From Dementia Fearful to Dementia Friendly
Be a Champion in Your Community

Dementia is an age-related condition linked to various brain pathologies. With population aging, the number of individuals living with dementia worldwide is expected to more than triple from 44 million in 2013 to more than 135 million by 2050 (Alzheimer’s Disease International, n.d.). However, despite the growing impact globally, “a lack of understanding of dementia contributes to fears and stigmatization” (World Health Organization & Alzheimer’s Disease International, 2012, p. 4).

A survey of 1,111 Italians indicated that more than 90% of respondents were afraid of Alzheimer’s disease (Riva et al., 2012). Similarly, a YouGov poll suggested that individuals feared dementia more than any other illness (Alzheimer’s Research UK, 2011). Those who have already developed dementia often experience additional stigmatization. For instance, McParland, Devine, Innes, and Gayle (2012) reported that residents of Northern Ireland have presented deeply stigmatizing attitudes toward individuals with dementia.

This pervasive fear and stigmatization of dementia among the general public begs the question: Is it possible to end fears and stigma associated with dementia? The answer is a resounding “yes.” One emerging but promising solution is to intentionally create communities where members are exposed to and equipped with accurate dementia knowledge and where individuals with dementia and their caregivers are acknowledged as equal community members who are provided with opportunities, resources, and support to remain engaged.

Currently, two approaches of building dementia-friendly communities can be observed internationally: the top-down approach (involving national leadership) and the bottom-up approach (driven by grassroots leadership). The two countries that are known for their nationwide efforts are the United Kingdom (UK) and Australia. In the UK, Prime Minister David Cameron initiated a national challenge regarding dementia in 2012, focusing on “driving improvements in health and care,” “creating dementia-friendly communities that understand how to help,” and “better research” (Department of Health, 2012, p. 5). With governmental support, UK cities such as Bradford, Plymouth, Sheffield, and York are currently
building dementia-friendly communities (Downs, 2013). More research efforts have also been inspired to address person-centered care for individuals with dementia and smooth the dementia journey from symptom recognition to end-of-life issues (Downs, 2013; Fortinsky & Downs, 2014).

In Australia, a recent dementia-friendly push was initiated by Alzheimer’s Australia (2014) when they published *Fight Dementia Campaign: Creating a Dementia-Friendly Australia*. With a vision to make Australia “the world’s first dementia-friendly nation” (Fight Alzheimer’s, Save Australia, 2014, para. 2), the authors of the document urged the Australian Federal Government to address dementia-related issues by “developing a national program of dementia advisors,” “expanding dementia-specific respite care,” “improving the quality of residential aged care,” “developing dementia-friendly communities and organizations,” and “taking action on health priorities, including a new National Action Framework on Dementia” (Alzheimer’s Australia, 2014, p. 2).

In contrast to these nationwide efforts occurring in the UK and Australia, dementia-friendly, community-building campaigns in the United States have been carried out predominantly by grassroots leaders; state and nationwide initiatives promoting a comprehensive approach to cognitive health, such as the Centers for Disease Control and Prevention’s Healthy Brain Initiative (access http://www.cdc.gov/aging/healthybrain), complement local efforts to build dementia-friendly communities. One such local, community-based exemplar is a dementia-friendly movement in Seattle, Washington, the onset of which was marked by the establishment of the Seattle Alzheimer’s Services Coalition. In early 2013, more than 20 organizations and community members convened with the intent to build a dementia-friendly Seattle by exponentially multiplying opportunities for individuals living with dementia to engage with the community (M. Becker, personal communication, November 2014). Inspired by Dr. John Zeisel and his *It Takes A Village* program (access http://www.imstillhere.org/takes-a-village), coalition members design and promote dementia-friendly creative and social engagement programs that acknowledge the capacity of individuals with dementia, harness the effectiveness of nonpharmacological approaches to dementia treatment, and mobilize community assets (i.e., theaters, museums, parks, galleries, and stadiums) as program venues (Becker et al., 2013).

As of 2014, the variety of dementia-friendly opportunities offered by coalition members include the Frye Art Museum’s *I’m still here—Arts Engagement for Individuals Living With Dementia* program (access http://fryemuseum.org/program/here_now), monthly Alzheimer’s café experiences (access http://www.fulllifecare.org/alzcafes), weekly zoo walks, volunteer programs at a food bank and an urban farm, watercolor painting classes in local parks, art appreciation walks, improvisational classes through the Taproot Theatre, and a memory loss chorus and drum circle (access http://www.momentiacalendar.com). In addition, the Elderwise adult day program (access http://www.elderwise.org) has added specific staff (i.e., Director of Creative Programming) to promote dementia-friendly programming. Another organization, Seattle Parks and Recreation, has also added a new division called “Dementia-Friendly Recreation” (access http://www.seattle.gov/parks/seniors/index.htm).

This increase in dementia-friendly opportunities, as well as the new hopeful dementia story that it reflects, has been termed *momentia*, a movement transforming what it means to live with dementia in a community (Becker, 2014b). In Seattle, momentia can be seen as individuals with dementia rise up to share stories of hope, courage, and finding joy in the moment, which serve to challenge the dominant fear-based framework. For example, members of Greenwood Senior Center’s Early Stage Memory Loss program completed an antistigma campaign in 2013, crafting their own personal statements about what they would like their community to know about living with dementia. One such sentiment was: “I’m still here. I’m still able. I have a lot to give.” (Becker, 2014a, para. 2).

How can health care providers get involved? Health care providers play a significant role in shaping and reshaping the way individuals diagnosed with dementia view their ability to maintain a meaningful life, as well as the extent to which they are referred to resources and dementia-friendly programs that...
encourage community connection. In Seattle, a growing campaign to include health care providers in the movement has involved coalition and community members (a) meeting with individual health care providers to educate them about dementia-friendly opportunities, (b) presenting at a geriatric grand rounds about the health benefits of dementia-friendly creative and social engagement programs, and (c) distributing business cards highlighting the URL for an online calendar of local dementia-friendly programs and events (access www.momentiacalendar.com).

INSPIRE CHANGE IN YOUR COMMUNITY

To inspire change in the community, the authors offer the following practical suggestions:

- Gather individuals with dementia, care partners, and organizational allies in the community and begin asking, “What would a dementia-friendly community look like?”
- Include individuals with dementia on organizations’ advisory boards.
- Start an Alzheimer’s Cafe at a local coffee shop.
- Approach a local museum, art gallery, park, library, or movie theater to explore what kinds of innovative, dementia-friendly programs could be initiated at these venues.
- Educate local officials about dementia-friendly initiatives around the United States and the world.
- Submit opinion editorials to a local newspaper.
- Include dementia-friendly issues on the agendas of neighborhood, workplace, or congregation meetings.
- Conduct Internet searches using the key term dementia-friendly community/communities to access information relevant to dementia-friendly community-building efforts around the globe.

CONCLUSION

Regardless of the current level of dementia-friendliness in your community, something we can all reflect on is how we can contribute to a different, hope-filled dementia story. Is it time to examine our own attitudes toward and beliefs about dementia? Is it time to become familiar with available dementia-friendly resources? Is it time to join a local coalition or start one? Let’s all be creative. As awareness (whether top down or bottom up) builds that individuals living with dementia remain a vital part of the community and maintain enormous capacity to stay engaged, and as more and more communities work together to create opportunities that reflect this perspective, we are convinced that our dementia-fearful society can successfully shift to a dementia-friendly one.

REFERENCES


Shih-Yin Lin, MM, MT-BC
PhD Nursing Science Student
School of Nursing
University of Washington

Marigrace Becker, MSW
Recreation Specialist
Lifelong Recreation
Seattle Parks and Recreation

Basia Belza, PhD, RN, FAAN
Aljoya Endowed Professor in Aging
School of Nursing
University of Washington
Seattle, Washington

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