

## The lived experience of people with dementia

**T**he most common degenerative brain disease causing dementia was identified by Dr Alzheimer in 1906. The Alzheimer Society of Canada was not founded until 1978. The society initially focused on educating the public that dementia was not a normal part of aging. The first support group for people with dementia was not formed until 1993, and it was 2003 before a person with dementia sat on the society's Board of Directors.

Books about dementia initially focused on the disease, the caregiver's journey, and perspectives about the patient's journey. Only in the past few years have memoirs been written by people with dementia. This pattern is a symptom of the stigma supporting the idea that a person with dementia dies inside a living body.

Medicine has done little to reduce this stigma; written material focuses on losses from the disease seen from a professional perspective. It is time for medical professionals, and society in general, to learn from qualitative studies about the experience of people actually living with dementia.

A meta-synthesis (from 2018) of the lived experience was derived from 626 individuals in 34 studies from various countries.<sup>1</sup> The introduction is particularly meaningful:

"The way certain conditions and phenomena are understood and conceptualized, shape professional approaches to treatment and sociocultural perceptions of those experiencing them. This in turn has implications

in terms of the experience of individuals living with a condition."<sup>1</sup>

The study found three major themes. First, people with dementia live with constant change due to the loss of cognitive capacity and altered perceptions of the physical environment. Second, they strive for continuity by using a variety of coping skills. Those who adapt well have their iden-

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tity invested in more than cognitive skills, and demonstrate resilience. The third theme is the double-edged impact of the environment, which consists of interpersonal relationships and the physical environment. A positive environment allows people with dementia to continue participating in life, and includes caregivers who facilitate retaining control and a sense of agency—key to a person's experience of dementia.

This echoes Kitwood's research into maintaining personhood in dementia.<sup>2</sup> He concluded that personhood is "a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust." Kitwood describes the following ways in which people act that undermine a person with dementia's personhood: ignoring (conversing with others as if

the person is not present), infantilizing, disempowering (no unsupervised walking), objectification during personal care, withholding, and imposing. Through recognition, collaboration, negotiation, facilitation, validation, celebration, as well as adapted physical environments (dementia villages) we can enable people with dementia to continue to live meaningful lives.

In a systematic review of 27 studies on positive experiences with dementia,<sup>3</sup> the authors found three themes across the experiences. First, they focused on aging well (as opposed to focusing on their dementia) by seeking pleasure and enjoyment and continuing to do what was important to them with the support of their loved ones. Second, they faced their challenges with hope and humor as opposed to focusing on loss. Third, they gave thanks through life review and cited personal growth from the illness, including preserving their identity.

Education and training in dementia care must emphasize the obligation we have to maintain not just the basic biological and physical needs of people with dementia, but also the higher needs—social activity, sense of belonging, self-esteem, and meaning in life. Maslow's hierarchy of needs has been adapted for dementia and serves as a reminder that care must focus on more than basic needs.<sup>4</sup>

While I am not trying to romanticize dementia, these studies indicate that how dementia is managed has a significant impact on how people with dementia perceive themselves and their life. As physicians, the care we provide must recognize personhood. As citizens, we should advocate for community services and facilities that allow people to continue to lead meaningful lives. While there

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currently is no cure for dementia, we can positively influence the lives of people living with the disease.

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**Tools for tracking down guidelines**

Locating clinical practice guidelines can be challenging. Many are simply posted on the Internet rather than being published in scholarly journals; thus, they escape the notice of medical databases such as Medline. Additionally, the US National Guideline Clearinghouse ([www.ahrq.gov/gam/updates/index.html](http://www.ahrq.gov/gam/updates/index.html)) was shut down in 2018 after US federal funding was cut. So what is left? Here are some recommended sources.

**CMA CPG Infobase** ([www.cma.ca/En/Pages/clinical-practice-guidelines.aspx](http://www.cma.ca/En/Pages/clinical-practice-guidelines.aspx)) is a free directory of guidelines from the last 5 years by Canadian health organizations. Given that the small number of Canadian clinical practice guidelines can be hard to find in the larger volume of international content, a Canadian source such as this is crucial.

**ECRI Institute.** The ECRI Institute is building a free directory of clinical practice guidelines, the ECRI Guidelines Trust (<https://guidelines.ecri.org>). US National Guideline Clearinghouse records were not made available, so the new directory must be built from the ground up. The directory includes summaries and links to full-text documents, and ratings on trustworthiness. Free registration is required.

**International Guideline Library.** The International Guideline Library ([www.g-i-n.net/library/international-guidelines-library](http://www.g-i-n.net/library/international-guidelines-library)) is a public directory from the not-for-profit Guidelines International Network. The linking function requires a membership, but consider using

the site as a search tool and then locate the full-text guidelines using a title search in Google, or ask your library for a copy.

**College librarians are available to locate guidelines for registrants of the College of Physicians and Surgeons of British Columbia.**

**Medline.** While incomplete, Medline remains a worthwhile site for locating clinical practice guidelines. Using PubMed.gov ([www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)), in the search results, limit the Article Types to “Guideline.”

**National Institute for Health and Care.** Results from the UK’s National Institute for Health and Care Excellence’s Evidence Search ([www.evidence.nhs.uk](http://www.evidence.nhs.uk)) can be filtered for guidelines.

Finally, explore the guidelines cited in point-of-care tools such as DynaMed, UpToDate, or BMJ Best Practice, and try using Internet search engines such as Google.

College librarians are available to locate guidelines for registrants of the College of Physicians and Surgeons of British Columbia. You are invited to call the library at 604 733-6671 or email [medlib@cpsbc.ca](mailto:medlib@cpsbc.ca).

—Karen MacDonell  
Director, Library Services

*This article is the opinion of the Library of the College of Physicians and Surgeons of BC and has not been peer reviewed by the BCMJ Editorial Board.*