was known about the disease, she said.

"People are able to access information much more readily now with the Internet," she said. "That wasn't there when I started. There weren't medications to treat Alzheimer's and there wasn't a lot we knew from research about how to manage home safety or understand what someone with Alzheimer's perceives."

The Dodge Park group members talked about how to stay in the moment with the patients. For Ms. Haran, that meant not fighting with her husband when he headed for the snow blower at the first flake. Instead, she told him it was out of gas.

Distraction can work, as can humor.

The worst can be those moments of lucidity when Alzheimer's patients recognize their plight.

Barbara Gould said her husband retired when he couldn't face going to work once he knew he wasn't doing it properly.

"All of a sudden he couldn't count the money in his pocket," she



Deanne Weissflog, Betty Belevick and Phyllis Bleau listen as Barbara Gould talks about her experiences dealing with a loved one with Alzheimer's during a Caregivers Support Group meeting at the Dodge Park Rest Home. (T&G Staff / PAUL KAPTEYN)



Virginia Richinick and Dorothy Bergstrom play bingo while their caregivers attend the meeting. (T&G Staff / PAUL KAPTEYN)

said. "That was humiliating for such a proud man. He was quick with numbers, like a calculator."

One woman who, like many in the room, is caring for not one but two relatives — a parent and a spouse — with Alzheimer's, said putting her husband in a nursing home was harder for her to get through than his death. Another woman said she had promised her aunt to keep her at home as long as she possibly could. Because her relatives disagree with her vow, she said, they don't help her with the care.

Some of the people the caregivers spoke about were elderly, but some were just in their 50s when they began to fail. Many of the caregivers in the group are still working full time, fraying when demands tear them apart.

Russ Varney said he hasn't taken a vacation in the three years since his mother became ill. He lives in Boston, works in Wellesley and takes care of his mother in Worcester. He's exhausted pretty much all the time.

At 89, she is in perfect health — except for her dementia. She attends a day program most weekdays, as did other relatives of group members. He was cleaning her bathroom one recent weekend when he realized he couldn't recall the last time he did the bathroom in his own house.

He recommended respite care, just to recharge.

That sounds good, but it's not so easily done. First, the caregivers have to get over the guilt they feel when they turn their attention to themselves for a change, said Ms. Rosa-Brady of the Alzheimer's Association. They feel guilt that they didn't notice the disease sooner, or that they still enjoy things they used to do together, or that they get angry.

"People feel guilty that they are not doing a better job," she said. "Any support group can dispel that right away. There's no such thing as a perfect caregiver. You're a human being."

And human beings need rest. Ms. Saba-Shapazian tells them they can't give good care if they don't take care of themselves.

There's even a study from the National Institutes of Health published in November that showed caregivers significantly improved their own quality of life and their loved ones' when they were visited by people trained in stress management and problem-solving techniques and had support groups to call on.

While the Dodge Park group members talked about their trials, they never forgot the patients, saying how painful it must be for them, both in the early stages when they know they are declining and later when they are afraid and can't be calmed.

Ms. Haran's husband asked her one morning, when he didn't know if he should get up, "What life is this, when I don't know if it's morning or night?"

Deanne's mother was frightened, asking her, "What's going to happen to me?"

Heads nodded as she said that.

"The strength from the people in this room is very encouraging," Ms. Haran said.

Ms. Rosa-Brady said that's the constant in support groups.

"You can read about Alzheimer's on the Internet all you want. You will find information that is useful but all of us need to sit down and talk to other people who are doing the same thing you are," she said. "You can read all you want, but that's not going to dispel the feeling that you are the only person in the world this is happening to."

That's what the newcomer heard.

"It's not easy being the ones who are left, trying to keep your head afloat. But here there's camaraderie, compassion and understanding," June Shack told her. "This is the right place to be."

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