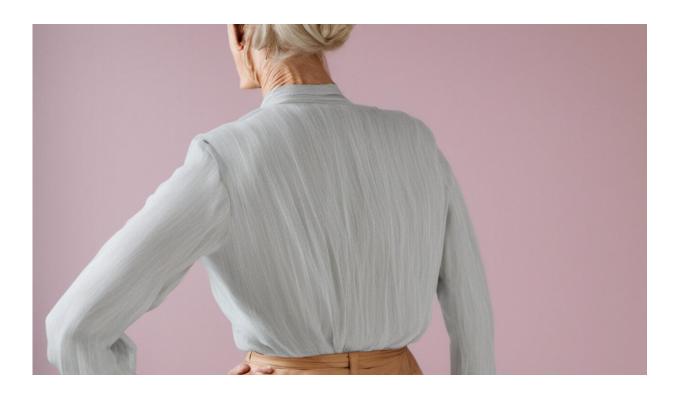


# Using technology to support caregivers of older people with dementia

September 17 2019, by Janet Fast



Credit: AI-generated image (disclaimer)

In June, the government of Canada released its long-awaited <u>Dementia</u> <u>Strategy for Canada: Together We Aspire</u>.

As a family caregiving researcher for more than two decades and a former family caregiver to my father, who had dementia, the strategy



was welcome news. But my own research and <u>personal experience</u> suggest that we're falling short of the aspiration to be "a Canada in which all people living with dementia and caregivers are valued and supported."

I agree, perhaps selfishly, that research and innovation are essential for effective implementation of the dementia strategy. <u>AGE-WELL NCE</u>, Canada's technology and aging network, engages older people, caregivers, product developers and designers in the development of technologies that can make their lives better.

I co-lead the AGE-WELL research project that is responsible for adding to what we already know about caregivers' needs, developing new technologies to meet those needs and advocating for new policies and practices that will reduce the negative consequences of care. My team's work shows clearly that caregiving takes a toll on the nearly half million Canadians caring for a family member or friend with dementia. Other caregivers also pay a price: poorer physical and mental health, social isolation and loneliness, financial hardship and insecurity. But that price is steeper when caring for someone with dementia.

### Caring time and labor

Caregiving is time-consuming for all caregivers, averaging nine-and-a-half hours per week. It is <u>more time-intensive for dementia caregivers</u>, who provide more than 13 hours per week on average. Collectively, those half million dementia caregivers spent <u>342 million hours on care tasks in 2012</u>, the equivalent of more than <u>171,000 full-time employees</u>.

Care also is a different experience for men and women and these differences are more pronounced among dementia caregivers than others. Women dementia caregivers are more likely than men to experience negative health, social, employment and financial outcomes.



Layer on persistent gender wage discrimination and ineffective financial compensation strategies and it's little wonder that a quarter of female dementia carers experienced care-related financial hardship. These caregivers often modify spending or defer savings to cover care-related expenses. This was a problem for only one in seven of their male counterparts.

## **Technological support**

Existing technologies that can make caregivers' jobs easier include GPS-enabled tracking and monitoring systems, smartphone and tablet applications, emergency alert systems, tele-<u>health services</u>, networking platforms and many others. But technology adoption and retention is poor, with 70 to 90 percent of innovations failing.

Sometimes this is because available technologies don't meet <u>caregiver</u> needs very well. Many product designers and developers create the technology for the sake of it, without knowing whether caregivers want it or are prepared to use it. As a result, <u>technology can have both</u> <u>negative and positive impacts on caregivers</u>.

Traditional problem-focused approaches to technology design can limit discussions to performing caregiving tasks, and fail to capture the complexity of "being in care relationships." Product developers and designers need to understand caregivers' complicated lives and unique needs if they're to develop successful strategies for developing, promoting and delivering technologies to support family caregivers effectively.

Disrupting how we develop technologies by <u>integrating caregivers into</u> <u>design practice</u> so that it's their experiences and expertise that drive the process is more likely to lead to products and services that solve their real-life problems, improve their well-being and, ultimately, succeed in



the marketplace.

#### **Supporting caregivers**

While there are technologies and services that can help support caregivers, it's usually up to caregivers to find them. Navigating a fragmented system of health and social supports is challenging, timeconsuming, frustrating and often futile.

One of our team's projects is addressing this challenge by applying a new type of artificial intelligence called cognitive computing. We have created an online tool that connects family caregivers to products that will support them and their family member or friend with <u>dementia</u>.

It will be far more specific and powerful than the usual search engines, allowing family carers to describe in plain language the problem they want to solve.

A second project uses a <u>co-creation process</u> that taps caregivers' experiences to develop a web portal that provides ongoing follow-up and <u>training in the use of mobility aids</u> such as canes, walkers, wheelchairs or scooters, when and where they need it.

A third project is <u>asking caregivers</u> to tell [researchers] about their preferences and priorities for technological solutions to some of their biggest challenges.

As our population grows older, disability rates increase and pressure on our health and continuing care sectors also grows. We have to understand, recognize and support family caregivers and their valuable work if we're to meet the challenge.

Of course, technology alone is not enough to sustain the largely unpaid



work of family caregivers. According to University of Birmingham social policy professor Paul Burstow, "getting the balance right between 'tech' and 'touch' is vital."

From my perspective: "We need to recognize the value of family caregivers' work and their right to 'have a life[']; ensure that there are adequate, accessible and affordable services for care receivers and caregivers; organize workplaces and labor policy so that caregivers can keep earning a living alongside their care work as long as possible; and when caregiving still results in financial hardship for some, we need to be ready with anti-poverty measures."

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