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Overcoming the Loneliness of Dementia Caregiving

Make connections that are real, empathetic and enduring

After her children and their families leave, 75-year-old Barbara is initially relieved to restore order to her house. She cleans up the kitchen, straightens the living room and gets her husband, who's suffering from dementia, ready for bed. Once he's asleep, though, and she sits in her recliner in the den, trying to read a novel her daughter recommended, the loneliness sets in.

While Barbara appreciates the support of her children, she knows they don't really understand the physical toll it takes on her to lead their father by the hand through each day's monotonous tasks. Nor does she believe any of them has an inkling of how sad, angry and mentally drained this caregiving work makes her.

Barbara's growing sense of loneliness isn't based on feeling socially isolated, although many dementia caregivers become more isolated as the disease slowly progresses. Her children do visit her frequently and offer to pitch in with caring for their dad.

It's that Barbara feels totally alone with her plight. She doesn't really tell her children what she is experiencing for fear of alarming and hurting them. She can't confide in her best friend — her husband of 50 years — because he is no longer capable of grasping her distress and expressing empathy. And because she doesn't want to complain to her girlfriends, her relationships with them have become more distant and superficial.

The loneliness felt by many family caregivers compounds their emotional suffering, making it harder for them to sustain themselves over time. Yet they make addressing their loneliness a lower priority than the thousand daily tasks of caring for a loved one with dementia. How can caregivers better balance the needs of care recipients and themselves? Here are some ideas.

First, connect

Caregivers can't benefit from the magical power of social supports if there are not enough caring people in their lives.

Sometimes this is beyond their control. Friends and even family members have an unfortunate tendency to edge away from people with dementia, as if they might catch the disease.

But caregivers can maximize their connections to others and minimize isolation by identifying those true-blue stalwarts in their lives who will be present for them throughout the caregiving ordeal. They then need to continually reach out to those supporters and keep them close.

In instances where there are no willing friends and family members, caregivers should make new connections with those who are most likely to understand their difficult circumstances — other dementia caregivers. This can be accomplished by contacting [caregiver support groups](#) run by the Alzheimer's Association and your county's area agency on aging or through the [online caregiver support group run by AARP](#)

Establish confidants

It's not enough to simply have people with whom you can occasionally go out to lunch or play cards. To combat loneliness, caregivers need to develop deeper connections with others who share the whole gamut of feelings common to dementia caregiving — sadness and hopelessness, pride and appreciation, guilt and regret.

It's only on that emotional level that the debilitating feeling of aloneness can be remedied with a sense of communion.

Express yourself

Barbara might say, "I don't want to burden others, particularly my children, with my feelings." I would respond by pointing out that by shutting them out of her inner life, she is preventing them from really understanding her and having the information to be truly helpful.

She might retort, "If I sit around talking about my feelings all the time, I'll become too overwhelmed to care for my husband." I would respond by saying that hunkering down on care tasks will only close herself off from parts of herself as well as the concerns of others, and make her a less flexible and effective caregiver.

Accept praise

Dementia caregivers often are often compared to marathon runners because the challenge before them is a long and arduous course. Marathoners feel alone with their physical and psychic pain. So, too, do caregivers. Throngs of cheerleaders may root for them on the sidelines, but no one else can actually run the race for them.

Marathoners accept the onlookers' praise. Caregivers often deflect it away, saying that others don't really understand. Accept others' good wishes, even if their understanding is limited. Battling loneliness means allowing people into your life in any way you can manage to connect.

----- Written by Barry J. Jacobs, a clinical psychologist, family therapist and healthcare consultant, is the co-author of [Love and Meaning After 50: The 10 Challenges to Great Relationships—and How to Overcome Them](#) and [AARP Meditations for Caregivers](#) (Da Capo, 2016).

AARP was founded in 1958 and has over 38 million members. It is a nonprofit, nonpartisan organization for people over the age of 50. AARP is well-known for its advocacy efforts, providing its members with important information, products and services that enhance quality of life as they age. They also promote community service and keep members and the public informed on issues relating to the over 50 age group.

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