



A media briefing will be held <u>today</u>, Monday, December 4, at 2:00pm EST with Alzheimer's leaders and representatives of the millennial community. Click <u>here</u> to participate in the live audio stream or dial 877-229-8493, ID code: 117056.

Embargoed until Monday, December 4, 2017 at 2:30 EST

New Analysis Released About the Role of Millennials in Dementia and Alzheimer's Caregiving

One out of six millennial caregivers cares for someone with Alzheimer's disease or other dementia, and the need for care is on rise

Youth Against Alzheimer's Coalition launched to position Alzheimer's as an urgent economic and public health issue impacting families across generations

Washington, DC (December 4, 2017) – A new report, <u>Millennials and Dementia Caregiving in the United States</u>, released today by UsAgainstAlzheimer's and the USC Edward R. Roybal Institute on Aging, shows that one out of six millennial caregivers cares for someone with dementia. With the prevalence of Alzheimer's disease and other dementias expected to reach nearly 16 million in the U.S. by 2050 from 5 million today, more millennials and young Americans are expected to face caregiving responsibilities in the future.

The first-of-its-kind analysis provides information about the characteristics of millennials caring for someone with Alzheimer's disease or other dementias, examines the caregiving activities they perform and the burden they experience through caregiving, and how their caregiving activities interfere with their workforce participation. The report also makes policy and programmatic recommendations for addressing these challenges.

Alzheimer's, the most common form of dementia, is the only disease in the top ten cause of death in the U.S. with no cure, no means of prevention, and no disease-modifying treatments. It is always fatal and individuals with the disease typically live for years or even decades. Alzheimer's and other dementias are characterized by a profound deterioration in memory, language and communication abilities, problem-solving capabilities, and other aspects of cognition that affect a person's ability to perform everyday activities.

"Caregiving to family members with dementia can approximate a full-time job. Providing information, services, and supports to millennial caregivers is a societal investment with

the potential of delaying family burdens and healthcare costs in the future," said **Dr. María Aranda, associate professor and interim executive director at the USC Edward R. Roybal Institute on Aging.**

Key findings of the report include:

- **Generational Status.** About one out of six millennial caregivers is caring for someone with dementia, with an average age of 27 years.
- **Gender**. More female (53%) than male (47%) millennials provided care for someone living with Alzheimer's disease or other dementia
- **Sole caregiver**. Roughly 42% of millennial dementia caregivers are sole caregivers and the overwhelming majority (79%) reported that accessing affordable outside help was very difficult.
- **Travel and transportation**. Most millennial dementia caregivers (84%) do not live in the same household with their care recipient/partner, and 16% had to travel more than an hour to provide care.
- **Caregiving activities**. The most common caregiving activities for millennial dementia caregivers includes helping with transportation (79%), grocery shopping/shopping for other items (76%), and communicating with health care professionals (70%).
- **Emotional distress**. Millennial dementia caregivers feel emotional distress (79%) was a major caregiving burden and wanted more help to deal with this hardship.
- **Interference with work**. About one out of two millennial dementia caregivers stated that caregiving interfered with work, and 33% reported severe interference with work (e.g., cutting back hours, losing job benefits, being fired).

"As someone deeply affected by Alzheimer's disease, the worst parts of my journey were the years that I didn't talk about it," said **Lauren Miller Rogen, co-founder of Hilarity for Charity**. "Young caregivers face isolation and emotional distress at alarming rates and we must talk about it and do more to engage and support young people in this fight."

Policy and Programming Recommendations

The report outlines solutions to address the challenges faced by young adults who act as caregivers for individuals living with Alzheimer's or other dementias, including:

• **Improving transportation solutions** by developing in-home medical services for the patient and telemedicine options, partnerships between share-riding providers

and medical systems, and piloting of autonomous cars to connect caregivers and care partners to medical and social services.

- **Increasing access to information** through the development of tailored training programs and support groups that account for the cultural and age-specific needs of millennials. Develop psychosocial and emotional support interventions that address the unique challenges and needs of younger caregivers.
- **Enhance communication with health care providers** by developing online communication platforms, technologies, and tools that help young caregivers track symptoms, medications, and execute care strategies for their care partners.
- **Introducing flexible work arrangements,** including flexible work hours and telecommuting to make alternative work arrangements more widely available, including at the beginning of employees' careers. Expanding paid leave policies to support family caregiving is another critical step.

Launch of Youth Movement Against Alzheimer's

The complex challenges of caregiving for someone with dementia creates a compelling need for greater support for this community. To answer this charge <u>UsAgainstAlzheimer's</u> and <u>The Youth Movement Against Alzheimer's</u> is launching the **Youth Against Alzheimer's Coalition (YAAC)** to position Alzheimer's as an urgent economic and public health issue impacting families across generations by mobilizing young people and youth-serving organizations through storytelling, advocacy, and coalition building.

YAAC founding members include:

- Active Schools
- Generations United
- Hilarity for Charity
- MemoryWell
- National Human Services Assembly/National Collaboration for Youth
- The National Youth Leadership Council
- Purple Orchard
- Undergraduate Student Association Council of the University of California Los Angeles (UCLA)
- University of Pittsburg Student Government Board
- Youth on Board

"We recognize that Alzheimer's needs as much investment from our generation as any other," said **Nihal Satyadev, CEO & Co-Founder of The Youth Movement Against Alzheimer's.** "I believe this inter-generational effort will be one of the most important efforts in creating care solutions for this disease. Together, we are creating a future worth remembering."

In the report, millennials are defined as the generation of young adults born from 1980 to 1998. At the time of the initial data collection on which this report was based, millennial caregivers were defined as persons between the ages of 18 and 34 years. The report analyzes data from the nationally representative study, *Caregiving in the U.S. 2015*, conducted by the National Alliance for Caregiving and AARP.

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<u>UsAgainstAlzheimer's</u> (UsA2) is an innovative non-profit organization demanding—and delivering—a solution to Alzheimer's. Driven by the suffering of millions of families, UsAgainstAlzheimer's presses for greater urgency from government, industry and the scientific community in the quest for an Alzheimer's cure—accomplishing this through effective leadership, collaborative advocacy, and strategic investments.

The <u>USC Edward R. Roybal Institute on Aging</u> builds upon the USC Suzanne Dworak-Peck School of Social Work's longstanding tradition of conducting socially relevant research, innovating educational practices, influencing policy making, fostering community-university partnerships and sharing best practices with direct service providers. The USC Roybal Institute maintains a strong interdisciplinary focus, with collaborations among faculty and professionals in such fields as social work, gerontology, psychology, preventive medicine, family medicine, psychiatry, oncology, American studies and ethnicity, and public policy. Its mission is to advance research whose goal is to enhance optimal aging for persons in minority and low-income communities.