

Dementia as a family disease

Most people think that Alzheimer's disease (or a related dementia) only affects the person and the primary caregiver, who is usually a spouse or adult child. But the reality is that dementia affects the entire family. Thankfully, most families want to help and be a part of the solution. Maybe not every family member, but most will, especially when they understand what is needed.

Many married couples think that they should keep the diagnosis and the care from the adult children. The "for better or for worse" vows prohibit sharing can in fact cause more harm to the adult children when something unexpected happens to the well spouse. Now they step in and don't have a clue where to begin! Ideally, a family meeting should take place following the dementia diagnosis and then as needed during the course of the condition. This allows the affected person to talk about what is important to them. And, it also allows for the primary caregiver to share important medical information and updates to that family members are informed. But as importantly, it is a great time to discuss the care that is needed and how family members can help whether they live in town or across the country.

If you can't hold an in-person meeting, think about having a group email where information can be shared with all parties. You may want to scan medical documents or share resources you've found on the internet so that as a family you can learn together. As the primary caregiver, it will be helpful to think ahead regarding how family members can help. This might include:

- Who could assist with paying bills or setting up autopay?
- Who can bring over a home cooked/home delivered meal once (or more) a week?
- Who could come a spend a few hours with the affected person each week to give the caregiver a break?
- Who could make daily (or as needed) calls to the affected person?
- Who could research care options?

One of the [only studies](#) to date that has shown a way to delay residential care for a person with dementia was through a family-based approach. That means, families who worked together to support the primary caregiver and the person living with dementia, were most successful. Families can be a blessing. Don't forget to include your family – you might be surprised how much they are able and willing to help!