

# PLAN MEMBER POINT OF VIEW

EMPLOYEE EXPERIENCES AND INSIGHTS

*Alzheimer's disease—a progressive and irreversible neurodegenerative brain disease—impairs thinking, memory and independence. The Alzheimer Society of Canada states unequivocally that it's “not a normal part of aging”<sup>1</sup> and can affect people during their working lives. Many people are still working when they're diagnosed with Alzheimer's disease and may have dependent children or parents, as well as major financial commitments. Geoffrey (a pseudonym) is one of these individuals; and his struggles to retain information at work started his path to diagnosis with mild cognitive impairment (MCI) due to Alzheimer's disease.*

## ***How did you learn you were at higher risk of developing Alzheimer's disease?***

My mother, who lived until she was 94, developed dementia. After she died, I volunteered for clinical trials every few years. I had never shown any of the early signs of dementia. But then I was asked to join a clinical trial that was studying drugs based on their genetic components. The test was simplicity itself: a mouth swab. It turns out I have a genetic marker (ApoEε4) that's linked to a higher incidence of Alzheimer's disease.

## ***When did you first notice changes that alerted you to the feeling that something wasn't right?***

I was reassigned to a new product line at work and there was a lot of new information to learn—but I was unable to recall much of anything I read or heard at meetings with the team. This was incredibly stressful and I ended up telling my manager about it, who advised human resources. I was then contacted by a third-party occupational health company that informed me (a bit too excitedly) that I was approved for 26 weeks of

disability leave. I would have preferred to have been offered other options.

One of the unexpected surprises following my diagnosis has been the realization that I no longer have an income—and that I likely never will again. After a lifetime of working and supporting my family, those days are in the past. For many reasons, an employer is unlikely to hire someone with MCI/Alzheimer's disease, along with all its attendant liabilities.

## ***How has MCI due to Alzheimer's disease impacted your day-to-day functioning?***

When I was employed, I relied on continuous help from colleagues to understand what we were being tasked to do—and I spent hours in the evenings trying to catch up. I wish my employer had inquired about my performance issues and asked me, “Are you OK? What's going on? How can we help you?” It was a lonely experience, doing my very best but always falling behind.

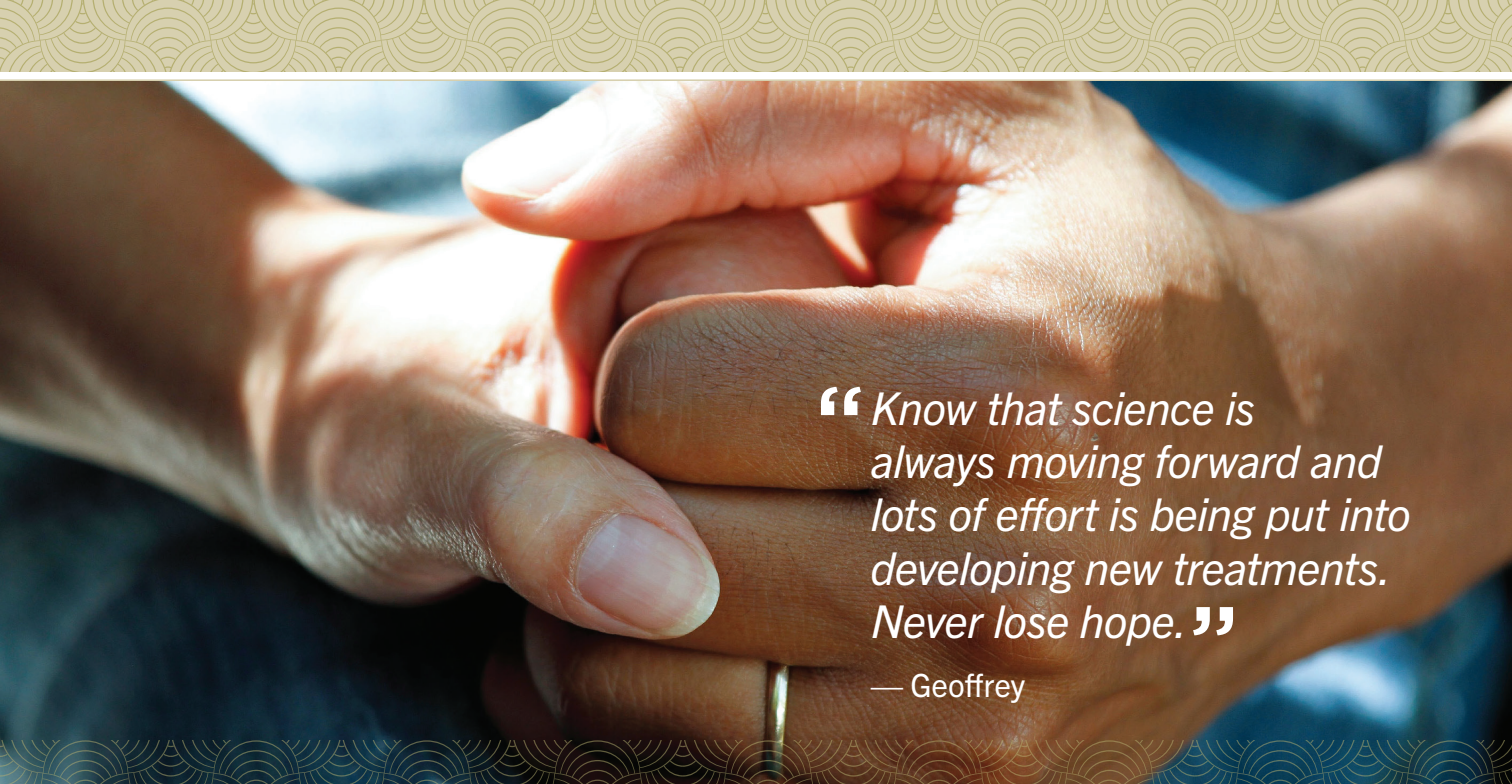
At home, losing my short-term memory means I can't remember where I've been physically a few

minutes after I change locations. I sometimes find myself somewhere in the house and am not sure why I'm there or even where I am. I also can't recall my most recent thoughts to help me find items I've mislaid. That said—and this is really important—my mid-term and long-term memory are excellent. It's very easy for me to appear mostly normal to other people. The downside here is that sometimes people think I'm just being difficult rather than experiencing the effects of my condition.

## ***How have your family and friends reacted to your diagnosis?***

It's been difficult for my family because this is a condition with no near-term cures. The additional effort needed to live with someone who has a slowly deteriorating condition requires a special level of patience.

I've only told a few friends about my diagnosis. They were sympathetic, but I haven't heard from them since. There's still a lot of stigma associated with Alzheimer's disease and I think people have trouble knowing what to say and do, so they avoid saying and doing anything.



**“ Know that science is always moving forward and lots of effort is being put into developing new treatments. Never lose hope. ”**

— Geoffrey

***Was it easy to access the information you needed to understand Alzheimer’s disease?***

I was grateful to have access to medical expertise through my quarterly clinical-trial visits, as well as MRI monitoring. But I had to do a lot of researching myself to find the information I needed to know about my condition. Unfortunately, I got very little direction from my health-care provider. I had to track down tools, resources and support on my own.

***What can employers do to better support people living with MCI due to Alzheimer’s disease?***

It’s important for employers to communicate fully to employees what the treatment and employment process will look like. I wanted to know what the plan was for me. I would have liked an honest, early assessment of the situation from my employer—with a clear and open discussion of the options available to me. For example, if an employee is agreeable, their employer could offer a phased transition out of the workplace upon diagnosis.

This could include an opportunity to work with the employee’s incoming replacement for an allotted period, followed by appropriate assessment.

Also, I expected regular weekly or biweekly cognitive training, diet change recommendations and other support that I didn’t get from my employee assistance program. I think these would have given me more of a sense of control over my condition.

***What would you tell someone who is newly diagnosed with Alzheimer’s disease?***

I’d say two things. First, accept that this is not a curable condition. It’s hard, but that’s the reality. Second, don’t give up on your future. Enjoy everything you still can. Take advantage of opportunities to talk with others who are sharing your experience. Know that science is always moving forward and lots of effort is being put into developing new treatments. Never lose hope.

***Looking to the future, what do you hope for the care, management and support of your disease?***

I hope researchers will keep working on medications to help people with mild Alzheimer’s disease and that newer agents will be approved quickly and made widely available. I’d also like to see the development of more patient support programs that are accessible to the people who need them. This is a disease that affects so many people. We need to slow down its progression and help everyone affected by it live their best quality of life for as long as possible.

Sponsorship for this interview was provided by Eisai Ltd. The statements, opinions and viewpoints expressed are those of the interviewee and may not be representative of all patients, nor do they reflect the views of Eisai Ltd.

<sup>1</sup> <https://alzheimer.ca/en/about-dementia/what-alzheimers-disease>

