

Dealing with dementia at work

With aging workforce, employers should better understand impact of disease

BY SARAH DOBSON

ABOUT four years back, Keith Barrett had a stroke-like event that led him to Ottawa Hospital. And with the subsequent testing, Barrett was diagnosed with young-onset dementia, probable Alzheimer's — at the age of 57.

As co-owner of Partners in Parenting in Ottawa, a social welfare company, Barrett deals with HR policies, bookkeeping and facility maintenance. And he still works there today, despite the disease.

He's lucky because his work is largely repetitious, he said.

"My cognitive reserve is good for me. So I've been doing this for so many years, hopefully it'll be one of the last things to go."

A neuropsychologist told Barrett he should have his work supervised, so when it comes to tasks like issuing cheques or processing invoices, there are safeguard measures such as another person checking the work.

"We work in tandem, so that we make sure that the accuracy is still there," he said.

Barrett often asks colleagues to write requests or replies down in emails, in bullet form, so he won't forget their input. And because he might have trouble following the "banter" of meetings, he relies on minute notes afterwards. Using an Apple watch also helps Barrett stay on task, and he works a shorter day, roughly from 7 a.m. to 1 p.m., he said.

"A shorter day helps me because it's exhausting at the end of the day, knowing that I'm doing things in duplicate, or I'm just having to spend more time trying to process things."

Facing the truth

Barrett is one of the lucky ones,

able to hold down a job despite the challenges of his condition.

In the United States, four out of five seniors think brief cognitive assessments are beneficial, and yet fewer than one-third (28 per cent) have had such an assessment, while just one in seven (16 per cent) are regularly checked, according to a recent report.

That's in contrast to those who seek routine assessments for other health issues such as blood pressure (91 per cent), cholesterol levels (83 per cent), vaccinations (80 per cent), hearing or vision loss (73 per cent), diabetes (66 per cent) or cancer (61 per cent).

Instead, many seniors expect their physicians to recommend the assessments, while the physicians wait for patients or family members to report symptoms or request an assessment, found the 2019 *Alzheimer's Disease Facts and Figures* from the Alzheimer's Association, which included a survey of 1,000 physicians.

Age is one of the highest risk factors for Alzheimer's disease, so it stands to reason with an aging workforce there will be more people in the workforce diagnosed with that and other dementia conditions, said Ruth Drew, director of information and support services at the Alzheimer's Association in Chicago.

And oftentimes the workplace is where people first notice that things are not as they have always been before. Symptoms can include changes in a person's judgment and problem-solving ability, the ability to do complex tasks that were OK before, or taking longer to do a task, she said.

"It's different from one person

to the next. Sometimes the person with the disease is the first one to know that something is wrong, something's not as it was; sometimes they're the last to know because a disease like Alzheimer's can affect different parts of the brain and insight and judgment can be one of the things that is affected in those early stages," said Drew.

"Sometimes the symptoms present in really classic ways that you would expect Alzheimer's to present. And sometimes they're atypical. And so that makes it harder to diagnose."

While age is a factor for the onset of Alzheimer's, the bigger contributor will be diagnosing cognitive impairment earlier, said Pauline Tardiff, CEO of Alzheimer Society of Canada.

"Our suspicion is that there are more people in the workplace living with some kind of cognitive impairments, call it mild cognitive impairments, for instance, that may not recognize it themselves... and don't take treatment because of the fear in the workplace... I'm going to lose my job automatically. It's the whole stigma tied into cognitive impairment or the word dementia."

Stigma issues

More than half a million Canadians have dementia, including Alzheimer's disease, according to the Alzheimer's Society. In less than 15 years, an estimated 937,000 Canadians will have dementia.

And yet 46 per cent of people would feel ashamed or embarrassed if they had dementia, while 61 per cent said they would face discrimination of some kind, according to a 2018 survey of 1,500

Canadians released by the society.

In addition, one in four Canadians believe their friends and family would avoid them if they were diagnosed with dementia, while only five per cent of Canadians would learn more about dementia if a family member, friend or co-worker were diagnosed.

Fear of disclosing your diagnosis is understandable, said Drew.

"If I tell you that I have a brain disease that is preventing me from being able to remember things accurately, or learn things or process information or do complex cognitive functions in the way that I used to, then you might tell me that I probably can't do my job anymore. So it can be very scary for people to share that they have a problem."

Making accommodations

Fortunately, the federal legislation around accessibility now includes dementia, said Tardiff.

"We fought hard to get that in there because when you think about access or accommodation, many people think either intellectual disability or physical disability... they don't necessarily always think of dementia," she said. "So when we talk about accommodation in the workplace, dementia is part of their responsibility."

It's about trying to avoid a person being fired for a performance issue that's actually caused by a medical diagnosis, said Drew.

"That's why we really want people in leadership positions and HR positions to know what Alzheimer's looks like in the early stages."

That can mean, for example, when an outstanding employee is suddenly making mistakes or turn-

ing in performance that just doesn't make any sense.

"It's important for both the employer and the person to have open and honest communication if you notice work performance issues."

Barrett was nervous about disclosing his diagnosis to his staff. He had his own stigma about the disease, knowing of a family friend who was locked in a Nova Scotia ward, heavily medicated.

"I was very apprehensive, saying it to my business partner and to my management team, but the whole organization, for the most part, knows now and they certainly are supportive."

Transparency is important, he said.

"If you're open with your people that are around you, they can play a supportive role, and help you continue on as best you can. I think it's

when you try and totally hide it and not be transparent, you'll end up making even more mistakes, and then it'll become a performance issue."

Employers and employees need to learn more about dementia, in terms of the warning signs, the impact it will have, and how to support those impacted in the workplace, said Tardiff.

"They can foster what we call the dementia-friendly workplace," she said. "If you're a supervisor and you see that someone is struggling a little, you can re-assign the work or focus on what the employee can do, as we would any other accommodation, not focus on their deficits. Focus on their capacity, maybe provide a quieter workplace or space so they can focus a bit better; allow for flexible hours."

It's also about providing time for

medical appointments, said Tardiff.

"There's a bunch of stuff people can do. But they need to think that through proactively and say, 'OK, we know what we're going to do when somebody presents to us with a physical disability, here is our accommodation, but what are we going to do when people come to us with a request for accommodation for cognitive impairment?'"

One of the organization's volunteers, for example, previously worked for Alberta Health Services for many years and started making mistakes with his spreadsheets. But the supervisor noticed and made a point to check in with his employee, which led to the diagnosis of Alzheimer's, she said.

"I don't want to underestimate the responsibility we have in workplaces to educate ourselves. We educate ourselves on how to give CPR if

somebody has a heart attack in the workplace. We educate ourselves around physical disabilities and accommodation — why wouldn't we proactively get educated and educate ourselves broadly on dementia and what cognitive impairment might look like in our workplace?"

As way of accommodation, people diagnosed with dementia may benefit by having more flexible hours and modified assignment for a period of time. And when they're no longer able to do the work, "it's about what is the path to helping them get the most benefit that they can so that they can move out of the workforce in the best possible way," said Drew.

"Also, remind people about what their options are, whether there are resources that they can reach out to. If there is medical attention that's needed, or testing that's needed, to point them in that direction."