



## Indiana Dementia Training for Direct Care Providers

### **Supporting Dementia Family Caregivers**

**Course Description:** *This course is a self-paced learning activity and will help direct care providers work with and understand what families caring for loved ones with dementia may be experiencing.*

**Learning Objectives:**

*Upon completion of this educational activity, the participant should be able to:*

- 1. Recognize how being a caregiver for a person with dementia might affect the family members.*
- 2. Understand the family members' responsibilities, such as caring for both children and parents. These may affect their role as caregivers for the person with dementia.*
- 3. Recognize common family issues and conflicts that may affect the caregiver's relationships.*
- 4. Understand feelings of guilt, grief, uncertainty, and stress may affect a family member's emotional or physical health.*

*This activity contains a post-test. You must complete the entire learning activity and test and score an 80% or higher to obtain a certificate of completion. Partial credit will not be given.*

**Contact Hours:** 30 min, including the required quiz

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When working in the home care environment, you are often brought into the home to provide respite for the over-stressed in-home caregiver. Very often, the family caregiver is an older spouse. Sometimes, the primary caregiver is an adult child or other family member. Regardless, the National Alliance for Caregiving (NAC) and AARP have released a research report, "Caregiving in the U.S. 2020." The study finds that the number of family caregivers in the United States increased by 9.5 million from 2015 to 2020 to **53 million people** and more than one in five Americans. The relationship between the caregiver and the person with dementia is often complicated. Sometimes, the difficulty and exhaustion of the actual physical caregiving, the psychological stress arising from caregiving, or the effects of the problems in navigating all the family dynamics may create a less than ideal environment for the caregiver and the client.

You may be put in situations with feuding family members who disagree on the care to be provided. You may face trying to support the caregiver who gives up everything to be the best caregiver they can be, yet they are stressed and/or depressed. So, what are you to do?



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First, let's look at some basic statistics about informal dementia caregivers and some facts about the enormity of what these caregivers may be going through. (From the 2022 Alzheimer's Facts and Figures):

- Approximately two-thirds of dementia caregivers are women.
- About 30% of caregivers are age 65 or older.
- Over 60% of caregivers are married, living with a partner, or in a long-term relationship.
- Over half of caregivers are assisting a parent or in-law with dementia.
- Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia.
- Most caregivers (66%) live with the person with dementia in the community.
- Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent but also for at least one child.
- According to another study, well over half (57%) of family caregivers of people with Alzheimer's or other dementias living in the community had provided care for four or more years.
- The prevalence of depression is higher among dementia caregivers (30% to 40%) than other caregivers, such as those who provide help to individuals with schizophrenia (20%) or stroke (19%).
- Caring for a spouse with dementia is associated with a 30% increase in depressive symptoms compared with spousal caregivers of partners without dementia.
- Caregivers of people with dementia report providing 27 hours more care per month on average (92 hours versus 65 hours) than caregivers of people without dementia.
- The total lifetime cost of care for someone with dementia was estimated at \$377,621 in 2021 dollars. Family caregivers bear seventy percent of the lifetime cost of care in unpaid caregiving and out-of-pocket expenses for items ranging from medications to food for the person with dementia.
- Caregivers of people with dementia are estimated to lose between 2.4 hours and 3.5 hours of sleep a week.
- The amount of time required for caregiving increases as dementia progresses; one study showed that people with dementia required 151 hours of caregiving per month at the outset of dementia and increased to 283 hours per month eight years later.
- Fifty-nine percent of family caregivers of people with Alzheimer's or other dementias rated the emotional stress of caregiving as high or very high.
- Many people with dementia have co-occurring chronic conditions, such as hypertension or arthritis. A national study of caregivers of people with dementia living with additional chronic conditions found that caregivers of people with dementia who had a diagnosis of diabetes or osteoporosis were 2.6 and 2.3 times more likely, respectively, to report emotional difficulties with care compared with caregivers of people with dementia who did not have these co-occurring conditions.



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- Caring for people with dementia who have four or more behavioral and psychological symptoms (for example, aggression, self-harm, and wandering) represents a “tipping point,” as these caregivers are more likely to report clinically significant depression and burden (that is, negative emotional reactions to providing care).
- Eighteen percent of spousal caregivers die before their partners with dementia.

As the statistics demonstrate, being an informal caregiver is challenging. Becoming a caregiver is often not chosen but develops as an expected obligation or because of location. It is often the person who lives closest to the parents who end up being the primary caregiver. What starts as providing a little help with errands and tasks around the house often develops into many hours and more intense care needing to be delivered. Understandably, family members who provide care due to duty or obligation have been shown to have more stress and psychological issues with caregiving and develop more feelings of resentment. Caregivers who perceive they have choices about caregiving will have more success adapting to the experience than caregivers who see no options.

Another major area of conflict for caregivers is the family conflict that often comes about due to disagreeing family members, usually children. Caregiving lasts a long time. Family members will be required to contend with unfamiliar and unpredictable situations. If the care recipient had been the one who provided leadership and stability to the family, the family would be more impacted by the experience. Although siblings grow up in the same household, they view their current situation through the lens of all their childhood traumas and past history.

When a family is dealing with a crisis, old established roles often reemerge. Old resentments or jealousy may redevelop. A family that grew up in conflict will usually have a similar response to the caregiving role. Also, gender may affect how a family responds. In many families, the daughter is expected to take on more hands-on caregiving tasks, while males are expected to help with care’s financial and legal aspects.

There is also a difference depending on the distance from the care recipient. The adult child living closest to the parents usually takes on the hands-on care and tasks. The far-away caregiver assumes that the nearest sibling can handle the situation and has no clue how much time is involved. When the caregiver who lives away does show up, they voice concerns for the person or lay a guilt trip on the person doing the majority of caregiving. Out-of-town caregivers may also live in denial about a parent’s condition as they want to keep living their own lives.

Whether the denial is the subconscious need to ignore the fact that a parent is declining or they want to pretend that caring for a declining parent isn’t all that big a deal, so they don’t have to get involved, denial is rampant. The absent sibling may acknowledge the parent is sick but may ignore that caregiving takes a significant toll on the caregiver. The hands-on caregiver can also experience denial. They may begin to take on tasks that the person with dementia used to do to cover the limitations. Denial is an effective coping mechanism and often protects someone



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until they have time to accept the harsh reality. However, when caregivers remain in denial, the care recipient may be in danger.

Guilt is often a normal reaction for the caregiver. Guilt that they are not doing enough or not doing things well enough. Much guilt can arise from family conflicts unresolved over the years. Family members may dwell on past regrets, wishing they could only do things over. When the care recipient has memory loss, there is another type of guilt. Guilt for not always being truthful. These “white lies” are sometimes a source of guilt because family members believe they are being dishonest with their loved one, tricking her or lying to them.

Caregiving may lead to significant levels of stress or even the development of depression. Physical health problems can precipitate or worsen caregiver depression. Often seriously depressed people don't know they are depressed. Research indicates that 30-40% of dementia caregivers are affected by depression. Depression is not determined by situations alone. And its symptoms go beyond feeling sad or hurt. Unlike short-lived symptoms related to upsetting situations, symptoms of depression persist beyond a few weeks. Depressed caregivers may use virtually all of their physical and emotional reserves to care for loved ones. Frequently, depressed persons say they don't want help because they don't believe anything will help or aren't worth helping. Depression causes an inability to think and act, and therefore depressed caregivers have difficulty getting the help they need. Some caregivers try ineffective coping mechanisms, such as using alcohol and drugs to feel better. Without treatment, caregiver depression does not improve.

Another increasing family complication is the emergence of stepfamilies involved in caregiving. According to the US census bureau, among men and women 60 to 69 years old, 23% had married twice, and less than 10% had married three times or more. Among those ages 70 or older, 22% of men and 19% of women had married twice, while 8% of men and 6% of women had married three times or more. In other words, older adults have a rich marital history that reflects the diverse experiences of long commitment, loss via divorce or widowhood, and new partnerships as they age. That number is projected to keep increasing, meaning more and more family caregivers will find themselves in situations where they are looking after an aging stepparent or discussing and managing a loved one's care with stepfamily members. Blended families can cause unrest because step-relatives haven't had decades to bond with one another. Research shows that women who remarried and cared for a husband often experienced increased strain from uncooperative or unhelpful stepchildren. There is often a disagreement between the step-parent and the care recipients' children and how to provide the needed care.

Finally, an issue that happens with dementia that usually doesn't occur with other physical conditions is that at some point, if dementia progresses to the later stages, a person may no longer recognize their family members. This is often devastating for the family. You can help the family cope with this by letting them know that even if their loved one is not able to recognize their association with them, they can still feel safe and happy around them. Keeping in touch with the people they have a positive history can help them continue to have these positive



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feelings and enjoy their company even if they don't remember their names or how they are related to them.

Elderly spouse caregivers who experience caregiving-related stress have a 63% higher mortality rate than non-caregivers of the same age. Female caregivers average three times as many stress symptoms, take more tranquilizers and antidepressants, and report substantially less participation in social and recreational activities. A study (Webmd.com) found that older men living with wives with dementia had an almost 12-fold increased risk of developing dementia. Older women whose husbands developed dementia had a four-fold increased risk. The development of dementia is thought to be a factor related to the stress of caregiving.

With all the stress caregivers often experience, why don't they ask for help? Often, they don't want to be a burden, and many may feel it is their "cross to bear." Caregivers may also not know how to ask for help or expect others to offer it. We know with most caregiving journeys that it is a long and lonely one. Friends and family are often helpful and supportive in the crisis phase. But as caregiving goes on, the amount of support diminishes. Also, the caregiver's primary support person may have been the care recipient. With the act of caregiving, this relationship may often change, and the caregiver loses their source of support.

Other barriers to family caregivers receiving support include a lack of education. Many caregiving tasks are not intuitive for caregivers. They don't know the best way to assist in providing the functions of ADLs or how to handle challenging behaviors as a result of cognitive impairment. Research has demonstrated that caregiver education in these areas significantly reduces the stress level of caregivers. Another barrier is financial. It is an economic burden to provide care to a family member. If finances are tight, in-home care may not be able to be offered in the amounts required. This forces the caregiver to take on more tasks than they may be able to provide.

### **How You Can Help**

So, what can you do to assist the family caregiver? Most importantly, you can listen. Caregivers need to have their feelings validated. You may say, "I know it is hard to keep this up; what is hardest for you now?". This may get the caregiver to express what they may need help with, and perhaps you can assist. It is important, though, to offer suggestions only when asked. If you make suggestions without being directly asked for your input, it is often taken as criticism. Finally, you can be patient with the caregiver. When someone is stressed, they often are irritable and quick to anger. You can remain calm and compassionate by recognizing this rather than reacting negatively.

So, with all the guilt, family dynamics, and the physical and psychosocial toll that caregiving often creates, it is no wonder that we find family caregivers difficult. They may lash out at you or find fault in how you are helping in the home. While this is hard to take, try to keep in mind all that the family caregivers are often dealing with. Recognize the stress, grief, and possible depression they may be experiencing.



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A tool can be given to the family caregiver as a self-report to recognize caregiver stress. This tool is found at: <https://www.healthinaging.org/sites/default/files/media/pdf/Caregiver-Self-Assessment-Questionnaire.pdf>. A copy of the Caregiver Self-Assessment Questionnaire can be found as a supplement to this lesson.

This assessment tool can be provided to family caregivers if you are concerned about their health and well-being due to their care responsibilities. It contains 18 questions, and they are to be answered with a yes/no. Scoring for the tool helps the caregiver understand if they are experiencing stress. Some of the following steps that the device may indicate include: recommending seeing a doctor for a check-up, having some relief from caregiving, or joining a support group for caregivers. This questionnaire was initially developed and tested by the American Medical Association.

The entire family experiences dramatic changes when a loved one has dementia. The family may go through a tough time and look to you for support. Families need understanding rather than criticism, and sometimes they need to talk with someone. Ask family members how they are doing and show interest in what they have to say. You do not need to provide all the answers; just be a compassionate listener and encourage them to care for themselves. Also, help family members accept the progressive nature of dementia and let them know that the person with dementia will need more help over time. If a family member seems unduly stressed or depressed, encourage that they get help. It's important for the caregivers to stay as healthy as possible to continue to be around the person with dementia.

### Resources:

2022 Alzheimer's Facts and Figures. <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf> Retrieved 4/25/22.

Boyles, S. Your Spouse Has Dementia. (2010). Webmd.com. <https://www.webmd.com/alzheimers/news/20100505/dementia-risk-higher-if-your-spouse-has-dementia>. Retrieved 4/22/22

Census.gov. Love and Loss Among Older Adults (2021). <https://www.census.gov/library/stories/2021/04/love-and-loss-among-older-adults.html> Retrieved 4/25/22