

Dr. Joanne Pike

Company culture, including the role for employee resource groups, is something that is really an opportunity for many of us, right? Employee resource groups, support groups, and a company culture of dementia capability can bring awareness and compassion to individuals who may be in the workforce.

Ellen Kelsay

That's Dr. Joanne Pike, President and CEO of the Alzheimer's Association, the global leader in Alzheimer's and dementia care, support, and research.

I'm Ellen Kelsay, and this is the Business Group on Health podcast, conversations with experts on the most relevant health and well-being issues facing employers.

Today, Dr. Joanne Pike and I talk about why Alzheimer's and other dementias, which 55 million people are living with worldwide, are increasingly relevant in the workplace. We discuss the experiences of employees impacted by Alzheimer's, both those living with this disease and those who are caregivers, and how employers can better support these individuals through workplace culture and benefits.

Joanne, welcome to the podcast. We're thrilled to have you.

Dr. Joanne Pike

Thank you for having me.

Ellen Kelsay

All right. Well, in this conversation, we are going to be discussing cognitive impairment due to dementia and Alzheimer's disease. But before we dive in, can you start by defining those terms for us? What is dementia and what is Alzheimer's disease?

Dr. Joanne Pike

Yes, thank you for this question. I think it's important to understand the relationship between the two, and it's often in a misunderstood area. Dementia is not a single disease. It's an overall term for a particular group of symptoms. The characteristics of those are really difficulty with memory, language, problem-solving, the things we typically think about from cognitive impairment. It's things that affect a person's ability to perform everyday activities. Now, Alzheimer's disease is one cause of dementia, and it is one of the diseases grouped under that term, the umbrella term of dementia. Alzheimer's accounts for about 60% to 80% of dementia cases. Dementia caused by Alzheimer's disease is what we think of as Alzheimer's dementia. And here in the U.S., nearly 7 million older Americans are living with Alzheimer's dementia.

Ellen Kelsay

Wow, that's significant. Well, one thing that really intrigued us and prompted us to reach out to you for this conversation today is a report that you recently released called *Cognitive Impairment in the Workplace*. Specifically, we're interested in exploring throughout the conversation with you today, why do cognitive impairment and dementia matter to employers seemingly now more so than perhaps in the past?

Dr. Joanne Pike

The report that you mentioned is a co-report that we wrote with Bank of America and published earlier this year, and it's available on <https://www.alz.org/> for anyone who is interested in seeing it. But I think one of the important features of this is U.S. workers are working longer. We know that nearly one in five U.S. workers are over the age of 65. That's nearly double the amount from 1987 to today. The other thing is the greatest known risk factor for Alzheimer's disease and other dementias is age. As workers age, their risk of developing a cognitive impairment certainly increases over time and will show up in the workplace if they stay long enough.

Ellen Kelsay

And the other thing that I think is also important to point out to our audience is that this isn't just an older person's disease. There is something called younger onset. Can you explain that and how that's also manifesting within the working population?

Dr. Joanne Pike

Absolutely. So younger onset is a smaller group of individuals who will experience cognitive impairment, whether that's due to Alzheimer's disease or another cause, younger, sometimes as young as 40. Like I mentioned, this is a smaller population. It is not as large as those who are over 65, but it's important to have the conversations around your cognition and understanding changes in cognition over time. Those individuals who do have younger onset deal with stigma in a different way and usually carry that within their employer-based health plans and their needs within their physician group differently than what we see with a Medicare population.

Ellen Kelsay

So let's talk about that. You just mentioned stigma. What does cognitive impairment look like in the workplace and what are some of the issues associated with it in addition to stigma?

Dr. Joanne Pike

I think it's important just to recognize also that the early stages of memory loss are called cognitive impairment. And anybody who experiences dementia or Alzheimer's disease goes through this early stage of memory loss that is referred to as cognitive impairment. So just in the lifecycle overall, I want to acknowledge that if you develop Alzheimer's disease or another dementia long-term, you have to go through this stage called cognitive impairment. These symptoms show up in day-to-day life and can vary greatly from person to person, but ultimately it's things that are routine. People will see changes in their ability to remember meetings or appointments, following instructions, or being able to multitask. These are some of the changes that individuals may see. Now, the stigma that comes along with that is part of why cognitive impairment, Alzheimer's disease, or another type of dementia, is hard for individuals to have those conversations about what is going on with them. A lot of people think about their employment as who they are and to think about that changing or them not being able to come to their workplace can be scary and also has a certain amount of personal meaning. So I think there's a certain amount of stigma from the standpoint of losing your potential identity, but then also what does that mean for your livelihood? There could be fear about having the conversation if you are noticing things within your own cognition, but there could also be stigma from individuals who are watching this around another individual as well. So it could be two-sided. Being the person who is experiencing those cognitive changes or being within a working group and seeing that occur for someone around you. We know that even outside of the workplace, stigma shows up within families, within conversations with physicians. I think it's important for us as a society and a community and anybody who is wanting to build dementia capability to understand that stigma only goes away with conversation and knowledge. Having opportunities to build knowledge within the workplace or to give individuals the language to have those conversations is incredibly important to changing stigma.

Ellen Kelsay

So important that you've highlighted all of those issues related to stigma and the fear of even acknowledging and talking about the challenges related to the workplace. There are other reasons, very practical, of course, people want to remain in the workforce because they need to financially, or maybe they're really dependent on the employer-provided health plan for the coverage for their condition. One other thing that your report noted in some of your focus groups, some of the participants mentioned being worried about some sort of, maybe not retribution, but performance management related to their cognitive impairment. How does that manifest itself in terms of kind of the complications and compounding effect of the stigma?

Dr. Joanne Pike

Yes, I think that's another contributor to why people delay those conversations or delay a diagnosis. They could have concerns about whether it's retribution or performance reviews to the very issues that you're talking about. People need financial stability, they need health insurance, or they need the social interaction. It could be just as simple as needing a place to be and needing a sense of purpose. But I think one of those things that's incredibly important within this is the importance within the supervisory or the HR conversations with individuals to make sure that when they are seeing a change in their cognition, they have the understanding that there is benefit to making sure their employer knows that these changes are occurring. Instead of thinking about it as a performance concern, this gives us the opportunity to actually help an individual stay in the workplace longer.

Ellen Kelsay

You mentioned something interesting about delay and diagnosis, you know, certainly related to stigma, related to fear, but there are also some medical, maybe some clinicians, primary care physicians, family members aren't really detecting that there actually is an underlying cognitive impairment issue at play. What else do you all see from just a delay in diagnosis related to kind of the medical aspect of it?

Dr. Joanne Pike

I think it's very common for whether it's individuals, physicians, or family members to dismiss changes in memory or thinking just as someone getting older. What we have historically seen in some of our research studies is that there is an average of a 15-month gap between when someone first experiences symptoms and when they first talk to their health care provider about it. That gap is unfortunate because the sooner someone is diagnosed, the more opportunities we have to intervene, especially because now there are treatments if someone has cognitive impairment due to Alzheimer's disease, and those treatments are most beneficial at the earliest stages of someone's memory loss. I think the other key piece is that delay also contributes to, at the workplace, someone potentially having a performance-related issue instead of accommodations.

Ellen Kelsay

That's so important. I do want to get to some of the treatments a little bit later in our conversation, so I appreciate you flagging that at this point. All right. So far we have spent most of our time talking about employees who themselves are experiencing cognitive impairment, but I also want to switch gears because we know that there are many employees who are serving as caregivers to other family members or people in their lives who are also struggling or maybe struggling with dementia. How common is the caregiver component of this?

Dr. Joanne Pike

It's huge and I'm glad you brought this up because I think this is an incredible area where employers and us as communities in a society have an opportunity to really impact the experience of caregivers. Fifty-seven percent of employed caregivers had to go into work late, so that is just right off the top a way that we are seeing caregivers experience work themselves as being a dementia caregiver. But the other thing that we need to think about in caregiving is the burden that we're putting on those individuals who are in the prime of their work years, who may be caring for someone older than them, like an aging parent, or also caring for children under the age of 18, the sandwich generation where we have a quarter of caregivers. That is an incredible amount of individuals who have a significant amount of caregiver burden experiencing both the children and also the aging parent, 25%. And those are the individuals who are in the prime of their livelihood, their careers. And that impact, unfortunately, usually shows up in ways like having to cut back hours, going from full-time to part-time, or having to give up work entirely because of the burden that they are experiencing. I think the other thing to think about from a caregiver perspective is about two-thirds of dementia caregivers are women. So those of us who are female in the workforce are more than likely carrying a burden of this type, whether as a sandwich caregiver or caring for a parent as well. I know I fall into this category as daughter, wife, and mother. This really speaks to me as an employee and as a leader, but also in the way I think about our own workforce or the potential for employers to intervene or create a caregiver-friendly environment.

Ellen Kelsay

Your report referenced a statistic that 11 million Americans are providing unpaid care for people living with dementia or Alzheimer's, and I would venture that that is a far underreported number. It's probably significantly more than the 11 million, just because, again, the stigma and other factors you discussed earlier, we probably don't even know the true extent, but the stats you just raised are quite eye-popping. So some degree more than that, I'm sure, is probably what the reality is.

Dr. Joanne Pike

Yes, I would completely agree with you. We know that dementia and Alzheimer's is under diagnosed. We anticipate that the caregiver burden is undercounted as well. And I think one of the other things, the other statistics that's kind of eye-popping along with that is 6 in 10 caregivers at the time of our survey were employed.

Ellen Kelsay

Let's switch gears and talk about recommendations. You've done a great job illuminating kind of the challenges and the issue, and there are a number of recommendations that your report does such a nice job of laying out. So let's take them kind of each one at a time, and let's start with the ADA or the Americans with Disability Act. What are some of your recommendations there?

Dr. Joanne Pike

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. As we think about that law, it defines eligible people as someone who has a physical or a mental impairment that substantially limits a major life activity. They have a history or a record of that impairment and are regarded as having that impairment in the workplace. So people with disabilities must be offered reasonable adjustments to permit continued employment. And I think this is one key area for employers to understand that those living with cognitive impairment or have an impairment due to dementia, it's important for employers to understand the ADA and what those implications are for their workforce as it relates to their cognitively impaired workforce. But it's also important to think about how this impacts certain circumstances, what those accommodations may need to be. So for instance, operating heavy machinery or working in health care, those laws may be impacted by state. So understanding what those disabilities, what that cognitive impairment means for the accommodation by state, but also the needs of an individual as well.

Ellen Kelsay

What might some other accommodations look like for those that are not in health care or not operating heavy machinery? What other types of accommodations most commonly might be considered here?

Dr. Joanne Pike

Part of that is, you know, medical care. The accommodations that are needed from a time perspective, but the other ones could be simple from a routine standpoint. Can we assist an individual with setting up their workplace or their systems to help with anything that they are experiencing with their cognitive impairment? As I mentioned before, cognitive impairment is a very personal change. So each person is going to potentially need something different in the workplace, whether it's time management, assistance with meetings, or even thinking about how an individual remembers projects from day to day. You know, I think we're also on the cusp of how we use technology in the workplace to assist ourselves in what we do and how we think about accommodations along with the technology advances that we're seeing and how we can create an environment for that. So for instance, even something simple as note-taking with AI.

Ellen Kelsay

It's going to be fascinating to see the role that technology and, like you said, AI plays in this space and in many spaces, but for sure in this space as well. Okay, now let's talk about some of your recommendations related to company culture.

Dr. Joanne Pike

Yes, company culture, including the role for employee resource groups, is something that is really an opportunity for many of us, right? Employee resource groups, support groups, and a company culture of dementia capability can bring awareness and compassion to individuals who may be in the workforce. It can also, you know, help us understand what policies can be in place that support individuals with that type of disability and maybe even those caregivers that are experiencing stress from their responsibilities on both sides. So overall, companies can create and foster that dementia-friendly and very capable workplace by including things like providing training for HR and managers on warning signs of dementia and how the disability law through ADA can support their employees. Encouraging employees to seek an early diagnosis, you know, maintaining healthy habits before and after diagnosis are important to manage. Managing health overall is one of those risk factors that we can actually be in control of whether you are making employer-based decisions or as an individual who needs to care for their health. And I think there's other things too, whether you have an outsourced third-party HR, making sure they're educated and understand what that looks like. And then, you know, just the simple inclusion of brain health

communications and strategies to employees, whether they are in the younger age groups or in midlife is an opportunity to really talk about reducing their risk of cognitive decline.

Ellen Kelsay

Well, you just listed so many things that I think tee up the next item I wanted to ask you about really nicely, and it's related to benefits and programmatic support. You mentioned earlier in the conversation, you know, flexibility around going to doctor's appointments. You just mentioned now, healthy habits, early diagnosis. What else would you cite in kind of the benefit and programmatic support area?

Dr. Joanne Pike

One of the first ones is around what are you providing within your medical insurance, you're purchasing choices in how you are providing potential diagnostic and treatment options for individuals who are diagnosed. So really looking at if someone is diagnosed, if they are using your health insurance plan, what options do you have to ensure that they have the most scientifically valid, up-to-date diagnostic, and also the new treatments that are available, including that within your plan or requiring it of your insurance carriers. You know, health savings accounts could be an area that is important. We know that cognitive impairment, dementia, and dementia due to AD are an expensive disease, and really thinking about what that means for individuals and helping them navigate their choices in how they save and how they use their medical spending. Also, disability insurance and also long-term care insurance are important options as well when we think about making sure people have those choices within their plans and looking at whether that's for another individual within their family or themselves. And then I think there's just the simple things that I call them simple, but they're always not so simple because they mean such important legacy for our families are things like wills and trusts and the legal services that we can make sure are available through our benefit plans and certainly having EAPs for counseling and other legal advice is important too. But the last one I would mention, which is certainly not the least of this, is paid family leave. This is incredibly important for individuals who certainly have any type of chronic disease, but also incredibly important for care partners or caregivers in the workplace.

Ellen Kelsay

That is an impressive list. I think just as you were going through it, for many employers who didn't think that there was a way they could support their workplace and their workforce with cognitive impairment, you just rattled off at least 10 or so things that are very concrete examples of many things that they're probably already doing, but just aren't aware of how extensively it could support those, you know, dealing with caregiving issues related to impairment or health issues related to it as well. And I'm so glad you mentioned the paid leave. We see a number of the employers that we work with offering now within paid leave, a new component of leave specifically related to caregiving and caregiving leave. So that is certainly on the rise.

Dr. Joanne Pike

Yes, absolutely. I think you mentioned earlier in the conversation around young onset Alzheimer's disease and the importance within the workplace for having knowledge and assistance within this. One of the things that's incredibly important within that young onset Alzheimer's disease group is depending on if they're able to continue working and receive their medical insurance through their workplace or if they need to roll on to whatever comes next post-work environment, it's important to understand that those with younger onset after a waiting period can qualify for social security disability insurance as well. And so this is an opportunity for HR professionals to know how to help individuals through this process if they have to go on disability.

Ellen Kelsay

You did mention earlier in our conversation treatment and I specifically wanted to ask you about prevention. Are there treatments or therapies that can help detect earlier or prevent even perhaps the onset of dementia or Alzheimer's? What are you seeing in terms of the innovation in that space?

Dr. Joanne Pike

This is one area that I think is incredibly exciting on two fronts. You know, we have a tendency to think about prevention two ways in the Alzheimer's space. One, drug prevention. Can we begin to treat someone before they have cognitive impairment symptoms based on the biology of the disease? And that

is actually being researched right now. If we can intervene with a drug treatment prior to symptom onset, can we reduce, delay, and prevent Alzheimer's disease? It's going to take us a couple of years to know whether there is a drug treatment that does work for prevention of Alzheimer's disease from that standpoint. However, there are things that we know work today for reducing risk. In fact, earlier this year, the Lancet Commission updated a previous publication that they had on risk factors that could prevent or delay the onset of dementia, many of which are also beneficial to risk factors for other chronic diseases. The Lancet Commission published 14 risk factors that impact up to 45% of dementia cases worldwide. Some of these are out of an individual's or an employer's control, but many of them are influenced by personal behaviors or employer options and wellness benefits. When we think about behavior change and what we know works within other chronic disease, it can work for reducing dementia risk as well. Simple rule of thumb is what's good for the heart is good for the brain. So there's a list of things that the Alzheimer's Association points to that are healthy habits that can help delay or potentially reduce someone risk, like physical activity, avoiding smoking, controlling blood pressure, managing diabetes. These are all things that are important to do in midlife. And usually midlife is when we are at the prime of our working lifespan. There are studies that the Alzheimer's Association is conducting right now, and we're really excited about the potential for lifestyle intervention on preventing or delaying Alzheimer's disease or other types of dementia. In fact, we're conducting a lifestyle intervention study for the past couple of years in five cities around the country, and that research study is reporting out at our Alzheimer's Association International Conference this summer in Toronto. It's going to give us insight on whether we can build interventions that change the risk for individuals and communities. And what we're studying is nutrition, physical activity, cognitive engagement strategies, and medical management of chronic conditions like blood pressure. And do those four interventions together change individual outcomes? Like I mentioned, we're really excited about that because I think that's going to point us potentially in a different direction around prevention for Alzheimer's disease.

Ellen Kelsay

Wow, we will be keeping our eyes peeled for your lifestyle intervention study. That sounds fascinating. You said this summer that comes out?

Dr. Joanne Pike

Yes, in July. We will be reporting out on that.

Ellen Kelsay

We'll keep a close eye out for that. Well, I always like to wrap these conversations with a note of optimism, and I think you've woven nicely throughout the conversation a lot of really great things to be excited about. But what particularly gives you hope as you look to the future related to Alzheimer's and all of the unbelievable work that is underway?

Dr. Joanne Pike

Yes, I think the last 18 to 24 months and what the next 24 months look like for us is just an incredibly transformational time right now in Alzheimer's and dementia. We are seeing new treatments. We're seeing more come out of the treatment pipeline, but not just treatments, diagnostics. And what that means for early detection for us is truly going to change how we treat, how we provide care, and how we think about and reduce the stigma of Alzheimer's disease and other dementia. I think conversations like this also give us hope, being able to think about reaching into new populations, new systems, and how we can impact together the population and communities across the country and globally, thinking about how employers provide support. You are a big piece of the landscape of how we provide medical care, how we can potentially talk about and incentivize that care throughout the country. So thank you for this conversation and we're very thankful to Bank of America for supporting this important research as well.

Ellen Kelsay

Well, Joanne, it's been a pleasure speaking with you. We greatly appreciate your expertise and the wonderful work and forward progress of your organization at the Alzheimer's Association. And we are really, again, looking forward to seeing what the next 18 to 24 months ahead looks like and all of your great work and research. So many thanks again for your time and expertise.

Dr. Joanne Pike
Thank you.

Ellen Kelsay

I've been speaking with Dr. Joanne Pike, President and CEO of the Alzheimer's Association, about why this disease matters in the workplace and to employers. For more information on the intersection of Alzheimer's and other dementias in the workplace, check out *Cognitive Impairment in the Workplace, Compassionate Approaches for a Hidden but Growing Concern*, a report prepared by the Alzheimer's Association.

I'm Ellen Kelsay, and this podcast is produced by Business Group on Health, with Connected Social Media. If you liked this episode, please rate us and consider leaving a review.