What to Do When Alzheimer's Threatens to Tear Your Family Apart

Mare Marley Alzheimer's Reading Room

Having a family member with Alzheimer's disease is a stressful situation.

According to the Alzheimer's Association,

"Dealing with Alzheimer's can bring out many strong emotions. As the disease progresses caregiving issues can often ignite or magnify [existing] family conflicts."



Carole Larkin (personal interview), a certified dementia consultant, estimates that 30% of her clients have conflict between family members. She says you can double that for blended families.

According to Larkin the most common types of conflict are:

- Disagreement between the spouse and the children on what needs to be done (especially likely when the primary caregiver is male).
- Disagreement among the children on what needs to be done.
- Disagreement among children of blended families about what needs to be done and who should pay for it.

Conflict is especially likely in families where people didn't get along previously, when the primary caregiver is not a direct family member (such as in a second marriage), and when some of the family members live out of town and only see the loved one for short, infrequent visits.

The conflict typically affects the primary caregiver more than other family members. It can be endlessly frustrating to have others make caregiving suggestions that are unreasonable because they're based on a lack of knowledge and understanding of the patient's condition and abilities.

For example if a parent living alone is no longer able to do laundry, a child might recommend using a laundry service. What the child might not know, however, is that the parent wouldn't even be capable of opening the door and giving the laundry to the service person when they arrive for the pickup.

Another example is that one of the children might suggest placing the loved one in an assisted living facility. Siblings who haven't been around their parent very often might not be aware that the person couldn't even find the dining room or find their way back to their apartment after the meal and a whole host of other problems.

The Mayo clinic has the following advice for families where there is significant strife: 1) Share responsibility, 2) Meet face-to-face regularly, 3) Ask someone to mediate if needed, 4) Be honest and don't criticize, 5) Join a support group, and/or seek family counseling.

Let's look at each of these in some detail:

- Share Responsibility: Families who do function well often split the caregiving duties among the various family members to avoid placing all the responsibility on the primary caregiver. For example one person may do the actual caregiving while others assume tasks such as handling the finances or helping out by doing errands or chores.
- Meet Regularly. Meet Face to Face Regularly: It's important for family members to meet and discuss the situation on a regular basis. (When one or more family members lives out of town, you may try using Skype.) It can also be helpful if the primary caregiver makes detailed lists of the patient's dementia symptoms. These lists should be updated frequently and shared with everyone on a regular basis in order to educate the others about the loved one's condition.
- Ask Someone to Mediate, if Necessary: Both Larkin and the Mayo Clinic recommend engaging the services of a mediator when all else fails. It can be helpful to involve a neutral third party. You can find qualified mediators on the website of the Academy of Professional Family Mediators. You can also talk to trained personnel at the Alzheimer's Association (24/7) at 1-800-272-3900.

- Be Honest and Don't Criticize: As is the case when dealing with any type of conflict, all family members should be honest about their feelings and try to avoid criticizing the others.
- Consider Counseling: The Mayo Clinic advises that if the conflict is serious enough try joining a support group or even getting family counseling. It can be helpful to share your difficulties with others in the same situation or, again, engaging the services of a neutral third party.

In my case the closest family member, who lived out of town, insisted - as in the example above - that Ed only needed to go to an assisted living facility. I knew that wouldn't work because of his incontinence (of both bowel and bladder), because he couldn't have found his way back and forth to dining room and, furthermore, he wouldn't have even wanted to go to the dining room.

Neither was he capable or showering and dressing himself or do his own laundry - and the list goes on and on. I was certain they would have asked him to leave after two or three days.

There was tremendous conflict between the two of us, and, unfortunately, I wasn't aware of the tips above and we didn't follow any of them. The conflict didn't disappear until Ed had passed away and there was no longer anything to argue about.

Has anyone else used these or other strategies for dealing with family conflict when a loved one has Alzheimer's

If so, how did it work out?

Carole Larkin, MA, CMC, CAEd, QDCS, EICS, is a certified dementia consultant and owner of <u>Third Age Services</u> in Dallas. She advises families about options they can consider for the best care of their loved one with dementia. She consults in person and also by telephone at 214-649-1392