

Coping with Alzheimer's and Dementia is a Family Affair

By Jennifer Wake

In a recent report, the Alzheimer's Association projected that approximately 10 million baby boomers will develop Alzheimer's disease in their lifetimes. It is a sobering statistic, especially for the 44 million American families and friends who provide unpaid care for loved ones affected by this disease and other forms of dementia.

According to Director of Eldercare Services, Linda Fodrini-Johnson, nearly 80 percent of all care provided in the United States is by families; it is taking its toll. Round the clock hours, power plays, and dealing with resistant parents make caregiving an arduous task.

"Every time a person with dementia fails to do something they could do the week before, it brings tears," she said. "For the primary caregiver, it hurts. It's so hard to see this person you love slip away.

If a spouse is the caregiver, they may compensate and cover for the other spouse, so adult children aren't completely aware. Usually the well spouse gets sick or gets a stress-related illness before the other's dementia is discovered."

Eldercare Services is dedicated to helping Alzheimer's and dementia patients throughout the Bay Area, and helps caregivers by offering free classes, support groups, and assistance finding supportive retirement living, pre-estate planning, or a number of other elder care needs.

The organization recently facilitated a lecture at the Moraga Library about how to have the difficult conversation with a parent who may be showing the early signs of dementia.

"Families are often in denial because it's part of the grieving process," explained Fodrini-Johnson, who has been a pioneer in geriatric care management for more than 20 years. "When you're suspicious in the beginning, it's important to start gathering information. Learning about dementias before there's a problem is a huge help."

Fodrini-Johnson suggests families take classes, research information on the Internet (two good sources are the Alzheimer's Association and Family Caregiver Alliance) and work with a professional geriatric care manager, who can help with long term planning needs.

But first, you need a diagnosis.

"A good diagnosis is extremely important for treatment. I like comprehensive evaluations offered at diagnostic memory clinics," Fodrini-Johnson said. "They have a multi-disciplinary team that diagnoses specifically which dementia they have."

Since some dementias are reversible, and others can be treated with the right medication, a proper diagnosis becomes vital.

"If someone is diagnosed with one of the degenerative/progressive dementias, that person can help in the planning," Fodrini-Johnson said. "They can go to Elder Care Law Attorneys, can look at assistive living places, and participate in choices that they won't be able to make later. It's much more respectful and dignified."

Unfortunately, not all dementias present themselves in the same way. "Most of us think all dementias have memory loss, but some forms present with a difficulty in judgment," Fodrini-Johnson explained. "A parent might just start making bad decisions, or become addicted to lotteries or sweepstakes. This could be a clue that they have dementia."

After a diagnosis, families need to remember to have a balance. "We need to take care of ourselves," she said.

One way to get help is through support groups and respite programs.

"Respite day care programs are low cost, they stimulate the mind to keep participants functioning longer, and offer failure-free activities so participants can feel that sense of accomplishment," said Fodrini-Johnson, who started one of the first Alzheimer's respite programs in 1984.



LARC Activity Coordinator Jack Richards leads participants in a reminiscing discussion

Photo Jennifer Wake

The Lamorinda Adult Respite Center (LARC) located at Holy Shepherd Lutheran Church in Orinda is a state-licensed adult day program that offers participants with Alzheimer's or other related dementias a safe place to interact with other adults.

"We have caregivers coming in under so much stress," said Lisa Milburn, administrative coordinator at LARC. "This is a social day program. We do all kinds of activities."

The respite program is offered Monday through Thursday from 11 a.m. to 3 p.m. and includes activities such as nostalgia/current event discussions, sing-alongs, cooking, crafts, and even basketball. Activities Coordinator Jack Richards has a way of getting participants to talk about their lives and keeps things going at a good pace. Caregiver support groups are available in tandem every other Tuesday, and the Center works with the onsite preschool to provide inter-generational activities.

"By offering a stimulating program, caregivers get respite because they know their loved-one is in a safe, respectful environment," Milburn said. "We don't treat these people like children. These are very accomplished adults. Our participants include former judges, nurses, teachers, engineers and business owners. These are very talented people."

Getting people to attend the respite programs, however, can take some maneuvering.

"The well spouse may keep them home, thinking of using a respite program as some kind of failure in their ability to provide care," Fodrini-Johnson said. "One of the wives I worked with said her husband would never do respite. I found out his talents or what he was interested in, went to their house and asked the husband to come as a quasi-volunteer. He came once, and never wanted to stop coming."

The main thing to remember is that caregivers need not do this alone.

"This is definitely an illness that takes a village," Fodrini-Johnson said.

To find helpful answers as a caregiver, you can visit Eldercare Services Web site at www.eldercareanswers.com, the Alzheimer's Association at www.alz.org, or the Family Caregiver Alliance at www.fca.org. For information about LARC, call (925) 254-3465.