

\*\*\*WHITE PAPER\*\*\*

## Work and Dementia (2016)

Susan H. McFadden, Ph.D.

Professor Emerita, Psychology, University of Wisconsin Oshkosh  
Research Consultant, Fox Valley Memory Project ([www.foxvalleymemoryproject.org](http://www.foxvalleymemoryproject.org))

Although there is growing public awareness of the prevalence of Alzheimer's disease and other dementias, most people associate these conditions with retired persons. However, recent research indicates that 4% of persons 64 and younger may have some diagnosable form of dementia (Hebert, Weuve, Scherr, & Evans, 2013). Also, many individuals are choosing to work past the time when they become eligible for Social Security benefits. The Hebert et al. study found that 13% of persons between 65 and 74 may have some type of dementia. This means that dementia is increasingly becoming an issue that must be faced in the workplace both in terms of employed persons with dementia as well as their employed care partners.

The Wisconsin Department of Health Services (DHS) has produced a "tool kit" for building dementia-friendly communities where "all are included, where all can experience a sense of belonging, and where all can continue to express themselves" (2015a, p. 9). Initial efforts have focused primarily on retired persons, but recently, more emphasis has been placed on employed individuals. For example, DHS recently developed a website with information for employers of persons caring for individuals with dementia (2015b).

Nevertheless, many agree that more needs to be done in the area of research, public policy, and the development of employment practices. For example, Roach and Drummond (2014) mention a "particular lack of research focused on younger people (under the age of 65 years) with dementia and virtually none focuses on the experience of the family unit" (p. 889). Others cite a "dearth of high quality research" on job retention and work performance associated with dementia (Ritchie, Banks, Danson, Tolson & Borrowman, 2015, p. 24). Finally, although there has been some effort to address workplace challenges for care partners, "very little is known about how organizations deal with employees" who have dementia (Cox & Pardasani, 2013, p. 644).

In the following sections, I briefly summarize literature on work and dementia that addresses the needs of persons with the diagnosis, family members, and employers. Suggestions for meeting these needs appear in research studies and guidelines offered by international, national, and Wisconsin organizations.

### *Addressing Needs of Persons with Dementia*

Often it is at work that people first note difficulties with memory, problem solving, time orientation, etc. The seriousness of these problems and their outcomes vary depending on the nature of the work. For example, it has been well documented that in the early stages of Alzheimer's disease, people may experience declines in their capacity to

manage finances at home and at work (Triebel et al., 2009). However, in contrast to the accountant whose problems can affect the viability of the organization, some individuals work in jobs where people's lives are at risk if they can no longer perform their jobs skillfully. Safety concerns are paramount and must be addressed (Shaw, 2011).

Many of the families interviewed by Roach and Drummond (2014) stated that employers lacked understanding and made no effort to keep the individual in a job as long as possible. Thus, cessation of work was often rapid and traumatic, causing tremendous psychological as well as financial stress for the families. At home, out of a job, individuals felt like they were no longer useful to other people and their communities. Often socially isolated because others in their age cohort were still working full time, some slipped into depression, which can exacerbate dementia-related cognitive problems.

Several researchers have suggested that greater effort should be made to enable persons to continue to experience meaning and purpose in life through volunteering, regular gatherings with social groups, and other activities that keep people engaged with others. Others have examined the effects of programs that help people continue to work alongside a "work-buddy" who has undergone special training. One such program at a hardware store in Australia was very successful and provided a sense of meaning not only to the person with dementia, but also to the workplace mentors (Robertson & Evans, 2015; Robertson, Evans, & Horsnell, 2013).

Following a review of the literature and their interviews with persons diagnosed with dementia, care partners, and employers, Ritchie et al. (2015) concluded that "little advice, guidance, and good practice support is available to help people with dementia to remain in the labour market" (p. 33). They called for greater focus on abilities retained rather than on deficits. However, this would require a major shift in public attitudes about a condition that elicits so much fear in the general population.

Communities seeking to become more dementia-friendly vary in many factors, including size, resources, and location (e.g., urban, suburban, rural). However, persons living with dementia in these different communities share a vital characteristic with those who do not have dementia: the need for a purposeful role in life, a role that most adults derive from their work and meeting the needs of their families. Leaders in these communities need to:

- Recognize that some individuals are experiencing dementia symptoms and receiving dementia diagnoses while still working and include them in planning and implementation of dementia-friendly practices
- Educate employers about dementia and the types of reasonable accommodations they might make to keep people employed
- Identify meaningful volunteer roles for those who no longer can meet the requirements of paid employment and educate organizations that provide these volunteer opportunities about the abilities of persons living with dementia

*Addressing Needs of Families*

Although many continue to think of Alzheimer's disease and other forms of dementia as an old persons' disease, the Alzheimer's Society of Canada found that 15% of Canadians with Alzheimer's disease are not yet 65 (Black et al., 2010). This contrasts with the US where it is typically claimed that four to five percent of persons with Alzheimer's disease are diagnosed before age 65 (Gibson, Anderson, & Acocks, 2014; Hebert et al., 2013). The difference seems to lie in *diagnosis* because in the US there is often at least a two-year or longer lag between the noticeable onset of symptoms and diagnosis.

Employed dementia care partners fall into several categories. Some are caring for a spouse/partner who is still in the workforce but struggling to hang onto employment. Others care for loved ones who have been forced to leave work because of dementia, or who retired and then developed dementia. Many are caring for parents or other relatives with dementia. In addition, some care for multiple persons with dementia along with children still living at home. The Wisconsin Department of Health Services (2015) reports that currently, 64% of dementia care partners are still employed.

A high percentage of care partners still in the workforce report that their work is disrupted because of caregiving responsibilities. They use their vacation time to provide care, thus depriving themselves of opportunities to reduce stress. They miss work, feel they are less effective on the job, and refuse promotions that would bring more responsibility and time commitments. Many are forced to retire early which results in additional financial challenges (Black et al., 2009).

Caring for a person with dementia is costly. Many families report not knowing about resources that might be available to help them. They also have difficulty navigating the challenges of managing finances. In one study conducted in Ohio, 21.3% of care partners were unemployed and frustrated in their attempts to find work while juggling caregiving responsibilities (Gibson et al., 2014).

Cost of care should not only be calculated monetarily. There is a psychological cost in watching a loved one respond to the loss of an occupation that had provided not only income, but also meaning. In addition, even before the individual elects to leave work, or is forced to do so, there may be worry on the part of the family members about the person's job performance. For example, one woman described how worried she was that her husband—an accountant—would be liable for mistakes he made in his clients' tax preparation.

Communities seeking to be more dementia-friendly must acknowledge that meeting the needs of persons with dementia must also involve meeting the needs of their care partners. Because many care partners are still employed, leaders in dementia-friendly community efforts should:

- Educate employers about the challenges of being a dementia care partner
- Identify employers that do a good job of responding to care partner needs and encourage them to be models for others

- Schedule care partner support programs at times convenient for those still employed

### *Addressing Needs of Employers*

Few studies of employers' knowledge and attitudes about dementia have been conducted, but one that surveyed 103 HR professionals revealed that over 70% had personal experience either with care partners or with individuals living with dementia. On the job, they most often observed employees' poor quality of work, lack of motivation, and absences due to dementia symptoms. Only 2% had a written policy for employees struggling with cognitive impairment, while 29% had written policies regarding care partners. Most did not feel comfortable talking about symptoms with employees and nearly all wished they had more education about dementia. They also wanted to know more about the legal issues and possible liabilities for the organization that employs persons with dementia (Cox & Pardasani, 2013).

In an effort to meet employers' needs for more information, the Alzheimer's Society in England has published a document called "Creating a dementia-friendly workplace: A practical guide for employers" (Alzheimer's Society, 2015). It provides excellent information about what it means to be a "dementia-friendly employer" that provides a "dementia-friendly workplace." This is not simply charity! Many employers cited in this document recognize that despite cognitive challenges, their employees retain skills and knowledge that are valuable to the organization.

The Alzheimer's Society guide addresses signs and symptoms of dementia and issues that commonly affect people, especially in the early stages when they may still be working. It offers a detailed discussion of the "reasonable adjustments" employers might make to enable persons with symptoms of dementia to remain at work longer and gives examples of various situations employers and employees might encounter when dementia becomes apparent. Suggestions for reasonable adjustments fall into several categories: the working environment, the working pattern (e.g., hours, duties), training, and supervision. This document also recognizes that at some point there will need to be a discussion about the transition out of work and the kind of support that can be offered post-employment. For example, some organizations have clubs for retired employees and club leaders can be educated in offering hospitality and inclusion to those with dementia.

The Office of Disability Employment Policy of the US Department of Labor offers a service called the Job Accommodation Network (JAN). JAN has published a document on accommodation and compliance for employees with Alzheimer's disease (2013). While not as detailed as the guide from the Alzheimer's Society, it does provide information for US employers about the fact that some people with Alzheimer's disease will be classified as having a disability and thus meet the requirements of the Americans with Disability Act (ADA) but others will not qualify. Like the Alzheimer's Society's guide, JAN offers ideas for accommodation but frames them in terms of the challenges experienced by the employee in terms of memory, organization, time management, and difficulty performing job duties. It

also gives suggestions for employees and for employers as well as examples of people who have developed various solutions to work challenges caused by their dementia symptoms.

Leaders of dementia-friendly community efforts need to become familiar with these and other resources to help employers and employees (both those with dementia and their care partners) dealing with dementia. Because this is a topic that many employers are reluctant to address, one place to start would be to survey their employees about how dementia is impacting their lives. The Wisconsin Department of Health Services' "toolkit" for employers provides a link to an anonymous family caregiver survey developed by the UW Extension (<http://articles.extension.org/pages/27975/employed-family-caregiver-survey>). Employers who administer it will receive an executive summary of the results that can be shared with employees.

### References

- Alzheimer's Society (2015). Creating a dementia-friendly workplace: A practical guide for employers. Retrieved from [http://www.ageingwellinwales.com/Libraries/Documents/Creating\\_a\\_dementia-friendly\\_workplace.pdf](http://www.ageingwellinwales.com/Libraries/Documents/Creating_a_dementia-friendly_workplace.pdf)
- Cox, C. B., & Pardasani, M. (2013). Alzheimer's in the workplace: A challenge for social work. *Journal of Gerontological Social Work, 56*, 643-656
- Black, S. E., Gauthier, S., Dalziel, W., Keren, R., Correia, J., Hew, H., & Binder, C. (2010). Canadian Alzheimer's disease caregiver survey: Baby-boomer caregivers and burden of care. *International Journal of Geriatric Psychiatry, 25*, 807-813.
- Gibson, A. K., Anderson, K. A., & Acocks, S. (2014). Exploring the serving and support needs of families with early-onset Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias, 29*, 596-600.
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology, 80*, 1778-1783.
- Job Accommodation Network (2013). Employees with Alzheimer's disease [Accommodation and Compliance Series]. Retrieved from <https://askjan.org/media/downloads/AlzheimersA&CSeries.pdf>
- Ritchie, L., Banks, P., Danson, M., Tolson, D., & Borrowman, F. (2015). Dementia in the workplace: A review. *Journal of Public Mental Health, 14*, 24-34.
- Roach, P., & Drummond, N. (2014). "It's nice to have something to do": Early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing, 21*, 889-895.

- Robertson, J., & Evans, D. (2015). Evaluation of a workplace engagement project for people with younger onset dementia. *Journal of Clinical Nursing*, 24, 2331-2339.
- Robertson, J., Evans, D., & Horsnell, T. (2013). Side by Side: A workplace engagement program for people with younger onset dementia. *Dementia*, 12, 666-674.
- Shaw, G. (December, 2011/January, 2012). Dementia in the workplace. *Neurology Now*, 8(6), 30-33.
- Triebel, K. L., Martin, R., Griffith, H. T., Marceaux, J., Okonkwo, O. C., Harrell, L.,... Marson, D. C. (2009). Declining financial capacity in mild cognitive impairment: A 1-year longitudinal study. *Neurology*, 73, 928-934.
- Wisconsin Department of Health Services (2015a). *A tool kit for building dementia-friendly communities*. Retrieved from <https://www.dhs.wisconsin.gov/publications/p01000.pdf>
- Wisconsin Department of Health Services (2015b). *Dementia friendly employers toolkit: Caregivers in the workplace*. Retrieved from <https://www.dhs.wisconsin.gov/dementia/employers.htm>