

## The Costs of Dementia: For the Patient and the Family

A recent report from the Alzheimer's Association states that one in nine Americans age 65 or older currently have Alzheimer's. With the baby boomer generation aging and people living longer, that number may nearly triple by 2050. Alzheimer's, of course, is just one cause of dementia—mini-strokes (TIAs) are also to blame—so the number of those with dementia may actually be higher.

Caring for someone with dementia is more expensive—and care is often needed longer—than for someone who does not have dementia. Because the cost of care in a facility is out of reach for many families, caregivers are often family members who risk their own financial security and health to care for a loved one. In this issue of *The ElderCounselor*, I will explore these issues and steps families can take to alleviate some of these burdens.

### Cost of Care for the Patient with Dementia—And How to Pay for It

As the disease progresses, so does the level of care the person requires—and so do the costs of that care. Options range from in-home care (starting at \$46,332 per year) to adult daycare (starting at \$17,676 per year) to assisted living facilities (\$43,536 per year) to nursing homes (\$82,128 per year for a semi-private room). These are the national average costs in 2016 as provided by Genworth in its most recent study. Costs have risen steadily over the past 13 years since Genworth began tracking them.

Care for a person with dementia can last years, and there are few outside resources to help pay for this kind of care. Health insurance does not cover assisted living or nursing home facilities, or help with activities of daily living (ADL), which include eating, bathing and dressing. Medicare covers some in-home health care and a limited number of days of skilled nursing home care, but not long-term care. Medicaid, which does cover long-term care, was designed for the indigent; the person's assets must be spent down to almost nothing to qualify. VA benefits for Aid & Attendance will help pay for some care, including assisted living and nursing home facilities, for veterans and their spouses who qualify.

Those who have significant assets can pay as they go. Home equity and retirement savings can also be a

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source of funds. Long-term care insurance may also be an option, but many people wait until they are not eligible or the cost is prohibitive.

However, for the most part, families are not prepared to pay these extraordinary costs, especially if they go on for years. As a result, family members are often required to provide the care for as long as possible.

### **Financial Costs for the Family**

Women routinely serve as caregivers for spouses, parents, in-laws and friends. While some men do serve as caregivers, women spend approximately 50% more time caregiving than men.

The financial impact on women caregivers is substantial. In another Genworth study, *Beyond Dollars 2015*, more than 60% of the women surveyed reported they pay for care with their own savings and retirement funds. These expenses include household expenses, personal items, transportation services, informal caregivers and long-term care facilities. Almost half report having to reduce their own quality of living in order to pay for the care.

In addition, absences, reduced hours and chronic tardiness can mean a significant reduction in a caregiver's pay. 77% of those surveyed missed time from work in order to provide care for a loved one, with an average of seven hours missed per week. About one-third of caregivers provide 30 or more hours of care per week, and half of those estimate they lost around one-third of their income. More than half had to work fewer hours, felt their career was negatively affected and had to leave their job as the result of a long-term care situation.

Caregivers who lose income also lose retirement benefits and social security benefits. They may be sacrificing their children's college funds and their own retirement. Other family members who contribute to the costs of care may also see their standard of living and savings reduced.

### **Emotional and Physical Costs to Caregivers**

In addition to the financial costs, caregivers report increased stress, anxiety and depression. The Genworth study found that while a high percentage of caregivers have some positive feelings about providing care for their loved one, almost half also experienced depression, mood swings and resentment, and admitted the event negatively affected their personal health and well-being. About a third reported an extremely high level of stress and said their relationships with their family and spouse were affected. More than half did not feel qualified to provide physical care and worried about the lack of time for themselves and their families.

Providing care to someone with dementia increases the levels of distress and depression higher than caring for someone without dementia. People with dementia may wander, become aggressive and often no longer recognize family members, even those caring for them. Caregivers can become exhausted physically and emotionally, and the patient may simply become too much for them to handle, especially when the caregiver is an older person providing care for his/her ill spouse. This can lead to feelings of failure and guilt. In addition, these caregivers often have high blood pressure, an increased risk of developing hypertension, spend less time on preventative care and have a higher risk of developing coronary heart disease.

### **What can be done?**

**Planning is important.** Challenges that caregivers face include finding relief from the emotional stress

associated with providing care for a loved one, planning to cover the responsibilities that could jeopardize the caregiver's job or career, and easing financial pressures that strain a family's budget. Having options—additional caregivers, alternate sources of funds, respite care for the caregiver—can help relieve many of these stresses. In addition, there are a number of legal options to help families protect hard-earned assets from the rising costs of long term care, and to access funds to help pay for that care.

The best way to have those options when they are needed is to plan ahead, but most people don't. According to the Genworth survey, the top reasons people fail to plan are they didn't want to admit care was needed; the timing of the long-term care need was unforeseen or unexpected; they didn't want to talk about it; they thought they had more time; and they hoped the issue would resolve itself.

Waiting too late to plan for the need for long-term care, especially for dementia, can throw a family into confusion about what Mom or Dad would want, what options are available, what resources can help pay for care and who is best-suited to help provide hands-on care, if needed. Having the courage to discuss the possibility of incapacity and/or dementia before it happens can go a long way toward being prepared should that time come.

**Watch for early signs of dementia.** The Alzheimer's Association ([www.alz.org](http://www.alz.org)) has prepared a list of signs and symptoms that can help individuals and family members recognize the beginnings of dementia. Early diagnosis provides the best opportunities for treatment, support and planning for the future. Some medications can slow the progress of the disease, and new discoveries are being made every year.

**Take good care of the caregiver.** Caregivers need support and time off to take care of themselves. Arrange for relief from outside caregivers or other family members. All will benefit from joining a caregiver support group to share questions and frustrations, and learn how other caregivers are coping. Caregivers need to determine what they need to maintain their stamina, energy and positive outlook. That may include regular exercise (a yoga class, golf, walk or run), a weekly Bible study, an outing with friends, or time to read or simply watch TV.

If the main caregiver currently works outside the home, they can inquire about resources that might be available. Depending on how long they expect to be caring for the person, they may be able to work on a flex time schedule or from home. Consider whether other family members can provide compensation to the one who will be the main caregiver.

**Seek assistance.** Find out what resources might be available. A local Elder Law attorney can prepare necessary legal documents, help maximize income, retirement savings and long-time care insurance, and apply for VA or Medicaid benefits. He or she will also be familiar with various living communities in the area and in-home care agencies.

### **Conclusion**

Caring for a loved one with dementia is more demanding and more expensive for a longer time than caring for a loved one without dementia. It requires the entire family to come together to discuss and explore all options so that the burden of providing care is shared by all.

I help families who may need long term care by creating an asset protection plan that will provide peace of mind to all. If I can be of assistance, please don't hesitate to call.