

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The A-LIST is an online community of more than 8,000 people living with Alzheimer's or other dementias, and current and former caregivers who are bringing research closer to the lived experience of this disease.

The Pulse of the Community

The A-LIST transforms the stories of more than 8,000 people living with Alzheimer's or other dementias into evidence-based insights by providing unique, rapid-response, self-reported data through virtual surveys on what matters most on a wide range of Alzheimer's-related topics. The A-LIST offers a powerful and validating voice for those living with Alzheimer's and those caring for them, and a pathway to help expand treatments and accelerate toward a cure.

The A-LIST is part of the broader work of UsAgainstAlzheimer's AD PACE, a groundbreaking patient and caregiver-led collaboration of industry, academics, government agencies, and advocates. It gives both those living with Alzheimer's and their caregivers a scientifically valid, collective voice and enables them to make their preferences heard on issues that span the entire scope of Alzheimer's disease.

WHAT MATTERS MOST:

Emotions, Dementia-Friendly Faith Communities, Caregiver-Physician Relationship

The A-LIST has fielded 20 surveys and received more than 26,000 responses. The three most recent surveys asked A-LIST members what matters most to them on topics ranging from the emotional toll of living with or caring for someone with Alzheimer's, to managing the disease through faith.

The results of the three surveys highlighted in this report provide unique data about caregivers—and in many ways, their responses mirror the responses of the people for whom they care.

More than 16 million Americans, 60% of whom are women, provide unpaid care for people with Alzheimer's or other dementias.¹ Too often, these caregivers become the “invisible patient.” In 2018, caregivers of people with Alzheimer's or other dementias provided an estimated 18.5 billion hours of informal assistance and unpaid caregiving, worth \$233.9 billion.² This tremendous dedication of time, finances, and emotions can often have a detrimental effect on a caregiver's well-being. Frequently, time dedicated to caregiving interrupts normal routines and careers. The consequences can lead to financial insecurity, depression, high levels of stress, and isolation—the effects of which can also manifest themselves physically.



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¹ www.alz.org/alzheimers-dementia/facts-figures

² www.alz.org/alzheimers-dementia/facts-figures

Staying connected to a support group or network and asking for help are key to ensuring caregivers stay positive in their journey caring for others.

Together, caregivers and people with Alzheimer's are on the front lines of combating this disease. To arm them for this fight, we must understand what matters most, and we can only do this through improved research. As we strive to mitigate the stigma of Alzheimer's, we must empower caregivers to chart their courses, tell their stories, and make their voices heard.

When we asked caregivers which feelings they experienced when supporting someone with Alzheimer's, another dementia, or Mild Cognitive Impairment (MCI), the top answers cited were frustration (86%) and fear (70%). However, our research also demonstrates that many still remain hopeful. **In fact, in response to the same question, 32% of caregivers also said that they feel inspired to make positive changes in their lives.**

32%



32% of caregivers said that supporting someone with Alzheimer's, dementia, or MCI made them feel inspired to make positive changes in their lives.

The same percentage (32%) of those diagnosed with Alzheimer's or another dementia share the exact same sentiment. Our research is telling us that both people living with the disease and caregivers are motivated and inspired by their diagnoses, or the diagnoses of those for whom they care, to change their outlook on life and to live each day with positivity and hope.

By understanding the emotions of both caregivers and those for whom they care, we can empower them to maintain a positive, proactive outlook on their own lives and the lives of those around them. We asked caregivers in the A-LIST how they best cope with the frustration and fear they cited earlier. **Our research revealed that positivity and support are key for those living with or caring for someone living with Alzheimer's. 24% of caregivers say they manage their emotions**

through therapy, exercise, and support from friends, faith, and family. Thankfully, taking proactive steps like these across the lifespan is exactly what the latest science is telling us about how to live "brain healthy." Physical activity, a healthy diet, and social interaction are pillars of maintaining a healthy brain to build cognitive resiliency and delay potential cognitive decline. (For example, the 30-Day [Brain Health Challenge](#)³ provides easy-to-incorporate steps towards making brain health a critical part of overall health.)

In addition, 56% of caregivers say their faith sustains them during the challenges of caring for a loved one with Alzheimer's, another dementia, or MCI. However, our research is telling us we have an opportunity to do so much more. In fact, **72% of respondents indicated they wanted more support from their faith communities.**

The highest number of survey respondents indicated they wish their faith communities were more welcoming, friendly, and offered a safe environment for those with dementia. Prompted by these results, we asked several leaders from the UsAgainstAlzheimer's Faith Coalition to reflect on the need, opportunities, and challenges that faith communities face in supporting those living with dementia and in the fight against Alzheimer's.



Faith-related activities, whether communal or individual, can greatly help those living with dementia [and Alzheimer's] to promote a sense of belonging in a group and to develop their spiritual life, thus contributing to better physical and mental wellbeing—by enhancing feelings of self-worth, by piercing sentiments of loneliness, and by creating hope.

Rabbi Israel de la Piedra

³ www.bebraintpowerful.org

In the words of Rabbi Israel de la Piedra, “Faith-related activities, whether communal or individual, can greatly help those living with dementia [and Alzheimer’s] to promote a sense of belonging in a group and to develop their spiritual life, thus contributing to better physical and mental wellbeing—by enhancing feelings of self-worth, by piercing sentiments of loneliness, and by creating hope.” (To learn more about how faith communities can become more dementia friendly, read our [Power of Faith in Alzheimer’s & Dementia](#) blog.)⁴



24% of caregivers say they manage their emotions through therapy, exercise, and support from friends, faith, and family.



56% of caregivers say their faith sustains them during the challenges of caring for a loved one.



36% of respondents say formal support groups are the most helpful.

Establishing a support system and trying to maintain a healthy lifestyle are critical for caregivers. **While 36% of respondents in the faith survey say formal support groups are the most helpful, another important support system can exist within the relationship between caregivers and physicians.**

While more than 60% of caregivers surveyed believe their doctors are aware of their status as caregivers, **almost 75% of doctors were reported to have provided no advice on caregiving.** This creates an opportunity for healthcare providers to incorporate what matters most to caregivers and patients during a visit. In fact, nearly a decade ago, the American College of Physicians (ACP) published a widely circulated [position paper](#)⁵ which recommended that doctors “be alert for signs of distress in the family caregiver and suggest appropriate referrals.”

⁴ www.usagainstalzheimer.org/faith

⁵ www.ncbi.nlm.nih.gov/pmc/articles/PMC2839338

⁶ www.usagainstalzheimer.org/physicians

⁷ www.sciencedaily.com/releases/2019/05/190514104058.htm

Today, **one in five caregivers** surveyed by the A-LIST indicated that clear information from healthcare providers written in digestible language that will help them better care for their loved one is their top priority. (Read our physician and caregiver [blog](#),⁶ authored by Barry J. Jacobs, Psy.D., and Mark J. Yaffe, M.D., for additional information on the survey.)



1 in 5

1 in 5 caregivers indicated that their top priority is access to clear information from healthcare providers that will help them better care for their loved one.

As we continue to fight the stigma of Alzheimer’s, the voices of those with the disease and their caregivers become ever more important. It is this community that will also help us find a cure through increased clinical trial participation. Knowing now that signs of Alzheimer’s may appear as early as 30 years before symptoms, according to a [recent report](#)⁷ by Johns Hopkins, the connection between patients and caregivers may continue to drive a positive outcome in research.

Whether discussing emotions, methods of support, or the caregiver-physician relationship, the research summarized here reveals a consistent truth among people with Alzheimer’s and caregivers alike: it is imperative that we all help this community remain engaged, hopeful, and empowered. It is no wonder that nearly half of caregiver respondents, when asked to give their best advice to others in their position, said to stay positive, be proactive, seek help, and take care of yourself.



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