

Alzheimer's Association

Highlights from Caregiver and Professionals Testimony: Listening Session on Behavioral Care and Dementia Needs March 20, 2018

Susan Hoffeecker, Family Caregiver, Carson City

Caregiver situation:

Susan is caring for her husband at home. She has issues of her own, including chronic pain from fibromyalgia. She had one knee operated on and desperately needs surgery on the other one, but she's used up all of her respite money on the first knee.

What would be/have been most helpful?

Susan needs funding for respite, so she can have her much-needed knee operation.

Julia Greenan, Family Caregiver, Sparks

Caregiver situation:

Julia's husband Gary was diagnosed with mixed dementia at 55 and is now 62. Julia cares for him at home.

Biggest behavioral issue:

Gary is very paranoid and this makes it almost impossible for her to leave the house. He frequently suffers from episodes that resemble psychotic breakdowns. She once had to call the Sparks Police because he became a danger in public during one such episode. Thanks to the training the officers had received, they were able to calm Gary down, allowing Julia to safely take him home. However, Gary once had a similar episode where the couple used to live. Those police were not well trained, and arrested Gary and placed him in jail where he then suffered a severe cardiac episode and had to be hospitalized for 2 weeks.

What would be/have been most helpful?

Making long-term care more affordable; greater availability of dementia-competent home care and money for respite services

Cathy Maupin, Family Caregiver, Reno

Caregiver situation:

Cathy had been caring for her mother with Alzheimer's for 21 years. For the first 10 years, Cathy cared for her mother in her mother's own home. She is now in a skilled nursing facility.

Biggest behavioral issue:

Cathy's mom used to wander late at night and ring her neighbors' doorbells, causing them to become frustrated.

Cathy wanted her mom to stay at home and explored options, but she didn't know where to look or where to start. She wanted her mother to remain at home for as long as possible, which would only have been possible with a live-in caregiver. However, that would have cost \$84,000 annually 10 years ago. Despite Cathy's wishes, Cathy moved her mother to a memory care facility because it was actually cheaper than home care.

Cathy's mom did very well in the memory care center but she later broke her hip, necessitating a move to a SNF. The staff were not well trained, and consequently Cathy noticed a sharp decline in her mom's condition. Not only were the SNF staff not well trained on dementia but it was significantly more expensive as Cathy's mom did not qualify for Medicaid. She is now on Medicaid because they spent down nearly all of her savings, over \$500,000.

What would be/have been most helpful?

Cathy's mom would have benefited from greater dementia training requirement for hands-on staff in skilled nursing facilities, as well as moderately priced options for memory care and in-home care.

Diane Ross, Professional, Sparks**Background:**

Diane is CEO of The Continuum, and adult day center in Sparks.

Feedback:

Diane discussed three issues she faces in her work with persons with dementia: lack of consumer and provider understanding of dementia, lack of awareness of community resources, and stigma attached to dementia and the resulting isolation from family and friends.

What would help?

Diane would like to see a statewide dementia awareness program that includes: whom to go to if you have concerns about memory, what community resources are available, when to talk to your doctor, and where are the community resources that may be available?

She suggested a model in which each community in Nevada ultimately has a "champion" to oversee community education efforts on dementia that span across sectors, as demonstrated in the Dementia Friendly program.

Diane also suggested reaching out to other NGOs such as the Community Foundation for Western Nevada, who may have resources and connections to promote community resources.

Sarah DeLaughter-Crawford, Family Caregiver, Las Vegas**Caregiver situation:**

Sarah lives with her mother and husband who both have Alzheimer's. They are fully dependent on her for their care needs. Sarah's mother is incontinent and requires a lot of hands-on care, while her husband is more middle stage.

Biggest behavioral issues:

Sarah's biggest behavioral challenges with her husband include: constantly following her and clinging on, wandering outside the home and getting lost, and constant angry outbursts which her mother only makes worse with derogatory remarks. In 2015 Sarah's husband worsened dramatically, and a psychiatrist mistakenly diagnosed him with depression and put him on an antidepressant. He was also put on Aricept and Namenda by a neurologist, and the two were clearly not talking to each other. Sarah takes comfort in her caregiver support group because they remind her to take care of herself. She would like to enroll both her mother and husband in adult day care, but can't afford it. Her local center is a very nice facility that provides round-the-clock activities, and she wishes she could take advantage of it.

What would be/have been most helpful?

Sarah said that respite services that provide social stimulation are her greatest need right now.

Paul Bailey, Family Caregiver, Las Vegas**Caregiver situation:**

Paul's wife Dixie was diagnosed with Alzheimer's in 2014. He has cared for her at home ever since and until recently was able to leave her alone for very short periods of time to run errands. Now she requires constant supervision.

Biggest behavioral issue:

Dixie spends large parts of the day tearing the house apart “looking for something”, and has taken to packing away as many household items she can find into laundry baskets. When she uses the bathroom, she puts the stopper in the sink and leaves the water running and has flooded their bathroom twice.

Dixie also asks the same question over and over again, and Paul gets so frustrated that he exclaims to her that she’d just asked that question. This only makes Dixie angry.

Thankfully, Dixie attends the Adult Day Care Center of Henderson 6 days a week. He says they have a caring staff with lots of activities and even live entertainment! He can afford it because of a grant he received from Nevada Senior Services in which only pays \$300 out of pocket as opposed to \$75 per day. Paul is looking into residential care options, but \$4,000+ per month is way out of Paul’s budget.

Paul uses paratransit to get Dixie to and from the adult day center, but there’s a 2 hour window for pickup each direction and he must sit with her the whole time.

What would be/have been most helpful?

Paul would like affordable respite services to come in during the morning and evening hours to get Dixie ready, bathe her, etc. He also would like to see an improved means of transportation for persons with dementia, and an expansion of the adult day care grant he receives, allowing more people to take advantage of it.

Alonzo Thornton, Professional, Las Vegas**Background:**

Alonzo is a psychiatric nurse with ASD.

Feedback:

Alonzo sees a lot of people with dementia who also have a co-occurring mental illness. In these individuals, depression worsens due to the dementia and the resulting social isolation, making these people at risk for suicide.

What would help:

Alonzo would like to see greater availability of geriatric psychiatrists to manage symptoms and ease suffering in persons with dementia and mental health conditions.

Patty Jones, Family Caregiver, Winnemucca**Caregiver situation:**

Patty is a 68 year old woman caring for her husband Harold of 45 years at home who is in late stage Alzheimer’s.

Biggest behavioral issue:

Harold is very aggressive, physically and verbally, and doesn’t like to be touched. He will hit Patty and hold her down any time she tries to touch him. Harold is also afraid of using the toilet, requiring Patty to keep him in diapers. His reaction to being touched makes it difficult for Patty to bathe him and change his diaper without getting injured.

Harold is a veteran and has received some services from the VA. Patty needs to place him, but the closest facility that the VA will cover is in Henderson, a 12 hour drive from Winnemucca. There is a new memory care facility in Winnemucca, but Patty can’t afford to place him there because the VA won’t pay.

Patty used to have respite services but the nurse whom Harold liked has moved away, and Patty won’t subject other workers to him because he’s prejudiced and doesn’t like anyone of color.

What would/have been most helpful?

Patty would like to see more respite services that have been trained to deal with dementia, as well as expansion of VA long-term care benefits, allowing greater access to more facilities.

Robin Gillis, Professional, Winnemucca**Background:**

Robin has worked in geriatrics for over 30 years, and is the Director of Nursing for Quail Corner and Harmony Manner. They have an 8-bed memory care facility in Winnemucca.

Feedback:

Barriers to families that Robin addressed include: lack of dementia education for caregivers and families, lack of dementia-competent professional in the community, and lack of resources to pay for dementia-competent care.

Robin also said when her residents exhibit difficult behaviors, they have nowhere to send them and under-trained staff have to do their best to manage these behaviors. Furthermore they must turn new residents away even when beds are available due to the nursing shortage in rural Nevada.

Robin also shared that there's a respite program in Winnemucca with no clients, because the community doesn't know it exists.

What would help:

Robin proposed the following:

- Hospital-based home care: hospitals and care facilities sharing resources and employees and share the cost of training them
- Professional development opportunities and incentives to encourage new nurses, physicians, and care managers to practice in the rural parts of Nevada
- Development of a statewide volunteer-driven or consumer-driven respite program
- A central repository of services to build awareness of community resources
- Subsidies for dementia caregivers to install home surveillance systems

Ellen Davidson, Family Caregiver, Elko**Caregiver situation:**

Ellen is a 70 year old woman and cares for her 83 year old husband at home in Elko. They have been married for 2 years, and it was only months after their wedding that Ellen started noticing cognitive changes.

Biggest behavioral issue:

Ellen's husband suffers from paranoia and has constant panic attacks. He obsessively drives to a house that he owns every day just to check on it, making Ellen unable to rent it out to supplement their income. He also panics whenever she tries to leave the house, making it impossible for her to attend her local Alzheimer's Association support group even though she found it helpful when she went.

Thankfully, Ellen has a friend from her church who comes and watches her husband so she can make it to Bible Study once a week, which is her biggest support system right now and only relief.

Ellen is forced to travel to Salt Lake City with her husband to see a dementia specialist. He also has significant heart disease that local providers can't appropriately manage. Ellen has tried to get her husband into Cleveland Clinic in Las Vegas, but the next available appointment isn't until June. Her husband's family lives in California and won't help because they are in denial, and Ellen is afraid to bring in respite workers because she's afraid of how her husband would react.

What would be/have been most helpful?

Ellen needs more access to local resources that could educate her on dementia, specifically coping with difficult behaviors, and respite workers with dementia-specific training.

Kerry Aguirre, Professional, Elko**Background:**

Kerry is in her fifth year as director of Elko Senior Center. They provide meals, socialization, and health screening.

Feedback:

She has found out from her work that many local providers do not accept Medicare, which forces them to travel 3 hours to Salt Lake City or 4 hours to Reno to get care.

Kerry pointed out that family caregivers who must still work have three choices: quit working to care for their loved one and jeopardize their financial wellbeing, hire someone to come in, or move to a new area altogether where greater respite services may be available, allowing them to find work.

What would help:

Kerry addressed a need for the dementia-competent social engagement that adult day care offers. She would like to see the state fund bricks and mortar to build more of these centers in rural Nevada.

Debbie Anderson, Professional, Elko**Background:**

Debbie is Director of Case Management at Northeastern Nevada Regional Hospital, and does case management for older clients; many of whom have dementia.

What would help:

Debbie highlighted the following needs for her community:

- Better coordination of healthcare services and community support as part of a managed care package
- Dementia education for physicians and inpatient hospital staff
- Greater availability of respite services
- Incentive programs to encourage new health providers to work in rural Nevada
- Expansion of affordable healthcare-related travel between rural and urban communities statewide.

COMMON BARRIERS AND NEEDS

- 7 speakers identified expansion of respite as something that would help, or would have helped them.
- 5 speakers identified dementia competency training for providers—medical, respite, and long-term care—as something that would help, or would have helped them.
- 4 speakers identified greater availability and access to affordable long-term care, whether home-based or residential, as something that would help, or would have helped them.
- 2 speakers identified dementia-capable and affordable transportation as something that would help, or would have helped them.
- 2 speakers identified addressing lack of providers in rural areas through professional development or incentive programs as something that would help, or would have helped them.
- 2 speakers identified a statewide, multi-sector dementia awareness campaign as something that would help.