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Programs like this in Palm Beach Gardens, Fla., with day care for Alzheimer's patients and children in the same building, have been found successful.

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Disease Brings Drastic Changes to Patients, and Stress to Family Members

By DENISE GRADY

Family members are sometimes shocked and mortified to hear a relative with Alzheimer's disease blurt out uncharacteristic, awful remarks — swear words, racial slurs, bitter complaints about a spouse. Many cannot help wondering if the disease has peeled back inhibitions to expose an ugly side that the patient was repressing all along. Was he or she a closet bigot, unhappily married, pleasant on the outside but hostile underneath? Or should the harsh words be dismissed as random sparks from sick and dying brain cells?

"To put a meaning on it is tough," said Dr. Steven T. DeKosky, director of the Alzheimer's Disease Research Center at the University of Pittsburgh. "I think it's unfair. Half of what they say is so nonsensical to begin with, to impute lifelong suppression, I would doubt that. It's too Freudian for me."

Those episodes are just one example of the many painful changes that families struggle to understand and deal with as Alzheimer's progresses. The disease scrambles far more than memory. It plays havoc with mood, personality, perception and thought, and can require constant adjustments by friends and relatives

just to keep life on an even keel. Calm, easygoing people may turn anxious and prone to fits of rage. Patients may wander and get lost, sleep by day and stay up all night, demand to drive when they no longer can, turn on an empty oven, refuse to bathe and accuse others of stealing items they have lost.

It is pointless to argue, correct, reason, explain or try to teach someone with dementia. Instead, experts say, agree, soothe and distract; enter the patients' skewed world and try to see things their way. Enjoy the sunset — the same one, six times.

But that is easier said than done, especially as exhaustion mounts, patience wears thin, and the disease only gets worse.

"It's very hard to give care with dignity to a severely impaired person who can't use the toilet and is frightened of anyone who tries to help," Dr. DeKosky said.

Dr. Richard Mayeux, a professor of neurology, psychiatry and epidemiology at Columbia University, and co-director of its Taub Institute for Research on Alzheimer's Disease and the Aging Brain, said relatives suffered enormous stress from not understanding the disease or knowing what to expect.

For instance, Dr. Mayeux said, a patient may tell a close relative: "I don't know who you are. Take me home." He recalled one patient who called her daughter, frightened because there was a stranger in the house — her husband.

"I spend more time with the caregivers than with the patients," Dr. Mayeux said.

For some, support groups for caregivers are a lifeline, along with adult day-care programs. Among the most successful are programs that let Alzheimer's patients spend time around children. In some communities, night-care programs are also available for restless patients, to give caregivers a chance to sleep.

Information for families is available from the Alzheimer's Association, www.alz.org, 1-800-272-3900; and the Alzheimer's Disease Education and Referral (Adear) Center, <http://www.nia.nih.gov/Alzheimers/>, 1-800-438-4380.

Useful books include "The 36-Hour Day" (Grand Central Publishing, 2001), by Nancy L. Mace and Peter V. Rabins, and "Learning to Speak Alzheimer's" (Houghton Mifflin, 2003), by Joanne Koenig Coste and Robert N. Butler.