

SPECIAL SUMMIT EDITION
**Uniting Communities
for a Cure and Better
Brain Health**

The Pulse of the Community

What Matters Most:

Effects on Travel and “Loss of Self” Feelings

A new UsAgainstAlzheimer's A-LIST® survey shows how Alzheimer's disease can be isolating, with both people with dementia and caregivers cutting back their travels and vacations because of concerns about traveling with the disease, and whether the costs of vacation would lead to less money for future care costs. This survey provides key insights at a time when millions of families are making plans for one of the nation's busiest travel periods: Thanksgiving through New Year's.

At the same time, in a new “loss of self” A-LIST® survey, about three-quarters of those living with the disease, caregivers and others concerned about brain health talk about their loss of independence and control over daily activities from a diagnosis, and two-thirds talk about challenges of isolation and the loss of a social life.

These are among the key findings of these two A-LIST® surveys conducted by UsAgainstAlzheimer's. A third survey found seven in 10 respondents are caring for a parent or other, older loved one, with a range of emotions resulting from this reversal of familiar family roles.

In addition, a new study by Mayo Clinic and UsAgainstAlzheimer's spotlights the often-overlooked need for family caregivers of people with Alzheimer's disease to be more engaged by physicians during

A-LIST®: A Powerful Voice for the Alzheimer's Community

The UsAgainstAlzheimer's A-LIST® is a growing online community of more than 8,000 people living with Alzheimer's, other dementias, or mild cognitive impairment, current and former caregivers, people who believe they are at risk, and those interested in brain health.

These survey responses are contributing to IRB research that illuminates and validates their lives and experiences. The surveys offer a way to make their views and preferences heard on issues that span the entire scope of living with Alzheimer's disease and dementia.

The A-LIST® is part of a broader effort by UsAgainstAlzheimer's called AD-PACE, a groundbreaking patient and caregiver-led collaboration of industry, academics, government agencies and advocates.

medical appointments with their loved ones. Published in the *Journal of Applied Gerontology*, the research engaged participants recruited through A-LIST® in online focus groups.

These surveys and research projects give voice to the stories of people directly affected by Alzheimer's and related dementias or deeply interested in it, spotlight their everyday dilemmas and decisions, and provide insights into their views as roles change with loved ones.

Moving Up, Revising or Halting Travel and Vacation Plans

The A-LIST® survey on travel and vacations shows how Alzheimer's disease, dementia or cognitive impairment affects the vacation and travel plans of people living with the disease, caregivers and those at risk. People are expediting traveling to get vacations in before disease progresses, simplifying, or revising plans by traveling with a partner.

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Among people already living with the disease, about half (47%) say their diagnosis has already affected their ability to travel, and 72% are concerned that it will affect their future travels. **More than four in five current caregivers**

(83%) say the Alzheimer's of a loved one has already affected their travel and vacations, and 92% expect that this will have an influence on their future travels.

People living with Alzheimer's or cognitive impairment have responded to these concerns by simplifying or moving up their travels: 43% said they simplified their vacation plans to account for their evolving condition, and 40% said they are taking vacations and traveling while they still can.

The survey also found that the disease caused them to change their travel arrangements, as nearly four in 10 (38%) said they chose to travel with a partner instead of alone. Concerns about how their condition would change the way they travel were already on their minds: 28% of people with Alzheimer's said they



Alzheimer's does not take a vacation. It comes along to new, unfamiliar locations and makes more work for the caregiver. Last trip we took I swore it'd be the last because I never had a minute of "down time."

already lacked energy to travel, and 28% said they were concerned about being afraid or overwhelmed in unfamiliar surroundings. About one in 7 (15%) of people living with the condition said they avoided airports because security and other personnel were not trained to help or care for people with cognitive impairment.

Current caregivers said the condition of their loved one affected their own travels and planning. **Nearly half (48%) found that a loved one had been afraid or overwhelmed by unfamiliar surroundings, and nearly four in 10 (38%) said a loved one had become anxious in a crowded place**, triggering an unexpected behavior. In addition, 38% of caregivers said their loved ones could no longer physically handle traveling and vacations.



Losing vacations is another aspect of this disease which robs us of "normal" life as we knew it; vacations to me are yet another thing to grieve.

Future financial worries also influence decisions today about vacations and traveling. One in five people (19%) said they worried whether they could afford traveling because of the anticipated future costs of the disease. More than one in four (22%) of current caregivers said these future financial concerns have an effect on their vacations and travels with loved ones.

Former caregivers found their vacation and travel plans affected in several ways. **Nearly five in 10 (47%) said that a loved one was anxious in an unfamiliar place that triggered an unexpected behavior**, 44% said their loved one was afraid or overwhelmed, and 41% of loved ones could not physically handle the travel. Nearly one in three (31%) of former caregivers said they didn't want to travel because the loved ones needed them to stay home.

More than three in four (76%) of people who are at risk say they are concerned about whether they will be able to vacation and travel in the future, with another 13% unsure about how they would be affected.

The vacation and travel survey findings are based on responses from 435 people, including people who have been diagnosed, current and former caregivers, people who believe they are at significant risk, and people interested in brain health.

How a Diagnosis Can Contribute to a “Loss of Self”

An Alzheimer’s diagnosis can lead to feelings of “loss of self” such as independence, self-identity and control over daily activities and isolation, according to an A-LIST® survey.



I’ve been a Mr. Fix It all my life; now when I do a repair of something, I suffer the next day like I’ve used up next day’s brain.

Survey respondents said that a diagnosis of Alzheimer’s can lead to a “loss of self” in a range of ways: **more than three in four (77%) said the diagnosis would mean a loss of independence**, 74% said it would cause feelings of a loss of control over daily living activities, 68% described a loss of self-identity, and 66% listed a loss of social life and isolation.

The A-LIST® “loss of self” survey had a total of 971 respondents, including people who have been diagnosed, current and former caregivers, those who believe they are at significant risk, and people generally interested in brain health.



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Role Reversal: Caring for a Parent or Older Loved One

Nearly seven in 10 Alzheimer’s caregivers find themselves caring for a parent or other older loved one, according to an A-LIST® survey of more than 2,600 Alzheimer’s caregivers.

This reversal of familiar family roles, where the child feels like they take on more of a parental role to their parent or in-law, brings around a range of emotions for the caregiver, especially stress (75%), frustration (57%), fear/anxiety (49%), guilt (35%), and anger (25%). One in four (25%) said they had grateful feelings about providing the care.



Loss of self means, essentially, loss of the “known,” which encompasses many things. But I also choose to not think of Alzheimer’s as a loss. That’s a negative viewpoint. I choose to see where my Mom is now is simply a different journey than the one she was on.

According to the survey, **69% of the respondents said they had experienced role reversal with a parent/parental figure/in-law who has dementia**, while 27% did not. Four percent said they didn’t know. The Alzheimer’s Association’s TrialMatch® was a partner in the survey.

The results of the role reversal survey provide important insight into the emotional toll that Alzheimer’s caregiving takes on people. It’s not just the time commitment of caregiving, it’s also the personal impact when the “child” and “parent” in a family find themselves switching to the opposite role – and how that feels for them.

New Study Highlights Need for Healthcare Providers to Engage Alzheimer's Caregivers

A new study by Mayo Clinic and UsAgainstAlzheimer's spotlights the often-overlooked need for family caregivers of people with Alzheimer's disease to be more engaged by physicians during medical appointments with their loved ones. The research, published in the *Journal of Applied Gerontology*, was based on online focus groups of people with mild cognitive impairment, as well as spousal and non-spousal caregivers. Participants were recruited through the A-LIST®.

This research provides a unique perspective, through the lens of people with Alzheimer's and dementia, on attending medical appointments. Previously, studies in this area have typically centered on the view of medical providers, and how they engage caregivers and people with Alzheimer's and dementia. The expectations of caregivers and people with Alzheimer's and dementia have generally not been considered.



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—Meryl Comer

The paper identified seven best practices to better integrate family caregivers into the clinical appointments of people with Alzheimer's and dementia. For example, the research team recommended that healthcare providers recognize the important perspectives of both the patient and the caregiver, the need to communicate directly with the patient, and provide opportunities for caregivers to have separate interactions with the providers. They also report healthcare providers should be trained in shared decision-making as the patient's condition evolves. and to remember there are different perspectives from caregivers and people with Alzheimer's and dementia.

"When doctors don't actively engage family members in the patient conversation during an appointment, it creates a void of vital information that could help the patient's care," said Meryl Comer, a 22 year at-home caregiver and co-author of the study.

"The UsAgainstAlzheimer's A-List® online community gives voice to those living with Alzheimer's and their caregivers, and validates what matters most for people across the disease spectrum," Comer said. "Sharing the survey results back with the patients and caregivers provides priceless feedback that you are not alone in your journey and that your insights help advance research to improve quality of life."



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