

Cognitive impairment in the workplace

Compassionate approaches for
a hidden but growing concern



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Executive summary

Due to the aging of the U.S. population, rates of cognitive impairment and dementia in the workplace are on the rise. This creates challenges for employers, many of whom may not know how to best support employees who are experiencing symptoms of cognitive impairment. Conversely, employees may be hesitant to share with their employer the challenges that they're experiencing.

Symptoms begin gradually and are often acknowledged first at work. Diagnosis may be difficult in younger people, since the majority of individuals diagnosed with cognitive impairment are 65 or older. Nevertheless, most persons living with dementia never tell their employer of their cognitive concerns due to stigma or fear of losing their job, and most employers have no policies or education on dementia.

Declining performance can wrongly be blamed on depression, substance use, stress or other issues, and many workers are demoted or fired. A supportive company culture increases the chances that a worker will disclose cognitive concerns, allowing critical conversations to occur. Providing accommodations for employees who wish to keep working and are able to, based on job responsibilities and safety, can retain historical knowledge, preserve workplace teams, and create a positive work culture where employees feel safe acknowledging health problems. Workplace awareness, compassion and policies regarding dementia as a disability can therefore protect and support employees and businesses alike. Overall, companies need to create and foster a dementia-friendly workplace.

Recommendations regarding dementia in the workplace

- Provide training to human resources personnel and supervisors on the warning signs of Alzheimer's and dementia and on basic disability law through the Americans with Disabilities Act.
- Encourage employees to seek medical advice for early diagnosis and treatment, maintain healthy habits, and manage their health.
- Educate any outsourced work resources (for example, third-party human resources teams) on the best way to support workers with disabilities to ensure they share your supportive company culture.
- Help employees fully understand disability benefits and retirement and work options.
- Consider accommodations that can be unique to workers and jobsites, including options such as:
 - Simplifying or modifying employees' roles, responsibilities, settings or routines
 - Flexible hours
 - Technology-based reminders
 - "Buddy" employees
 - Additional supervision.

- Include employees' trusted family members or friends, physician, and other members of the care team in discussions when feasible and desirable.
- Evaluate the status of any accommodations (from both workers' and the employer's perspective), adjustments that may be needed, and employees' interest in remaining at work versus retiring.
- Provide training for employees — particularly client-facing employees — on recognizing the warning signs of cognitive decline in the event they experience it in those with whom they interact.
- Help to positively transition those living with dementia out of the workplace at the appropriate time by providing support and allowing for a dignified exit.

Future directions

Corporate America can play an important role in promoting dementia-friendly workplaces and communities. Employers can foster trusted relationships with employees and their families through workplace events that build comradery and combat social isolation. Additionally, employers may consider flexibility in work-from-home options, which can ease family burden.

Additional system-level changes are needed as well. Legislation is necessary to protect the benefits of persons who are fired for performance reasons but later found to have had dementia. An easier process for employees and family caregivers to execute and utilize power of attorney (POA) documents should also be created and may lessen family burden. Addressing these and other issues will help ensure that persons living with dementia can devote their remaining years to the activities that give their life meaning and joy, including work, while at the same time providing tangible and intangible benefits to employers and coworkers.

Scenario 1

An experienced night nurse four years from retirement begins to notice lapses in her memory. Did she bring Room 110 the water they asked for? Did she document that the patient in Room 119 refused her Tylenol dose? Out of fear of how her employer might react, she tells no one about her lapses in memory but creates a new note-taking and reminder system for herself. Financially, she can't afford to quit, and she's not yet eligible for Social Security and Medicare. Things are less hectic for night nurses than they are for day nurses, but colleagues are beginning to notice things. "I always thought I might make a mistake on a medication. I never did, thank goodness, but it was demanding and exhausting."

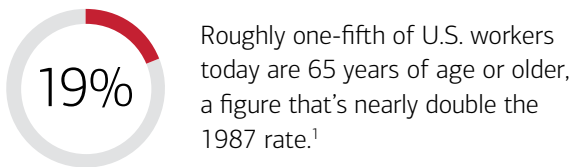
Scenario 2

A highly placed employee at a major internet security company is asked to help train a new associate. However, recently he's been struggling to complete some of his job responsibilities and finds he can no longer remember how to write a basic project plan. He retires, not telling anyone at work about the growing issues with memory and complex thinking. The company has a good retirement package and will never know he was experiencing younger-onset dementia or the potentially serious risks the employee's declining cognitive health may have posed to the business.

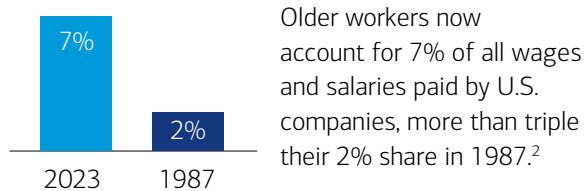
In any context, dementia and mild cognitive impairment (MCI) can be a frightening and uncomfortable topic, and most people associate it with individuals of advanced age. In the workplace, dementia is often discussed only when employees need additional support and flexibility to provide care for a family member (for example, a parent or grandparent) living with a disease that causes

dementia, such as Alzheimer's disease. However, dementia and MCI occur among workers as well, especially as their average age rises. Workplaces can no longer ignore this "hidden" issue, which can impact job performance, threaten the cohesiveness and effectiveness of work teams, and have potentially serious financial and legal implications for both the company and employees.

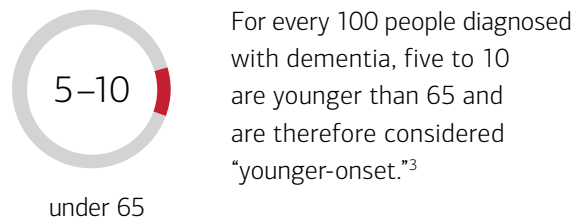
The U.S. workforce is aging.



They're also more likely to have employer-provided benefits, such as pensions and health insurance.



The greatest known risk factor for Alzheimer's disease and other dementias is increasing age. As workers age, their risk of developing a cognitive impairment increases.



A recent study estimated that, for every 100,000 workers aged 30 to 64, 119 develop younger-onset dementia, translating to:

 **3.9 million cases** worldwide⁴

Due to underdiagnosis and a lack of studies on the topic of dementia in the workplace, this is most likely an underestimate.⁵

The purpose of this paper is to begin a conversation about how workplace awareness, compassion and policies can protect and support employees and businesses alike. In

addition to a review of the literature, two interviews and two focus groups were conducted with:

- Persons who experienced the onset of dementia while still working (specifically all experienced early onset prior to the age of 65)
- Spouses of persons diagnosed with dementia while still working
- Human resource managers

A brief overview of dementia is provided, including its symptoms, diagnosis and potential impacts on the workplace. This is followed by a discussion of the ways in which workplaces can prepare for an increasing number of employees facing cognitive impairment and dementia, including a list of accommodations that can be tailored to workers' changing capacities. A discussion of broader efforts that corporate America should consider engaging in to foster the development of a more dementia-friendly society serves as a conclusion.



Full report

Introduction

Dementia affects memory, language, thinking, completion of everyday activities, mood, behavior, personality and mobility.⁶ The most common type is Alzheimer's disease, which is caused by an abnormal buildup of certain proteins in the brain. Other forms include vascular dementia, frontotemporal dementia, dementia with Lewy bodies and dementia related to Parkinson's disease.

Dementia types can overlap,⁷ and dementia can also occur secondary to another health issue, such as infection, autoimmune disease, substance use, thyroid disorders, repetitive head injury or severe nutritional deficiency. The largest risk factor of dementia is increased age.⁸ Symptoms are progressive and can be seen on a continuum that ebbs and flows, while overall symptoms worsen over time. The three stages described as part of this continuum are:

- Early, which lasts about two years
- Middle, which lasts two to four years
- Late, which lasts one to two years and generally involves full-time care with no possibility of working⁹

However, not all individuals proceed through the stages in the same manner or timing. Fatigue and stress can worsen symptoms temporarily, leading to the impression that symptoms are waxing and waning. Time of day can also affect symptoms, with most individuals finding evening to be the most taxing.¹⁰



Diagnosis

Dementia and mild cognitive impairment (MCI) are diagnosed based on a series of neuropsychological tests of language, memory, attention and other cognitive functions. Symptoms vary between persons with differing underlying causes for their dementia and people with the same type of dementia. Separating the normal, age-based changes in cognition from the early stages of dementia contributes to delays in diagnosis. In addition, interactions with primary care doctors may play a part in delaying a diagnosis, as some doctors dismiss the symptoms or attribute them to another cause, especially in younger individuals, or they may have a lack of confidence or knowledge in how to detect and diagnose. Stigma and fear of the disease can keep people living with dementia from talking to their family or friends and doctors about subtle but persistent cognitive changes they've noticed in themselves. In the meantime, family and friends may gradually begin assisting with or taking over more complicated domestic tasks, masking the severity of the problem. All of this helps to explain why dementia symptoms generally begin years before formal cognitive testing and diagnosis.

For those diagnosed before age 65, the lag between symptom onset and a confirmed diagnosis is even longer,¹¹ and they're often initially misdiagnosed.¹² Even when concerns are shared with a medical provider, lack of familiarity with the signs of MCI and/or dementia in relatively young people can further delay referral for a diagnostic workup.¹³

A member of our focus group was initially told by her doctor that her perceived language problems stemmed from spending too much time on Zoom during the COVID-19 pandemic. She waited a full year before advocating for additional testing, after which it took three months to undergo new testing and an additional three months to see a neurologist and be formally diagnosed.

Any delay in diagnosis can be devastating to individuals and their families, as this can prevent access to treatments, therapies and resources.

For Alzheimer's disease specifically, there are FDA-approved therapies that can slow cognitive decline in the earliest stage. Additionally, receiving a specific diagnosis that reveals the cause of their symptoms can provide a sense of relief. Without a diagnosis, individuals who have symptoms may endure prolonged confusion and helplessness about what they're experiencing, and it impedes access to supports and entitlements.¹⁴ As one focus group member explained, "I just started working with my senator on Social Security Disability because I've applied for several years, and I've been fighting it, fighting it, fighting it."

On the job

The workplace as discovery point

Because responsibilities tend to be more clearly defined and allocated at work, the seriousness of a person's cognitive issues is often acknowledged first in relation to one's job.¹⁵ In the earliest stages of memory changes and cognitive impairment, managers and co-workers are unlikely to notice, especially as individuals put their own compensatory strategies in place.¹⁶ As cognitive functioning continues to gradually decline, persons may exhibit uncharacteristic or increased difficulty remembering meetings and appointments, following instructions, multitasking, maintaining previous work output, remembering the faces and names of colleagues and customers, making decisions, and executive functioning. Personality changes, such as rigid thinking, impulsivity, irritability, anxiety and depressed mood can also occur.

Some colleagues may start to surreptitiously “cover” for employees, fixing their errors or making excuses for them, while supervisors may begin covert surveillance of their work.¹⁷ Tensions can also arise with coworkers and supervisors, some of whom may attribute the problems to psychiatric illness, laziness or substance use.¹⁸ The resulting stress can further negatively affect functioning, setting up a vicious cycle that precipitates a work crisis.¹⁹ Those living with dementia may be reprimanded, demoted or even fired for performance reasons before anyone at the workplace (or even the persons living with undiagnosed dementia) suspects that they have a health problem, disability or disease. In such situations, diagnosis can come as a relief, offering an explanation for their uncharacteristic performance issues.²⁰



The Americans with Disabilities Act (ADA) in relation to dementia

The ADA guarantees that “people with disabilities have the same opportunities as everyone else to enjoy employment opportunities, purchase goods and services, and participate in state and local government programs.”²¹ Rather than provide a list of qualifying medical conditions, the ADA defines an eligible person as someone who:

- Has a physical or mental impairment that substantially limits one or more major life activities
- Has a history or record of such an impairment
- Is regarded as having such an impairment

Persons with disabilities must be offered reasonable adjustments to permit continued employment. Thus, employers need to understand and be prepared to provide the accommodations necessary for meeting the human rights of employees living with dementia. Those still waiting for a formal diagnosis can fall between the legal cracks in terms of disability law²² but shouldn't have to do so on the job. Recognizing dementia within the framework of disability creates a focus on helping people to remain contributing members of society.²³

Generally speaking, employees aren't required to disclose a neurological or psychiatric disability unless they ask for accommodation. In some cases, workers may be required to notify someone of their diagnosis. For example, if their work involves driving or operating heavy machinery, employees may be required to notify the Department of Motor Vehicles (depending on the state in which they reside). They may also be legally required to tell their employer of a diagnosis if their job impacts the health and safety of others (for example, working in health care). Disclosure can also be relayed in steps. One interviewee disclosed the information only to an immediate supervisor for the first two years, then shared it more widely once it became necessary for the employee to move to a simpler role within the company.

Benefits of continuing to work

Some workers choose to retire in the face of clear signs or a diagnosis of dementia, but, for a variety of reasons, others don't. For many people who were interviewed, the position and title they hold at work is very closely tied to their identity. In addition, work colleagues can be a second family that will be missed. The work routine and setting offer continuity when other aspects of living are changing.²⁴ Work provides socialization with colleagues and work-related mental stimulation.

Finances are a major reason many continue to work. Younger-onset dementia occurs at a time of life when people may have significant family obligations, and early or unplanned retirement can represent a major financial hit. Keeping one's health insurance can be another major driver of the decision, especially with the added costs of repeated cognitive and other medical testing, medications, and recommended therapies. For financial and/or health insurance reasons, spouses and adult children will sometimes have to take up employment or increase their own work hours to compensate for any loss of income, all while simultaneously taking on more of their spouse's former domestic activities to act as a caregiver.²⁵

One focus group member shared that her husband had to delay his own retirement, saying, “He'll work as long as he can, but we hope at some point he's able to retire.” Another stated, “My husband is 13 years older than me, so I had planned on being his caregiver, not the other way around. So this really messed up our whole plan. He's 77 and still working because we can't afford for him not to work. He works two part-time jobs.”

Benefits of retaining workers

Fortunately, while a diagnosis of dementia will impact how people function on the job, it doesn't always mean they must immediately give up working. Of course this depends on the job, the position and the responsibilities. Nor is leaving their position necessarily the best option from the employer's perspective. Declines in cognitive function can be slow and affect certain aspects of performance more than others. Finding workers who are familiar with and committed to the job and fit within the company culture can be challenging. As one employer we interviewed put it, "You're going to lose a lot of historical knowledge over the next five to 10 years if you're not able to implement transitional work arrangements or support people to contribute effectively as they're going through something like this."

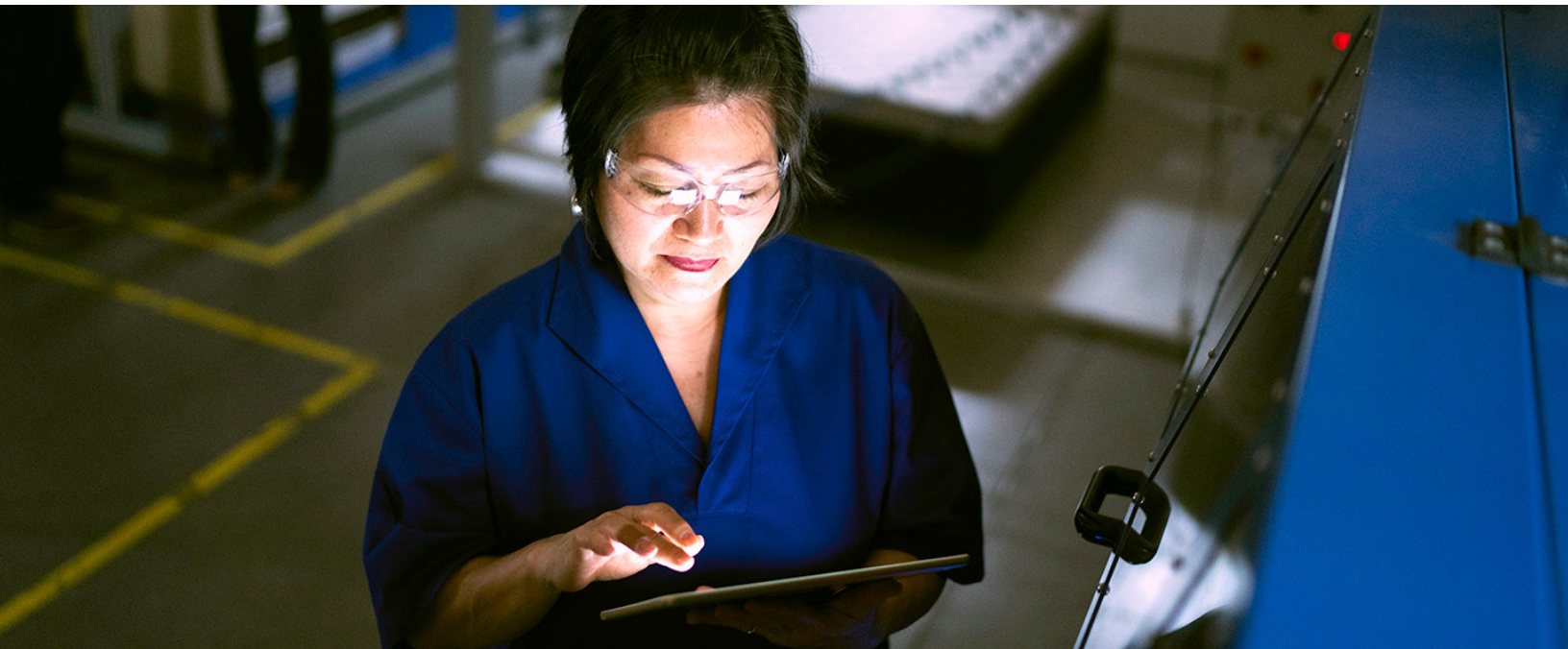
Employers who support those who wish to continue working with declining cognitive function demonstrate to other employees that they're committed to helping all employees and their families through difficult times, contributing to employee trust, an overall healthier work culture, and greater employee loyalty and retention. Finally, when employees feel comfortable expressing concerns about their health and work performance to supervisors, potential risks to the business from presenteeism (that is, employees physically at work but not fully functioning due to illness) is reduced, including its associated errors, oversights and accidents. By some estimates, the costs of presenteeism may be 10 times higher than that of absenteeism, leading to as much as \$150 billion per year in reduced productivity.²⁶

A dementia-supportive company culture

Thanks to the ADA, disability rights are increasingly in the forefront; however, cognitive disabilities resulting from dementia haven't received the same level of societal or corporate attention as other, more visible or mobility-related disabilities.²⁷ The needs of persons living with younger-onset dementia in particular require more awareness and specialist approaches.²⁸ A large study of employees and employers found that, while most people were familiar with dementia through helping a person living with the disease, they didn't feel confident addressing the issue in relation to the workplace.²⁹ When employers did suspect dementia, they worried about recommending medical help and how it would be received, given privacy issues and the stigma of the disease and its symptoms.³⁰

Not surprisingly, then, among persons who quit work due to dementia, the lack of employer and collegial understanding of the disease was a roadblock to their being able to continue working or to exit work in a dignified manner.³¹ A member of our focus group stated that she was treated as if she were any other employee being let go, saying, "When they ended my position entirely, I was required to go out and apply for other jobs at the university, and there was no way. I just couldn't do it. I could sit down for an interview, but I couldn't go through all the steps."

A study in Ireland found that four out of five workers living with dementia were forced to leave their jobs with no compensation,³² and a number of studies have shown that employees left work despite believing they still had sufficient skills and expertise to contribute.³³ At least half of the focus group members we spoke with had been too afraid to tell their employers for fear of how they'd be treated. And one group member would have told someone had the person believed the employer "was trying to help and not trying to get rid of me."



The members of our focus group who had been able to remain on the job for a period of time described highly positive company cultures. Each had worked at their job for over two decades and, when they began having problems, felt comfortable speaking to their supervisor about it. One supervisor was described as a longtime friend with whom the employee was still in touch, even after retirement. More than one spoke about how everyone at the workplace not only knew about their difficulties, but were a part of their active support system. One stated, “My coworkers were great because they all pitched in. They carried me for the last year [of working].”

However, even in a company with a supportive culture, there can be critical gaps. One spouse of a person living with younger-onset dementia described how his spouse’s company had been highly supportive and would no doubt describe itself as such, yet it outsourced its human resources department. This third-party payor had an entirely different culture and didn’t personally know the worker living with dementia. Significant efforts were

required to complete disability and other paperwork, after which the parent company switched contracts to a different outside human resource provider, forcing the already exhausted spouse to repeat the entire lengthy and grueling procedure. Issues also arose concerning policies requiring that discussions about the status of the disability claim take place only with the person claiming the disability. Eventually this wasn’t possible, and the spouse “had to fight these battles numerous times,” often having to get the employee’s company to call the third-party payor and intervene.

In short, a company culture is only truly supportive when it extends to all the work-related services available to employees. Company culture may also differ depending on one’s position at the company. A lower-level employee might be fired for performance issues, while a higher-level employee might be offered a conversation that may lead to accommodations. As one focus group member stated, “To tell someone making \$100,000 or less to hire a caregiver [for the spouse living with dementia]—that’s thoughtless.”

Need for dementia-specific guidance

Increased awareness of the complex and sensitive issues surrounding dementia in the workplace is needed, but this doesn't necessarily require the creation of dementia-specific policies. In a study in which 13% of the employers interviewed had prior experience working with an employee living with dementia, most had no dementia-specific policies in place or in development.³⁴ Two-thirds of employers felt their existing disability-related policies were sufficient to encompass these needs, and they worried that specific policies might lead to a "proliferation of diluted policies." However, policies should be examined for their "fit" with progressive and incurable diseases such as dementia. One focus group member described how a spouse's company required that a disability claim be medically recertified every six months. The person was forced to comply with this time-consuming and humiliating process twice a year for over a decade, infuriating both the doctor and the family.

But while specific policies may not be needed, increased guidance specific to dementia in the workplace is critical.³⁵ During our interviews, human resources managers expressed gratitude for the opportunity to consider how dementia as a disability might differ from other types of disabilities, and they strongly echoed the need for more education, awareness and guidance on the topic. One human resources manager at a company with more than 70,000 employees stated, "We do have lots of coaching programs in place, but I don't know if we have a specific program for cognitive decline. I'll reach out to see if there's anything we're doing in that particular space."

Simply making employees aware of programs and policies that may benefit them in the case of dementia is a challenge in itself. As one human resources manager explained, "We communicate every which way to try to make employees and their families aware of all the great benefits we invest in. It's probably one of the biggest challenges we have." Sadly, lack of awareness may create its own vicious cycle. As another HR manager explained, they look

at "what's driving the most apparent costs on our medical plan and then create programs to address those costs." To the extent that persons living with dementia are unaware of or are hiding the cognitive issues they're experiencing, those costs and risks won't be counted, resulting in a continued lack of programs to minimize those risks.

Available employer-provided benefits

A variety of benefits should be made available to employees, including persons living with dementia, those who are caregivers, and those who may find themselves in these situations in the future. Employers should consider providing comprehensive benefits for people living with dementia:

- **Medical insurance** helps cover the costs that come from receiving and managing a dementia diagnosis, including associated care and medication expenses.
- **Health savings accounts (HSAs) and flexible spending accounts (FSAs)** assist with medical savings and planning ahead for expected future medical costs.
- **Long-term-care insurance** helps pay for the costs associated with long-term care, including in-home and residential care.
- **Disability insurance** provides financial protection by replacing income that's lost due to the disability.
- **Employee assistance programs (EAPs)** offer counseling sessions, legal and financial services, and assistance with developing a care plan. Typically, some sessions may be offered for free or at a discounted rate. Additional legal service benefits provide help with a variety of protections that should be put in place, such as wills, trusts, advanced directives and powers of attorney (POAs).
- **Family paid leave** allows for paid leave, which can be taken on an intermittent or consecutive basis. The number of weeks permitted depends on the employer.

Recommended steps

Whether employees initiate a discussion about their cognition with their employer or a supervisor has concerns about employees' cognition and initiates a discussion about their work performance, the following steps, adapted from the Job Accommodation Network (JAN), may be helpful. JAN is a free service that provides guidance on workplace accommodations for people with disabilities. These actions should be taken before or after employees seek or obtain a diagnosis. Human resources personnel should be involved as early as possible in these steps.

1. Conduct a nonconfrontational conversation with employees citing specific, documented concerns and performance issues, their impact on others, and any prior actions taken. Age- or disability-related questions and comments should be avoided. JAN recommends that employees begin this conversation before their cognitive impairments have a significant impact on their work life. Employers should keep an open mind about the possibility of retaining workers via accommodations. If an employee agrees and provides permission, it may be helpful to speak with the doctor of the person living with dementia about the expected progression of the disease. As previously mentioned, involve HR when planning for a discussion and potential next steps with employees.

2. Confirm ADA protections are taking effect if employees disclose that they are or may be experiencing the onset of dementia. Businesses with 15 or more workers must explore accommodations. Persons with a disability cannot be excluded from or denied benefits offered to others, including services, programs or activities. The ADA also protects people who are associated with a person who has a disability, such as a spouse with dementia.

3. Help employees fully understand their retirement and work options. Including close family or friends in these conversations and providing the information

in written form (for example, meeting notes, a pamphlet, specific steps) may help employees use the information more effectively. Our focus group members all wished there had been more open information from their employers about their employment and retirement rights and options in relation to dementia. Rather than simply telling them which agencies to call, they also needed help making these calls and organizing and understanding the information given to them by outside agencies. As one person explained, "I had to do it all myself, jumping through all the hoops and making all the calls. [My workplace] could have made that a lot easier."

One of the human resources managers interviewed indicated that employees at her business qualified for 10 free counseling sessions per year, and that these could perhaps be used to help those living with dementia deal with the emotional challenges of receiving a diagnosis. See the list of organizations in Appendix A that employees can connect with for support. We encourage HR and executive leadership to keep copies of this list as a resource for employees who might need it.

4. Determine which accommodations will be necessary for those who are able to continue working. Accommodations will be highly specific and unique to each individual worker within each job type and setting, and they'll also change over time.³⁶

However, the accommodations cannot create undue hardship for the organization. Larger organizations may have more flexibility in terms of the accommodations that should be made, while smaller ones may offer closer working relationships and support.³⁷ The financial costs will also influence what's reasonable (for example, equipment purchases, reductions in hours, additional training and supervisory costs), but most accommodations aren't expensive.

To explore accommodation options, begin with a safety assessment for physical and financial risk. When conducting a work-specific assessment, focusing on what employees can do rather than what they can no longer do is a positive approach that can lead to more effective accommodations.³⁸ If employees desire, consider again including the spouse or other close caregiver in these discussions, as they may have additional insights and concerns, and their consensus may be critical to the success of the eventual accommodations. With permission from the person living with dementia, consulting with the person's doctor may also be useful.

Finally, occupational therapists should be consulted by either the employer or employee to provide expert advice to help enable continued meaningful participation in work activities, advocate for and help identify reasonable and successful accommodations, plan for and track changing needs over time, and help create plans to ease the individual into retirement when desired.³⁹ Workplaces that discussed work options directly with employees, their families and other key persons (such as their doctor or an occupational therapist) arrived at more favorable outcomes than those that made such decisions unilaterally.⁴⁰ See Appendix B for tips on fostering a dementia-friendly workplace.

5. Regularly evaluate any health or safety risks and document in employees' records how well the accommodations are working. Information and feedback should be gleaned from employees, their spouse or other caregiver (if appropriate and available), coworkers (especially a "buddy" coworker) and documented employee information (for example, absences, awards, injuries).

6. Decide how often to meet with employees and their families to discuss whether more accommodations or support are needed, or whether they're ready to begin the transition to retirement. Keeping open communication about the accommodations is key to their success. Regular, preplanned and agreed-upon "check-ins" will avoid the perception that they're conducted only when the employer has an issue. See the list of organizations in Appendix A that employees and their families can connect with for support.

7. Help employees make a dignified work exit once they express a readiness to retire or the workplace determines that the accommodations required to continue would no longer be "reasonable." One's occupation is crucial to developing and maintaining personal identity and self-esteem,⁴¹ and retirement is a major life transition. The shift to a positive retirement requires people to redefine themselves through activities and hobbies. This may be more difficult for someone living with dementia, but the individuals with whom we spoke were uniformly positive about their retirement. One said, "I do photography for a hobby and get to hang out with my wife. I've always been a workaholic, and I don't want to be anymore." Another stated, "I'm really enjoying having time with my grandkids that I didn't get to have when I was always working." A third added, "We're so much more than our jobs. I love this part of my life."

Corporate America's role

Creating more dementia-friendly workplaces contributes to the wider goal of fostering dementia-friendly communities.⁴² Corporate America needs to be more mindful of this disease and the unique needs of the employees and their families personally affected by it. For example, after the COVID-19 pandemic, many employers and employees are struggling to find the best balance between working from home versus being physically at the office or workplace. Extra consideration should be offered to employees living with dementia, who may benefit from greater flexibility, as well as for spouses wanting to spend as much time as possible at home with their partner.

Another way that corporate America should create dementia-friendly communities is by encouraging the development of personal friendships at work, for example, by providing opportunities for employees to get to know each other and their families through holiday parties and after-work events. Greater comradery at work helps to combat our growing

societal isolation, leading to benefits far beyond the workplace doors in terms of mental health and community cohesion. One human resource manager we spoke with suggested the creation of support groups, in-person or virtually, so that people coping with dementia won't feel so isolated and alone. Employers without the resources to spearhead a support group should point employees to local forums and even financially support those forums.

Corporate America should also help push for updated company or corporate policies to make the lives of families dealing with dementia easier. As it currently stands, employees terminated for performance reasons lose their benefits — regardless of whether they're later diagnosed with dementia.⁴³ Updated policies should cover this employment-to-diagnosis gap by providing resources, such as back pay, to continue to support past employees upon diagnosis. Additionally, mechanisms should be designed for transferring employees from fired to retired so they're able to continue to offer benefits.



The bureaucracy surrounding using a POA should also be minimized. One interviewee explained how, even when a POA was in place, organizations required submission of documentation with a wait of up to three months for it to be approved before they were willing to speak with the caregiver. This is untenable when financial and medical decisions must be made quickly.

Finally, self-insured companies should work toward insurance coverage change for dementia treatments shown to improve the disease course, including medications. Companies that aren't self-insured could support legislative change to support this type of insurance coverage.

The workforce is aging both because our society overall is aging and because financial pressures are increasing. As one interviewee put it, "People retiring at 62, 63 and even 65 — that's not the norm anymore. People just can't afford it."

Most Americans have already been touched by dementia through a person living with the disease. People live in fear not only of the disease but of the

financial and social ramifications that accompany it, including the hassles encountered related to getting the benefits they've earned and deserve. Corporate America must do its part to ease these fears so that persons living with dementia can devote their remaining years to the activities that give their life meaning and joy, including work. These efforts start "at home," with businesses and human resources personnel ensuring that their employees:

- Are familiar with their retirement benefits
- Understand that basic disability law applies to persons living with dementia
- Have access to reasonable accommodations
- Feel safe discussing these issues at work

Perhaps one day there will be a corporate rating system designating how prepared each business is for dealing with brain health issues, both in relation to their own employees and their employees' family members. Dementia is a unique and increasing form of work disability and should be treated with additional care and attention.



Appendix A: Organizations to provide support

Here's a list of resources. You can search for these organizations online to learn more:

- AARP
- Alzheimer's Association (there are more than 70 chapters across the U.S.)
- Area Agency on Aging (there are 622 offices across the U.S.)
- Benefits.gov
- BenefitsCheckUp, National Council on Aging
- Caregiver Action Network
- Eldercare Locator
- Family Caregiver Alliance
- Medicaid
- Medicare
- National Alliance for Caregiving
- National Council on Aging
- Social Security
- State Health Insurance Assistance Program

For more information go to [alz.org](https://www.alz.org)

Appendix B: Tips for fostering a dementia-friendly workplace

✓ Simplify the physical work setting.

Reducing distractions, such as noise, can help with concentration. Where possible, maintaining consistency and familiarity in meeting times and settings is another way to reduce distractions and minimize stress.

✓ Allow working from home.

Working from home full- or part-time allows workers to avoid commutes that can sap their energy and may pose physical risks. Avoiding the commute also gives employees more time in their day, which may facilitate working during the hours in which they function best. Consider whether workers will have trouble with the technologies needed to work from home and whether they have a friend or family member who can assist should such issues arise.

✓ Simplify routines.

Sometimes workers are capable of completing the job, but not at the same pace or with the same complexities. For example, one focus group member had worked as a scheduler for a busy surgery clinic that dealt with trauma cases. When she brought her issues to her employer, she was first moved to a much less busy section of the clinic, where scheduling was simpler and there was less time pressure. Later, she was moved to the even less demanding registration desk.

✓ Provide reminders of activities, events and appointments.

Many technology-based reminder systems are now available. Close coworkers might also volunteer to offer reminders of key meetings and events.

✓ Create a “buddy” employee (or peer support) system.

A “buddy” is a close coworker who checks in and is available to help workers with the more complicated aspects of tasks. An added benefit of buddy employees is that they should be consulted over time as to how well the current accommodations are working and whether safety or business risks are a concern.

✓ Offer additional IT support.

Work technologies tend to change frequently and may therefore create an added barrier to workers with difficulty learning or remembering new software. Some additional IT support and/or more detailed written instructions may be all that’s needed.

✓ Adjust roles and responsibilities.

As abilities change, workers may need to take on a different role or job in the company. For example, one focus group member had worked in an academic department, mostly writing manuscripts and reports and sometimes conducting soil assessments. After the employee developed language difficulties, duties were shifted away from writing and toward field sample testing, a job the employee not only could still perform but could train others to do as well. Keep in mind, however, that a new position that’s too different from a previous one (for example, that requires new skills and routines) can set up the person living with dementia to fail, as issues with learning and memory are key components of the disease.⁴⁴

✔ **Provide more supervision.**

Additional supervision of employees' work product may be required to monitor things like timeliness, accuracy and client satisfaction. This supervision (and any supervision that will be provided by a "buddy" employee) should be agreed upon and overt, as covert supervision risks undermining trust and employees' dignity and confidence.⁴⁵

✔ **Allow for flexible or modified hours and scheduling.**

Simply shortening hours can be sufficient to maintain employees in their current role. Ideally, hours should be limited to those in which persons function best. Alternatively, the most critical aspects of the job might also be scheduled during these optimal hours. One interviewee stated, "I worked and came home and nothing else. Just trying to save some of my energy. By afternoon, I was pretty well spent."



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