shifting our perceptions of dementia

A flourishing community seeks to honor, value and include all of its members in a common life. It actively seeks creative improvements in a shared life because it understands that meeting the needs of the most vulnerable and dependent members cannot be separated from its own.

— Reverend John McFadden
Fox Valley Memory Project
The Faces of Dementia

Dementia can affect anyone regardless of age, culture, gender, income status and education. As in the photograph below from the Alzheimer’s Association of Southeastern Wisconsin, individuals with Alzheimer’s disease or other dementias include all ages and many different professions, including interior designers, managers, beauticians, pharmacists, systems analysts, supervisors or journalists.

Most individuals with dementia do not fit the stereotype of someone who is confused and living in either an assisted living or nursing home facility. The World Health Organization states, “According to different estimates, between 2% and 10% of all cases of dementia start before the age of 65.” Four percent of the more than five million Americans affected with Alzheimer’s are estimated to be under the age of 65 and considered “early” onset.¹ Alzheimer’s disease and other dementias may be present for decades before symptoms begin to interfere with daily life.

Individuals with dementia are most likely neighbors, co-workers, customers or relatives who live independently and access community businesses, such as banks, grocery stores, department stores and restaurants. Seventy percent of individuals with dementia are living in communities. According to the Wisconsin
Division of Long Term Care dementia population estimates, there are approximately 100,000 individuals in Wisconsin with dementia who reside in their homes, with 22 percent living alone.

African Americans and Latinos are at increased risk for dementia when compared with the Caucasian population. Latinos are at one and a half times the risk, and African Americans at twice the risk of developing dementia. Possible explanations for this disparity include the large number of people from communities of color with chronic health conditions, including diabetes, obesity, heart disease and other cardiovascular illnesses that are known to increase risk for developing dementia. Limited access and lower utilization of medical care, including preventative care, are also considered to increase risk among these two groups. It is important for local and state public health agencies and communities of color to understand this increased risk when working to create dementia-friendly communities.

Native Americans are thought to be at increased risk due to a higher incidence of chronic conditions. Tribal governments and structures that oversee businesses, schools and health care systems on tribal grounds are in a position to implement dementia-friendly concepts throughout the tribal community.

The number of Americans with Alzheimer’s disease and other dementias will grow each year as the number and proportion of the U.S. population age 65 and older continues to increase. The number will escalate rapidly in coming years as the baby boomer generation ages. — Act on Alzheimer’s
As the population in the United States ages, the number of individuals with Alzheimer’s disease and other dementias is expected to increase as well. Current estimates predict those with dementia will double by 2030 and more than triple by 2050.\textsuperscript{2} Providing care for individuals with dementia can occur over a long period of time. The number of people whose lives are altered by dementia, combined with the social, economic and health care issues faced by families and communities, supports the importance of considering dementia a public health priority.

As the symptoms of those living with dementia slowly increase, they may worry about others noticing their difficulties and retreat into their homes. Without stimulation, social interaction and physical exercise, individuals with dementia decline more rapidly.

According to the Alzheimer’s Society (United Kingdom), those with dementia report the following barriers to daily living: lack of confidence, being worried about becoming confused, fear of getting lost, mobility difficulties, physical health issues and not wanting to be a burden to others.\textsuperscript{3} Individuals with dementia also report fearing the reactions of others and a lower perceived status within society. These perceptions lead to social exclusion, a reluctance to seek help, a sense of shame and inadequacy, low self-esteem, depression and an overdependence on the caregiver.\textsuperscript{4}

Creating a community where all are included, where all can experience a sense of belonging and where all can continue to express themselves is critical to dementia-friendly community efforts.
What is Dementia?

Dementia is a term used to describe the symptoms of a group of more than 100 conditions characterized by a decline in memory or other thinking skills that affects a person’s ability to perform everyday activities. Alzheimer’s disease is the most common type of dementia. Because Alzheimer’s disease is underdiagnosed, as many as half of the estimated 5.2 million Americans with Alzheimer’s may not be aware that they have the disease.  

The most common types of dementia are:

- Alzheimer’s Disease (60-80 percent)
- Vascular Dementia
- Lewy Body Dementia
- Frontotemporal Dementia
- Parkinson’s Disease Dementia
- Mixed Dementia
- Creutzfeld-Jakob Disease
- Substance-Induced Dementia

When medical care providers and aging persons collaborate to promote heart and vascular health, the age of onset of dementia can be delayed and prevalence reduced.

— Vladimir Hachinski, CM, MD, FRCPC, DSc Ontario

Additional information on these and other types of dementia are available on the following websites:

- www.alz.org (Alzheimer’s Association)
- www.alzwisc.org (Alzheimer’s & Dementia Alliance of Wisconsin)

The same risk factors that contribute to other chronic diseases, such as heart disease and stroke, diabetes and cancer, are also linked to Alzheimer’s disease and other dementias. To delay the onset of dementia and other chronic diseases, health care providers recommend incorporating healthy behaviors into an individual’s lifestyle, such as regular exercise, a healthy diet, moderate alcohol use, staying socially active, and avoiding tobacco products. Taking