

# Families in Rural Appalachia Caring for Older Relatives with Dementia



Center for Gerontology  
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## Recognizing the Signs and Symptoms of Dementia

As a caregiver, it is important to know about the warning signs of Alzheimer's disease or other kinds of dementia. Though no two people will have the same number and types of signs, listed below are some common early signs of Alzheimer's and dementia.

- Memory changes that upset daily life
- A hard time finishing everyday tasks
- Losing things and difficulty retracing steps
- Lowered or poor judgement
- Changes in mood and personality
- A struggle solving problems
- Confusion about time or place
- Trouble understanding pictures
- Less active with work or friends
- Problems with words in talking or writing

## About the Research

This report gives information from two different sets of projects that were conducted in 2016-2017. In the first set, we interviewed 10 caregivers of people with dementia. Each caregiver answered questions to explore different features and care needs of families. In the second set, we called 39 caregivers every day for a week and asked some questions to get an idea of the daily lives of family members caring for persons with dementia.



## Common Themes among Caregivers

1. Not wanting to accept or ask for help
2. Needing to help family
3. Leaning on friends and family
4. Not using services in the area
5. Overwhelmed by the caregiving role

## Not Wanting to Accept/Ask for Help

Some caregivers did not want to accept help if it was offered, either for personal reasons or the person with dementia did not want anyone else to help. Other caregivers did not want to ask for help directly, but said they would take help if people offered it.

*"I just hate to ask anybody in the church to come. I'm sure they would try if I asked them but I just haven't asked anybody."*

*"I think bathing is so personal...so I try to do that to give her some dignity...."*

## Needing to Help Family

Many caregivers talked about how they take care of their family members because of their personal values (like marriage vows) or when growing up they were taught to care for family.

*"Cause it's my responsibility. When I took my marriage vows, I didn't take them lightly, so I'm going to take care of her as long as I can."*

*"That's what family does. It's just what you do."*

## Leaning on Friends and Family

Many caregivers lean on people, usually friends or family, to help them with care for a loved one. This included emotional support, getting items like food and supplies, and helping with money problems. Caregivers are thankful for the support, but sometimes wish that they had more help with their caregiving tasks.

*"He helps me do maintenance around the house and stuff. And then while he's here he'll take—my mama loves to go out to eat. Even though she doesn't eat like she used to, she still loves to get dressed up and go out to eat. So he'll take her out to eat and things that I don't always have the money to do. "*

*"They'll [neighbors] come mow the yard or anything. If they know I'm not feeling it or Dad's not feeling it, they don't even ask. They can usually just tell and they just come over and do it themselves. And we're very thankful for that. I'm just glad for the close community that we live in."*



## Not Using Services

Caregiver services, while available, are not often used for 5 main reasons:

- ▶ Unwanted – The person with dementia does not want services
- ▶ Cost – Caregivers would prefer to spend money left over at the end of the month on other things
- ▶ Location – Both the type and quality of care is not locally available
- ▶ Delivery – Caregivers said that services can take months to get
- ▶ Don't Know the System – Caregivers have a hard time navigating the system to sign up for resources

*"I am afraid of how he {person with dementia} might react to a stranger in the house."*

*"You know I have a little left over at the end of each month and I don't like to be down to nothing which I probably would be if I was hiring extra help to come in and do things."*

*"I think people around here try to provide care themselves. But I don't think they realize the resources that are available. If my daughter didn't work for social services, I wouldn't have known where to go, who to reach out to, what to do. I wouldn't have known. I'm sure a lot of the people around here wouldn't know."*



Caregivers who did not like community services and had strong beliefs about caring for their own family members were less likely to use paid help.

- 41% of caregivers did not use any paid services for their loved one.
- Among that group, 38% provided most of the care (without any help).

## How Do People See Their Role as a Caregiver?

Caregivers said that caring for their loved one could be rewarding but also very stressful. Caregivers felt overwhelmed and overloaded, some days more than others. Many felt that they were the only ones responsible for the care role. Caregivers, out of guilt, often put the needs of the person with dementia before their own. Caregivers gave up many of the things that they previously enjoyed doing. In spite of their own stress, caregivers also worried about problems that other family members were facing.

Caregivers who felt they had little control over their life and used few to no caregiver services had more distress than other caregivers.

*“Overwhelming responsibility is the biggest thing... trying to take care of another person’s finances, trying to take care of them, to oversee their medical care.”*

*“So that’s one of the big things is just being tied to home. There’s so many things I miss because he can’t go or it’s too much trouble for me to take him.”*

*“Sometimes I feel guilty. Even if I go—I had a doctor appointment last Monday in Roanoke. I feel guilty if I’m that far away.”*

*“It just tries your patience. You have to have plenty of patience and sometimes they run mighty thin. I tell her so, sometimes. I say, ‘You’re really trying my patience today.’”*

*“I have a lot of things like that that I’d like to do... but just don’t have the time.”*

Caregivers who dealt with more memory and behavior problems of the person with dementia, but used paid help for caregiving, felt much less distress. This shows that formal services can help ease high levels of distress.

## **Plans for Providing Care to People with Dementia**

Caring for a person with dementia takes patience and flexibility. Here are some tips to help deal with the frustrations you may have when caring for someone with dementia.

- Make a routine
- Give choices
- Be flexible
- Create a safe environment
- Ask for help from others
- Take your time when finishing tasks
- Give simple instructions
- Involve the person in daily tasks (when possible)
- Focus on care that works for the person
- Find a support group for yourself

## **How Family and Friends Can Support Caregivers**

Being a caregiver for a person with dementia can be rewarding. But it can take a lot of time and be hard on the caregiver. Remember that caregivers may need some help from other family members and friends. Here are some simple ways to help a caregiver.

- Be there to listen
- Let the caregiver express feelings
- Offer specific help: “I’ll bring lunch on Tuesday” or “I’m going to the store, what do you need?”
- Do not judge caregiver’s decisions
- Offer comfort and emotional support
- Do not stop inviting the caregiver because of some missed events
- Give the caregiver a break by visiting with the person with dementia while the caregiver rests or runs errands

## Strategies for Finding Resources

Before looking for resources, think about the needs of the person with dementia and your needs as a caregiver. Here are some important questions to ask yourself before starting your search:

- What types of help does the care receiver need now?
- What types of help might be needed in the future?
- What days and times do I need help?
- What can I do to help myself feel better?
- Are friends and family able to help?
- Can we get used to having a stranger in our home to help us?
- Do we want out-of-home care? If so, what kind and for how long?



Thinking about these questions, your needs, and the care receiver's needs might make it easier to find the right resources nearby. To the right is a list of community care options that might suit your needs.

Informal care  
Case management services  
Transportation services  
Adult day centers  
Information and referral  
Legal and financial counseling  
Respite care  
Home care

Once you have thought about your needs and know the types of resources you want to use, begin contacting services in your area. Case managers and referral agencies can help you find resources that fit your needs, so do not be afraid to ask for help.



### Contact Information

NRV Agency on Aging: (540) 980-7720  
Center for Gerontology: (540) 231-7657