

## Alzheimer's TX Newsletter Article

**Title:** Impacts of COVID Social Isolation on People Living with Dementia and their Care Partners

### **Definitions and Broader Impact on Older Adults**

Profound adverse health and mental health challenges stemming from the COVID19 pandemic are still a daily reality for many people living in the U.S. and globally. Large studies of the general population during the pandemic showed that many people experienced uncontrolled fears related to infection, pervasive anxiety, frustration, boredom, disabling loneliness, and depression [1, 2]. While social distancing measures were essential for controlling the infection rate and keeping vulnerable groups safe, the impact of prolonged social isolation has resulted in significant negative outcomes for countless individuals and families. Social isolation and loneliness have been identified in recent research as serious problems for many people nationally and globally, especially for older adults. Recent research has defined social isolation as “the tangible absence of strong and supportive social networks”, while in contrast loneliness has been defined as “the perception or felt experience that one is without meaningful connections” [3]. Social isolation and loneliness are consistently correlated with one another, and research over recent decades has highlighted their harmful effects, including correlations with poorer health and mental health outcomes and mortality (4, 5; 6]. A person’s social and community context has been identified as a social determinant of health, along with economic stability, neighborhood and built environment, and education and health care access and quality [7].

Older adults are at increased risk for social isolation and loneliness because they are more likely to experience life factors such as living alone, loss of family or friends, chronic illness, and hearing loss [8]. Older adults also experience the duality of a higher risk for developing some form of dementia as they age while also representing a significant portion of the those caring for people living with dementia. Recent demographic data indicates that an estimated 34% of care partners for those living with dementia are over 65 [9], and roughly 6.5 million Americans age 65 and older are living with Alzheimer's Disease [10]. Prior to the unprecedented stressors related to the recent pandemic, older adults and older people living with dementia often experienced additional hardships associated with social isolation and loneliness. Studies show that as many as 40% of older adults in the U.S. are socially isolated [11], while up to 60% experience loneliness [12, 13]. Research has also pointed to a relationship between social isolation and a decline in cognitive functioning [14] and depressive symptoms for older adults [15]. A growing body of evidence is signaling the need for innovative programs, services, and supports to protect older care partners and people living with dementia from the harmful effects of social isolation and loneliness.

### **Impact on People Living with Dementia and Their Care Partners**

During the pandemic, negative effects on mental and cognitive functioning appeared to be especially prevalent for older adults, many of whom were dementia care partners or living with dementia themselves. A 2021 AARP survey on the emotional wellbeing of adults 50 and older in the U.S. showed that a majority said the pandemic increased their level of concern about the

future (77%) and general worry (76%) [16]. This same study showed that a majority of respondents experienced increased levels of depression (68%) and anxiety (68%) [16]. As the global pandemic wanes, the ongoing negative impacts of prolonged social isolation and loneliness on people living with dementia and their care partners have become clearer. Early research during the pandemic showed challenging behaviors increased in people living with dementia [17]. One recent qualitative study described the debilitating effects of social distancing measures, which restricted movement and resulted in the deterioration of physical health of people living with dementia. The same study described harmful impacts on home dwelling people living with more severe dementia, who reportedly experienced negative emotions (e.g anger, aggression) due to a lack of additional home care services and community support (respite and support groups) [18]. According to this same study, care partners for people living with dementia, both those receiving home care and those living in long-term care settings, also struggled with complex emotional, health, and social stressors [18]. Family care partners of community dwelling people living with dementia reported that care routines often intensified and few to no organized activities existed for their family members [18]. Many respite and day care programs shut down, leaving community dwelling people living with dementia and their care partners with a limited network of social support. Another recent study reported that a majority of dementia care partners reported feeling more tired and overwhelmed, with approximately one third experiencing health problems [19]. While people living with dementia are slowly enjoying more opportunities to engage socially, the vast majority are older adults and remain in a high-risk category for infection. This threat continues to burden care partners with the difficult task of balancing infection risk for their loved one with taking care of their own mental and physical health.

### **Assessing Needs and Accessing Support**

The dire outcomes of social isolation stemming from the pandemic point to the need for individual, industry, and policy level interventions to reduce future harm during public health crises. For people living with dementia and their care partners, creating a plan for regular, meaningful social interaction will be vital during times when infectious disease precautions are recommended for the general public. When public health officials call for isolation and social distancing, concerted efforts must be made to maintain socialization opportunities for vulnerable groups, such as people living with dementia and their care partners. A combination of virtual and in-person socialization opportunities, combined with best practices for infection control, should be part of an overall plan for people living with dementia and their care partners to stay healthy (emotionally and physically) during such national crises. Increased public and private funds to support various social service and health care sectors will be vital to provide additional care for people living with dementia when social distancing and isolation measures are necessary. These efforts will be especially important for those with a limited social support network and/or with higher care needs [18]. Both community-based programs (respite and day care programs) and long-term care (skilled nursing facilities and assisted livings) will require additional funding for increased staffing and planning collaboratively with each person's support network to provide safe and sustained socialization when infection rates are dangerous. For example, in long term care settings, people living with dementia, social support representatives, advocates, and health care professionals should be included in

discussions around any restrictions on socialization and how to mitigate harmful impacts. As with other health related behaviors, social workers and other mental health professionals can help families develop plans for maintaining social connectedness by assessing for various needs and identifying resources to prevent adverse outcomes of social isolation.

Prioritizing social connection in public health agendas is another essential component in a comprehensive approach to addressing the negative impacts of social isolation on people living with dementia and our society. While social determinants of health (SDOH) focused campaigns, such as the U.S. Department of and Human Service's *Healthy People 2030*, emphasize the importance of social and community context, few to no SDOH initiatives include a focus directly on components of social connectedness [4]. Public health administrators and researchers have a vital role to play in addressing the negative implications of social isolation on vulnerable groups within our country and globally. Data collection at a national level is also a vital part of developing impactful and sustainable interventions to address the detrimental impacts of social isolation, especially for people living with higher risks of negative outcomes. Widely accessible and disseminated national guidelines, such as those for nutrition and physical activity, will be essential tools for individuals, health care professionals, and policymakers to apply commonly understood benchmarks. Collaboration between sectors could also yield innovative and accelerated solutions, such as ride sharing transportation tailored to facilitate community engagement for people living with dementia and their care partners [4]. While social isolation is a serious problem impacting people living with dementia, nationally and globally, strategies to mitigate and prevent this experience are becoming clearer. With clear dedication and advocacy from a wide range of stakeholders and policymakers, many more people will benefit from meaningful socialization throughout their health and aging journeys.

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