

Wayne Detzler, PhD
Respite for Caregivers

My name is Wayne Detzler. I am an adjunct professor of history at Sacred Heart University in Fairfield, and I am also a part-time resident chaplain at Elim Park in Cheshire. I hold a PhD in the study of social and political theory from the University of Manchester in England. Additionally, I did post-doctoral research at Yale.

Teaching and pastoral care are part-time occupations. Full-time, I am a caregiver for my wife of 58 years, as she walks through the dark valley of Alzheimer's disease. When she was diagnosed in 2012, the neuropsychologist said: "From this moment on, you will be the caregiver." I am aware that this challenge may last for up to fifteen or twenty years. And the prospect is daunting at best; depressing at worst.

There are more than 400,000 family caregivers in the State of Connecticut, and five million nationwide. In other words, our number is disproportionate in this state. We all share some handicaps. We are untrained for the task. We are unprepared to do it. We are unskilled to one degree or another. We are obviously unpaid. And caregiving is unrelenting. It is a 24/7 responsibility.

From the standpoint of public policy, the dedication of these family caregivers is beyond important. It is essential. The average cost for full-time nursing care of an Alzheimer's patient is in the area of \$40,000 per year. If multiplied by the need of our state alone, this would further deplete or even exhaust public coffers. Family caregivers are as essential as they are ubiquitous.

Added to the statistical evidence of this phenomenon is the personal cost. From earliest stages, our loved ones cannot be left on their own. As various neurological

disease regresses, our dear ones forget the most elemental skills of living. This includes personal hygiene, eating, reading and writing, speaking, and ultimately even eating. The caregiver becomes both a prompter of behavior and also an aide to the accomplishment that behavior.

Additionally, from earliest days of the disease there is overwhelming separation anxiety. Our loved ones cannot endure any absence from us. Even if we are in the next room, simply being out of sight triggers angst. Both the psychological and physical effects intensify by the day. But this is not all.

Socially the cost may be even more devastating. Sometimes, my dear one looks at me and says: "Did you ever think about getting married?" When I assured her that we married 58 years ago, she pressed the case: "Do you have any paper to prove that?" I had to dig out a yellowed copy of our marriage certificate. Her body language indicated that she was not yet convinced.

So, what is needed? The greatest need of most caregivers is some brief respite in each week. This is a problem common to all family caregivers. Each day, as we move around our community, we as caregivers touch each other in passing. We try to encourage each other. We attempt to help each other carry the heavy load.

We all agree. Some form of scheduled respite is essential. Alas, the cost of a paid aide is prohibitive for most of us. Please join with us in developing a means to lift the burden; to extend the care we are giving.

Thank you for your willingness to hear us.