Alzheimer’s Disease Caregivers

With Alzheimer’s disease, it is not just those with the disease who suffer. It’s also their caregivers – a job that usually falls on family and friends.

- In 2016, more than 15 million family members and friends provided 18.2 billion hours of unpaid care to people with Alzheimer’s and other dementias, at an economic value of over $230 billion.
- Of the unpaid Alzheimer’s and dementia caregivers, 69 percent have provided care for at least the past year, and more than 39 percent have been providing care for four or more years.
- Nearly one-fourth of Alzheimer’s and dementia caregivers are “sandwich generation” caregivers – caring for both someone with the disease and a child or grandchild.

Caring for people with Alzheimer’s and other dementias is often very intimate and very intrusive.

- Nearly 80 percent of older adults with dementia receive help with a daily personal care activity such as bathing, dressing, grooming, or eating. In contrast, only 20 percent of older adults without dementia need help with these activities.
- One in 3 Alzheimer’s caregivers provide help bathing or showering, feeding, or getting to and from the toilet – a higher percentage than caregivers for other older adults.
- About one-third of Alzheimer’s and dementia caregivers deal with incontinence or diapers. For caregivers of older adults without dementia, just 12 percent help with this personal care task.

Proportion of Caregivers Who Provide Help With Specific Daily Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Alzheimer’s Caregivers</th>
<th>Other Older People</th>
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</thead>
<tbody>
<tr>
<td>Getting in and out of bed</td>
<td>45%</td>
<td>43%</td>
</tr>
<tr>
<td>Getting dressed</td>
<td>38%</td>
<td>30%</td>
</tr>
<tr>
<td>Bathing or showering</td>
<td>34%</td>
<td>23%</td>
</tr>
<tr>
<td>Feeding</td>
<td>33%</td>
<td>20%</td>
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<tr>
<td>Getting to and from the toilet</td>
<td>32%</td>
<td>25%</td>
</tr>
<tr>
<td>Dealing with incontinence or diapers</td>
<td>32%</td>
<td>12%</td>
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Caring for an individual with Alzheimer’s disease creates or aggravates the health problems of a caregiver.

- Nearly 75 percent of Alzheimer’s and dementia caregivers are somewhat or very concerned about maintaining their own health since becoming a caregiver. In addition, over one in three dementia caregivers say their health has gotten worse due to their care responsibilities.

- Nearly 60 percent of Alzheimer’s and dementia caregivers rate the emotional stress of caregiving as high or very high. As many as 40 percent of family caregivers of people with Alzheimer’s and other dementias report symptoms of depression.

- One study found that spousal caregivers of people hospitalized for dementia (compared with people hospitalized for other conditions) were more likely to die in the following year, even after accounting for the age of the spousal caregiver.

- The physical and emotional impact of caregiving on Alzheimer’s and other dementia caregivers resulted in an estimated $10.9 billion in increased caregiver health costs in 2016.

Caring for an individual with Alzheimer’s has a negative effect on employment, income and financial security.

- Among Alzheimer’s and dementia caregivers who are employed full or part time, 57 percent said they had to go in late, leave early or take time off because of their caregiving responsibilities.

- In addition, 18 percent had to go from working full time to part time, 16 percent had to take a leave of absence, and 8 percent turned down a promotion due to the burden of caregiving.

- More than 1 in 6 Alzheimer’s and dementia caregivers had to quit work entirely either to become a caregiver in the first place or because their caregiving duties became too burdensome.

- Among female caregivers, 17 percent believe they have been penalized at work because of the need to care for someone with Alzheimer’s.