

Health & Retirement

Caregiving experts offer tips to avoid burnout

By Rob Cullivan
Staff writer

She often hides items that they need and wakes them up in the middle of the night.

She throws temper tantrums if they argue with her, and fights their attempts to bathe her.

One time she even bit a dog, and she has been known to pick up pairs of eyeglasses and put them in the freezer.

If her behavior brings to mind that of a growing toddler, guess again — she's 80 years old. And a mother to boot.

Adeline Szczewinski has Alzheimer's disease, a progressive, irreversible condition characterized by degeneration of the brain cells, commonly leading to severe dementia. She was diagnosed with Alzheimer's in 1989, about five years after she began showing signs of the disease.

Until less than a month ago, Szczewinski was cared for almost exclusively by her daughter, JoAnn Malvaso and her son-in-law, Anthony F. Malvaso.

The Malvasos are also assisted by their daughter, Therese Hurley, who regularly comes to their house to bathe and care for Szczewinski.

Parishioners at St. Theodore's in Gates and married for 40 years, the Malvasos both suffer severe health problems themselves. Yet they are spending their retirement years caring for JoAnn's mother, who, ironically, is in great physical health.

"It's a 36-hour job," JoAnn said, adding that her mother can frustrate her to no end at times. "The lady will put on six outfits before she puts on the one that you laid out," she said.

The Malvasos noted that the toughest part of caring for an Alzheimer's patient is treating the increasingly childlike behavior in a manner that affords them the dignity due to an adult.

"Sometimes I'm her mother; sometimes I'm her sister; sometimes I'm her aunt; and sometimes, I'm her real daughter," JoAnn said, "I'm her real daughter."

"There's still the parent there — that's a difficult thing," said Maureen Kennedy Williams, therapeutic recreational specialist for the Monroe County Health Department's Alzheimer's Dementia Outreach Program.

As part of her duties with the outreach program, Williams



S. John Wilkin/Staff photographer

Maureen Kennedy Williams, therapeutic recreational specialist for Monroe County's Health and Dementia Outreach Program, stands with JoAnn Malvaso (seated) and her daughter Therese Hurley. Along with Joanne's husband Tony, the two women have been providing care for JoAnn's mother, Adeline Szczewinski, who has Alzheimer's disease.

works with families like the Malvasos who often need outside help in dealing with relatives who have Alzheimer's. Families may turn to a social agency when considering whether to place a relative in a nursing home or a day care program, or sometimes when they're just looking to have a home health aide come in for a few hours during the week, she noted.

Needless to say, living and

caring for an Alzheimer's patient can bring on tremendous stress among caregivers while it slowly burns them out emotionally.

"You don't argue with her," Anthony said of Szczewinski. "It just defeats a happy home life. Otherwise, she'll get violent."

Yet, if caregivers keep in mind some vital facts, they can not only avoid burnout but even regain a semblance of normal

life, according to such experts as Linda Hartnett, Williams' director at the outreach program and an ad hoc consultant to the Mercy Center with the Aging, a Rochester-based agency of the Sisters of Mercy of Rochester.

Hartnett has collected a wealth of information on caregiving, including a list of 10 tips authored by Jane Royse of Minnesota, and Mirca Liberti of Pennsylvania, both experts in

care for the aged. These tips are as applicable to families caring for Alzheimer's patients as they are to families with relatives facing ailments of any kind:

- Take care of yourself *first*, not last. Unless you're physically and mentally fit, you can't take care of anyone else, and you'll have trouble maintaining healthy relationships — including your marriage.

- Realize that you're not alone. Accept the fact that you may need help, not only from social service agencies but also from your siblings.

- Avoid isolating your spouse, family and friends to become a "model" caregiver. While caregiving may be temporary, those primary relationships should last a lifetime.

- Ask, but don't assume that your immediate family will help with caregiving. Discuss caregiving as a family and work out solutions that everyone can accept.

- Plan time for yourself, your spouse and your family — in that order — without the involvement of the relative for whom you are caring.

- Set limits. You're entitled to restrict the amount of time you spend with your parent/relative and to change those limits as the caregiving situation changes.

- Talk it out. Couples and families sometimes use caregiving as a scapegoat for all of their problems when simple communications would suffice.

- Recognize the difference between caregiving "needs" and "wants." Don't be too proud to use services that make your caregiving easier. Consider these as "overhead" rather than "luxuries."

- Learn to say "No." Caregivers often doom their chances for success by accepting more tasks than they can possibly accomplish.

- Learn to let go. Don't be afraid to throw in the towel if the caregiving burden overwhelms you.

The Malvasos somewhat followed the last tip recently when they turned to Williams for help in finding respite from their around-the-clock duties caring for JoAnn's mother.

Williams helped find a social day care center for the Alzheimer's patient, an arrangement that gives the Malvasos several hours of free time during weekdays — free time they have not had in years.

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