

Dementia-Friendly Movement Seeks to Move People Out of the Shadows



Dancer Audrey Albert-King (back right), a frequent guest artist at memory cafés, leads an exercise at the Jewish Family & Children's Service Memory Café in Waltham, which is co-sponsored by Brandeis University. (Courtesy photo)

BY PAM MACLEOD

Nearly everyone knows someone—a friend, family member or neighbor—living with dementia, according to the Alzheimer's Association. Although dementia is more common in older adults, it is not a part of normal aging. Contrary to popular belief, it isn't a specific disease, but rather a group of symptoms. The symptoms can include memory loss, challenges in planning and problem solving, trouble with visual/spatial perception, and other cognitive issues that disrupt daily life. The Alzheimer's Association reports that people can live with the challenges of dementia for as long as twenty years.

A 2017 report from RTI International found that about four out of five people

living with dementia live in their homes—with family, friends or alone—rather than in residential care settings or nursing homes. An estimated one in three residents with dementia lives alone.

Dementia-Friendly Movement Comes to Massachusetts

It's not uncommon for people to isolate themselves and loved ones with dementia due to embarrassment, stigma and a basic lack of understanding within their communities. In response, a nationwide grassroots movement emerged in 2015 to make our communities "dementia-friendly." This push, part of a worldwide movement, has gained momentum across Massachusetts in recent years, similar to the age-friendly movement.

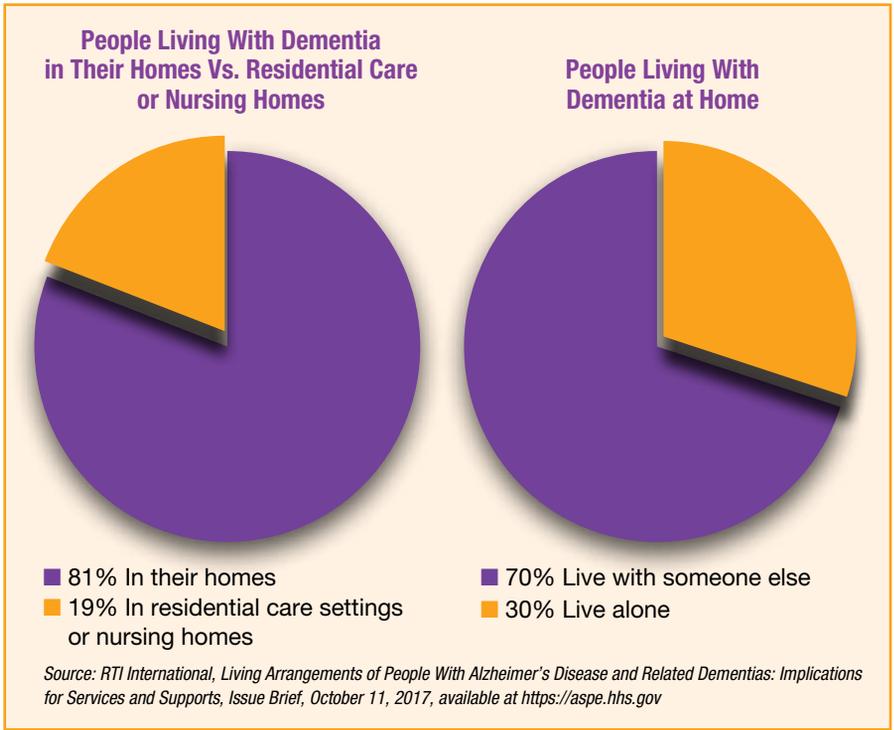
Simply stated, a dementia-friendly community is a place where people living with dementia and their care partners

are understood, respected, included and supported in community life. The "community" could be the city or town where they live or work, a neighborhood, a club, a group of friends, a library, a local grocery store, a barber shop, a faith community, the local bank, a park, a school, a community event, and so on. The dementia-friendly movement involves municipal leaders, individuals and organizations working together to bring a sense of belonging and "community" to residents living with the challenges of dementia.

This sense of belonging is not unlike what we all want, with or without dementia. The problem is that many people don't know the signs of dementia, or how to communicate or act around their fellow community members living with this condition.

The Executive Office of Elder Affairs launched Dementia Friendly Massachusetts

Pam MacLeod is the Director of Dementia Friendly Massachusetts for the Executive Office of Elder Affairs.



in May 2016. By December 2017, there were fewer than sixty cities and towns working to become dementia-friendly in Massachusetts. Currently, that number is up to 160 cities and towns—more than in any other state in the nation, according to Dementia Friendly America.

While fostering community learning and collaboration, Dementia Friendly Massachusetts helps to ease a community's work to become dementia-friendly. The program provides free technical assistance to any municipal official interested in making their community dementia-friendly and engages community participants at all stages of their work. Dementia Friendly Massachusetts (www.mass.gov/dementia-friendly-massachusetts)

offers webinars and opportunities for municipal officials and others to participate in regional Idea Exchanges. A full-time Dementia Friendly Massachusetts project manager at the Massachusetts Association of Councils on Aging provides much of the technical assistance, with support from a Tufts Health Plan Foundation grant.

The leadership of Dementia Friendly Massachusetts includes representatives from the Massachusetts Association of Councils on Aging, the Executive Office of Elder Affairs, the Alzheimer's Association's Massachusetts/New Hampshire chapter, the Massachusetts Healthy Aging

Collaborative, and Jewish Family and Children's Service. The team provides the program with strategic advice that drives its goal to accelerate the spread of dementia-friendly communities throughout the state. Additionally, its member organizations develop, manage and implement dementia-friendly programs and trainings available to municipalities.

At the municipal level, council on aging directors play a key role in dementia-friendly work not only by bringing essential stakeholders to the table, but by participating in and sometimes leading their community's action planning. Councils on aging often bring together municipal leaders, resident advocates, community advisors, individuals and families affected by dementia, business leaders, faith leaders, community and health organizations, and others interested in the community's age- and dementia-friendly efforts.

Dementia-Friendly Topsfield

In October 2017, the Topsfield Council on Aging announced the launch of Dementia Friendly Topsfield with a mission to encourage everyone to "see the person, not the dementia." Topsfield is helping its residents and visitors living with dementia, along with their care partners, engage in community life.

Dementia Friendly Topsfield is working to improve customer service among residents and organizations that serve persons living with dementia. For example, the Alzheimer's Association provided training for the town's Police and Fire departments to help participants understand what to keep in mind as they interact with residents living with dementia. The Alzheimer's Association also provided customer service training to staff of Town Hall, municipal departments and the public library.

This year, local businesses have an opportunity to participate in a pilot training program on dementia-friendly customer service. The Alzheimer's Association developed the training with Dementia Friendly Massachusetts. Participants learn about dementia-friendly communication, physical environments, employee training, signage and menus.

The two-hundred-year-old Topsfield Fair, which draws close to 500,000 visitors

The Relationship Between Dementia and Alzheimer's

According to the Alzheimer's Association, an estimated 60 to 80 percent of people who experience the challenges of dementia are living with Alzheimer's disease (www.alz.org/facts).

An estimated 130,000 individuals in Massachusetts—about one in nine residents age sixty-five and over—are currently living with Alzheimer's, according to data from the Alzheimer's Association and the U.S. Census Bureau.

Because the prevalence of the disease increases with age, the number of Americans with Alzheimer's is expected to rise significantly in coming years, from an estimated 5.8 million in 2019 to as many as 14 million in 2050.

every fall, is not only the oldest agricultural fair in America, but last year became the first to join the dementia-friendly movement, thanks to Dementia Friendly Topsfield. Volunteers, staff and food vendors all played a role in helping fairgoers living with dementia and their care partners enjoy their visit. Hundreds of fair workers participated in information sessions to become “dementia friends” by learning the signs of dementia and helpful communication tips.

During the fair, dementia-friendly volunteers wore recognizable buttons and provided assistance to individuals and their care partners when needed. A “Dementia-Friendly Fair Map” was provided to make it easier to get in and out of the fair and locate restrooms and specific exhibits. The map also indicated the location of dementia-friendly food vendors, who were able to recognize the signs of dementia and, when needed, offer visitors extra assistance and a simplified, illustrated menu.

Jerry Buckley, a former Topsfield selectman, has attended the Topsfield Fair each year for most of his life. Buckley, who lives with dementia, experiences periods of confusion and has some difficulty communicating. When asked if he enjoyed the 2018 fair, he responded with a big smile. “The people were nice,” he said. Dick Cullinan, Buckley’s friend and Topsfield’s veterans’ officer, accompanied Buckley at the fair. “The Dementia-Friendly Fair Map was very helpful, as it identified a calmer route for Jerry to walk, see people he knew, and enjoy the animals,” Cullinan said. “The new picture menu at the Congregational Church restaurant was great—very easy to use, and it let Jerry order his own lunch by pointing to a photo. After all Jerry has given to the town, it’s great to see the fair making these enhancements to give back to Jerry and others like him living with dementia.”

The fair plans to implement more dementia-friendly features in the coming years. This fall, the fair plans to introduce



Students at Assabet Valley Regional Technical High School in Marlborough show their commitment to being dementia-friendly. They learn about the signs of dementia and how to effectively serve clients living with dementia.

(Courtesy photo)

better signage, with both words and pictures. “It doesn’t hurt to be nice,” Topsfield Fair General Manager James O’Brien said in a recent newspaper interview. “It’s really important. It’s not hard. It’s just trying to be thoughtful.”

Assabet Valley District Creates Dementia-Friendly School

Students at Assabet Valley Regional Technical High School in Marlborough participate in seventeen different technical programs—called “shops”—to prepare them for work or college. The Health Technology Shop is for students interested in careers in health care and human services. Housed in the same building is the post-secondary Assabet Valley Practical Nurse Program, attended by high school graduates ranging in age from nineteen to sixty.

When the city of Marlborough began its work to become dementia-friendly, officials asked Practical Nursing Director Ellen Santos and Kathy Faddoul, an instructor in the Health Technology Shop, to join their committee. Assabet’s Practical Nurse Program and Health Technology Shop students had an expertise in caring for people with dementia and received

training in habilitation in dementia care from the Alzheimer’s Association. After being contacted by the city, Santos and Faddoul began thinking about ways their students could help prepare Assabet’s other students to effectively serve clients living with dementia.

This is important because many of the school’s students are future tradespeople—electricians, carpenters, plumbers and so forth. “Many students already interact with older adults in their shops and will do so regularly after graduation,” Santos said. This reality sparked an idea: Why not become a dementia-friendly school? As a first step, the practical nurse and health technology students worked together to develop a dementia-related curriculum for Assabet’s juniors. Next, the health technology juniors convened educational sessions about dementia for juniors within each of the school’s seventeen technical shops. Faddoul has since incorporated this peer-to-peer program into Assabet’s curriculum for juniors, ensuring that it continues for years to come.

Assabet’s peer-to-peer program helps students learn how to recognize the signs of dementia. It also offers shop-specific

strategies, communication strategies, how to talk to a client's family member if needed, problem-solving skills, and more. The sessions, which are interactive and practical in nature, help to make the students feel prepared. Students often share stories about their grandparents or other family members, and how they address the challenges of dementia in their own lives. Some students said that they initially felt anxious and unsure of what they would do when interacting with a person with dementia. The sessions, however, provide opportunities for acting out different scenarios, giving students the confidence they need when encountering similar situations in real life.

"It's really just promoting kindness—stopping, taking a breath and reacting with kindness," Faddoul said. Oksana McQuiggins, a health technology student from the Class of 2019, said, "Being able to educate other shops about [dementia] is great because when the students go out into the workplace and own their own businesses, they can be aware of how to treat people."

At the end of their sessions, the shops displayed decals identifying them as dementia-friendly. The school's student-run Epicurean restaurant, which is open to the public, is now a Purple Table Restaurant, a designation conceived by a Massachusetts restaurant owner. With specially trained staff, Purple Table Restaurants help provide a successful dining experience for individuals living with dementia or other conditions that may benefit from special accommodations.

Since June 2017, the school's entrances have displayed decals designating Assabet as dementia-friendly, the first dementia-friendly high school in the Commonwealth.

How to Participate in This Movement

Thanks to the work of municipal leaders, residents and community organizations, individuals and families affected by



The aim of the Brookline Memory Connections Memory Café is to make everyone feel part of the community, with activities such as art therapy, often involving volunteers of various ages.

(Courtesy photos)

dementia across Massachusetts are coming out of the shadows, engaging in community life and living as meaningful a life as they can.

There are many roles municipal leaders can play in the dementia-friendly movement. Here are some examples:

1. Contact your local council on aging director or Dementia Friendly Massachusetts Project Manager Patty Sullivan at patty@mcoaonline.com to:

- Take advantage of free assistance, guidance, training and programs to initiate dementia-friendly efforts in your community;
- Discuss opportunities for you or your staff to participate in your community's dementia-friendly action team;
- Participate in a Dementia Friendly Massachusetts idea exchange meeting to share your successes and learn from and collaborate with others in your region; and

- Take advantage of free training and information sessions available for all municipal staff, including first responders.

2. Examine data specific to your community available in the Tufts Health Plan Foundation's Massachusetts Healthy Aging Data Report: Community Profiles (available at <https://mahealthyagingcollaborative.org/data-report/explore-the-profiles>).
3. Support your community's efforts, applaud the progress already made, and highlight dementia-friendly initiatives in your publications, speeches and social media.
4. Understand the ten signs of Alzheimer's and spread awareness among your family and friends. (See www.alz.org.)
5. Find ways to ensure sustainable success in your city or town and continue to take advantage of the free support that is available. 🌟