When Families Do Not Agree

Working with the person with dementia can be difficult, but most people find more difficulty working with their family because of the emotional nature of dementia caregiving and misinformation about the disease. Three main causes of family friction are discussed: (1) Spouse Caregiver/Children Issues, (2) Sibling Issues, and (3) Step Families Issues. After a discussion of each area and tips for handling the issues, ideas for moving forward will be suggested.

Spouse Caregiver/Children Issues

*Example of Issue*: Mom is 78 years old and is the primary caregiver. She wants to keep her husband of 47 years home, but her health is failing. The children are called in on emergencies and here constant concerns, but the parent is unwilling to look at different options. The parent often voices that though their children are trying to help, they just wished they would listen and support them. The children, who see the caregiving dyad from the outside, see the wear on both individuals and are concerned what will happen if the caregiver’s health wears out. The family finds itself at an impasse – unable to plan, communicate and even begin feelings of resentment.

Sometimes, a parent who is caring for his or her spouse will have different views than their children about what care is needed. Some common issues that can be challenging to the relationship:

1. Parent caregiver sacrifices his or her own health and well being
2. Quality time with family members sometimes goes by the wayside, and special events are not attended by either parent
3. Unwillingness of parents to accept more help from outside of the family, placing an unrealistic or unmanageable burden on the children who often have the added responsibilities of their job and family
4. Conflicting views about what outside help can offer and who can provide services
5. Disagreements about paying for outside help or unwilling to share important financial information in order to apply for funding options
6. Ineffective communication techniques

Tips for Parents that are the Primary Caregiver

1. Pay attention to and address your own physical and mental health needs.
2. Arrange for care from others so you can be at important family events whenever possible.

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3. Obtain as much outside help as possible, lessening the burden and worry on your children.
4. Don’t expect the impossible from your children.
5. Recognize your own boundaries and what is most important to you in caring for your spouse.
6. As a rule, don’t “cover” for your spouse. It is a disservice to you, your spouse, and your children to shield your children from the diagnosis and deficits.
7. Communicate, communicate, communicate

Tips for Children of Parents caring for a Spouse

1. Support your parent by listening – not fixing. Sometimes a parent needs to vent/talk.
2. Don’t let planning be held hostage. Look for appropriate care options for the person with the disease in case of an emergency for the parent caregiver. Keep in mind that a health emergency may be more likely for caregivers due to stress, distraction and fatigue.
3. Do what you can, but do not enable a situation that needs to change. Set and keep your own boundaries for your own health and peace of mind. Sometimes, not always being there allows your parents to look for and engage outside help.
4. Communicate, communicate, communicate

(Next See Sibling Issues)
Sibling Issues

Example of Issue: The person with dementia is living home alone and has three children – two live in the community and one lives 1000 miles away and must fly in at times. The daughter who lives in town is the oldest and she jumps in and over time finds herself providing 24/7 care to keep her dad home. She realizes that she needs help, but it seems that her sister in town is unwilling to help and the brother who lives out of town thinks Dad is “just fine.” “They are just getting older.” He decided this after visiting during a weekend when he flew in and stayed with his dad. The other in-town sister is upset at her “controlling” older sister who is always the martyr. She thinks that they should just place their dad in a facility and no one is overwhelmed with daily caregiving. Therefore, since the other sister want place their Dad, she will not help her sister. Now, the caregiving sister has lost her job and is living with Dad to provide care.

Dementia is a long and complex disease which places increased strain on family systems. For caregivers, siblings can be a source of strength and support or aggravation and difficulty. Some common issues that cause difficulty:

1. Denial of disease/unwillingness to learn about the disease
2. Good days/bad days and “command performances” at visits
3. Differing amounts of time caring for the person living with dementia
4. Established family issues prior to disease (child/parent or child/child or family system)
5. Different views of “inheritance”
6. Ineffective communication techniques
7. Unemployed caregiver (available to provide care, may be financially dependent on parent)

Tips for Siblings that are Primary Caregivers

Siblings in the role of primary caregiver face specific issues because they are often the one carrying the bulk of the care load. Other family members often have unrealistic expectations and no sense of the overwhelming responsibility that 24/7 care for a person with Alzheimer’s requires. Most difficult can be siblings who offer much advice, but little help. Here are some practical tips for primary caregivers:

1. You set/define what you can and will do. Do not allow the other siblings to define this for you.
2. Make a long list of needs. Find out what they might be willing to do to help. Try several times, but if they are not willing to help, move on.
3. Use communication logs.
4. Think about how your siblings perceive your communication.
5. Work with their strengths.
6. Consider appropriate reimbursement for services. Have a Personal Care Contract.
7. Communicate, communicate, communicate.

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Tips for Siblings that are Secondary Caregivers

Some siblings simply provide a supportive role, but are not involved in the day-to-day care responsibilities. This could be due to demands from jobs and/or families living out of town.

1. Learn all that you can about the disease. Understand that you cannot see the full scope of impairment during short visits, and that the person living with dementia can act “normal” during your visit.
2. Advice without help or understanding is unwelcome. Find out what you can do to be helpful and then help.
3. Respite is absolutely necessary for the primary caregiver. Either step up and provide respite or offer to help pay for respite services (adult day care or in-home care).
4. Think about how your siblings perceive your communication.
5. Be aware of the stress the primary caregiver is under. Remain thankful and encouraging to the primary caregiver.
6. Communicate, communicate, communicate.

(Next See Step Family Issues)
Step Family Issues

Example of Issue 1: Divorced after 35 years, the Dad remarried quickly but now has dementia and is living with a woman the children refer to as “gold digger.” He has wandered away twice and the kids are worried sick, but the wife sees “no problem” with the husband and continues to leave him alone for hours at a time. The children feel helpless.

Example of Issue 2: Mom is diagnosed with Alzheimer’s and the step-child is in town and has been a part of the family for over 20 years, but the siblings did not always get along and still seem to struggle. The step child sees the problems and gets Power of Attorney to manage the affairs of their step parent whom they love dearly as their own parent. The actual son lives 45 minutes away and has never liked the step-sister. He thinks she is simply trying to take his inheritance. He does not help in any way, but constantly fights her regarding decisions. He says, “That is my Mom. I should make the decisions.” Another son who lives out of town does not like conflict so he remains uninvolved. “I am neutral,” he says.

The role of step children in the family can be murky, especially with dementia as the needs can be so great and the symptoms confusing. Communication between all parties is extremely important to help avoid the following:

1. Confusion over who is “in charge”
2. Lack of agreement on how care will be provided
3. Assumptions (not shared by all parties) about responsibilities and care, which leads to resentment and disappointment
4. Financial disagreements

Tips for Step Parent as Primary Caregiver

1. Listen to the concerns. Your children may primarily be worried about you, your spouse’s children may be most concerned about their parent.
2. Ask for input from step children. You may have different ideas about how care actually gets provided, but getting input can be an invaluable place to start.
3. Review the tips listed in the Parent section above, including communication!

Tips for Step Children

1. Whether you are the child of the person with the disease or the child of the primary caregiver, your help and input are needed in one way or another. Offer to help, don’t wait for an invitation.
2. Find ways to offer support – a card, flowers, an offer to run errands or pick up needed items at the store.
3. Respect the wishes of the primary caregiver as much as possible.
4. If you suspect physical or emotional abuse or neglect, call the chapter or your county Adult Protective Services organization.
5. Communicate, communicate, communicate.

(Next See Moving Forward)

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Moving Forward

Many families find positive ways to work together, regardless of how challenging the issues may be. Feelings of grief and guilt are usually factors for all parties involved. The following steps are available to help you navigate and reach your goals:

1. *Family meeting.* Give each person a chance to share their viewpoint, look at the needs, and decide on the resources needed to accomplish the family’s goals.

2. *Alzheimer’s Association Family Assistance Staff.* The chapter staff can lead a family meeting, acting at times as a buffer for emotional issues that can be a barrier to effective communication. Some families value an outside representative with knowledge of the disease and family issues to help the family work together to identify and move towards a common goal.

3. *Mediation.* Some families have great difficulty coming to a common goal for the care of a parent. Professional mediation services are available in the community and offer professional trained mediators who will lead the group to a binding resolution.

4. *Guardianship.* Legal action is the final step for families who cannot resolve differences, or for a person with the disease who is unwilling to accept help when safety is at risk. This can be a difficult and costly process, but necessary in some situations.