



“Dementia doesn’t rob someone of their dignity it’s our reaction to them that does.”

-Teepa Snow; Dementia Care Educator

Generations Family Newsletter

A Support Guide for Caregivers By Ava M. Stinnett

Whether it happens gradually or overnight, there’s a distinct possibility that one day you will become a caregiver for a loved one. It may be for a parent, a spouse, or even one of your children. According to the National Alliance for Caregiving, there are over 65 million unpaid caregivers of adults aged 65 and older in the United States. Often, there’s very little preparation for the daily challenges that caregivers face.

There are numerous city and state education programs and services to address the needs of those who provide long-term care for loved ones at home. You’ll also find many wonderful books that address the topic of caregiving. But what about those times when you need to talk to someone who is traveling a parallel journey, another caregiver who can offer not just a sympathetic ear but a possible solution to a challenge? A support group—whether it’s a local set of folks who meet regularly or an online group—may be the perfect solution. The Alzheimer’s Association, the Family Caregiver Alliance, A Place for Mom, and Eldercare Locator are just a few of many online organizations that provide valuable information and links to support groups.

You may also be able to locate a support group on Facebook. Numerous private groups (new members must be approved by the group’s administrator) allow community members to reach out to other caregivers. Some members are new to being care partners, while others have already made the climb and broken the trail for those who are following behind them.

Perhaps what is most helpful in these communities is an open forum for the types of questions, comments, and emotional support that one may not find in a best-selling book. For example, practical questions, such as how to manage doctor’s appointments, insurance paperwork, and

how to take time off work are addressed. But there are also very poignant and soul-searching posts, such as:

- “I miss my mom, even though she’s asleep in the next room.”
- “How do I tell my husband that I’ve decided to have someone come in for a few hours a day while I’m at work? I’m exhausted and could really use some help but I don’t want to upset him.”
- “My mom is receiving birthday cards from friends who may not be aware of her Alzheimer’s diagnosis. Should I let them know and if so, how?”
- “My dad seems lonely and fearful and follows me from room to room. I’ve assured him that he’s safe and that I’ll always be here. How do I deal with the resentment that’s building because other family members aren’t here to help out?”

Sometimes, just knowing that you’re not alone is all it takes to stay the course.

Keeping Family Members on the Same Page By Ava M. Stinnett

As our loved ones enter their senior years, a new set of challenges often develops. Some concerns involve financial security; loneliness due to a changing social environment and the passing of friends; conditions such as arthritis, cataracts, and heart disease; and physical aging with a loss of mobility and independence. It is important

to learn about coping with these types of issues before they happen.

When the diagnosis is Alzheimer's or other dementias that threaten a senior's cognitive and physical abilities, however, there isn't always time to prepare. And as the disease progresses, family conflicts about care decisions can bring out strong feelings.

According to writer Jeff Anderson (2014), family disputes generally revolve around the following:

- Differing views on a parent's condition and, therefore, their needs
- Parents who value their independence and resist any change in their care
- When caring for an aging parent falls to one particular family member (e.g., the oldest sibling, the child who lives closest), which can cause resentment if others are unable or unwilling to help
- When family members feel left out—whether it involves getting regular updates on an elder person's condition or feeling that they don't have a voice in the decision-making
- Determining how to pay for care if a loved one does not have the necessary resources

There are numerous organizations and educational resources—both online and at your local library or a health care provider's office—that can provide assistance for families with aging parents. Some provide support services and guidance to help families develop a practical care plan for when the need arises. Others offer family conflict programs to help improve communication, clarify roles, and develop a feasible team approach to making decisions when a parent can no longer live independently. Arranging for a visiting nurse with a background in elder care assessments or getting information from the senior's primary physician can also clarify what level of care is needed when family members disagree.

Dealing with dementia-related diseases can intensify emotions. Developing strategies to keep the focus on a loved one's needs is the key.

After an Alzheimer's Diagnosis: The Emotional Impact

By Ava M. Stinnett

When a friend or loved one is formally diagnosed with Alzheimer's disease, it's likely that you've already noticed some symptoms. These may include impaired speech or memory loss that interferes with daily life, such as remembering events that just happened, repeatedly asking for the same information, or forgetting how to drive to a familiar place. Difficulty holding a conversation or struggling to do practical tasks, such as paying bills or doing household chores, might also be noticeable.

Although symptoms will vary for each person, it's important to consider not only the cognitive and practical aspects associated with Alzheimer's disease but also the psychological and emotional impact. Experiencing memory loss or being unable to perform daily routines can be quite challenging. For the person with Alzheimer's, this will sometimes lead to low self-esteem, lack of confidence, and feelings of isolation as personal relationships change.

However, numerous studies have confirmed that even when memories fade, even when a loved one no longer recognizes friends and family members, the disease does not erase the lasting effect of feelings and a sense of being socially connected. Although it may seem like the person with Alzheimer's "can't differentiate between you and other caretakers in the later stages, the research underlines the importance of emotionally supporting those living with the disease. The influence of positive caretaking and emotional support... goes a long way. [Although he or she] may not remember the most recent visit from loved ones, those feelings will still remain; caring actions can have a lasting impact." (Bushak 2014)

According to a research study from the University of Iowa, "Providing... small joys really does make a difference—even if you automatically assume they won't remember these things." The findings "should empower caregivers by showing them that their actions toward patients really do matter. Frequent visits and social interactions, exercise, music, dance, jokes, and serving favorite foods are all simple things that can have a lasting emotional impact on quality of life and subjective well-being." (Guzmán-Vélez, Feinstein & Tranel, 2014)

Some believe that those who have Alzheimer's disease know that pieces of the puzzle are missing. They may not be able to remember who we are, but they feel us just the same. Therefore, if we learn to listen for clues for how they feel instead of what they say, we'll understand them much better.

Pointing Fingers: Dementia-Related Suspicion and Paranoia

By Ava M. Stinnett

As busy adults, we sometimes forget things. Perhaps it's an appointment, the location of our keys, or why we just walked from the living room into the kitchen. Although this might be annoying, we're usually able to laugh at ourselves, retrace our steps, and get back on track. The same can't be said for a person with dementia; the memory loss in dementia is caused by physical changes. The parts of the brain that record and store new information become damaged, so the person is unable to hold the memory of what they've said, asked, or done and any response they've received.

As the disease progresses, memory loss and changes in personality can sometimes lead the individual to become suspicious and to misperceive certain events or situations. It's not unusual for a family member, friend, or caregiver to be accused of theft (when your loved one can't locate possessions), withholding information (because they have forgotten a planned activity or a daily routine), or other offenses. Such circumstances can cause caregivers to feel hurt or guilty and lead to difficulty maintaining an even temper. How can you cope?

First, try not to take it personally. It's important to be aware that the individual's poor memory is something they can't help. If there's a glitch in their memory, they may try to fill in that faulty memory with a delusion that makes sense to them. It's perfectly normal for a caregiver to become distressed when you see a loved one experiencing suspicion, paranoia, or feelings of betrayal when you know that you're doing your best.

Second, don't argue or try to convince. When a loved one affected by dementia continuously complains that you're

not telling them anything, that they never know what's going on, or that they feel tricked or betrayed, it's more than just frustrating. Sometimes the best response is to say, "Oh, I'm sorry; I must've forgotten to mention (a particular activity or event)." Or, if an item goes missing, offer to help locate it.

Finally, when you're at your wit's end, it might help to take a deep breath and read the first two stanzas from "Do Not Ask Me to Remember – An Alzheimer's Poem," by Owen Darnel.

Do not ask me to remember,

Don't try to make me understand,

Let me rest and know you're with me,

Kiss my cheek and hold my hand.

I'm confused beyond your concept,

I am sad and sick and lost.

All I know is that I need you

To be with me at all cost.