

New tool helps predict risk of death, admission to long-term care for people with dementia

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A new tool that predicts risk of death and admission to a long-term care facility for patients with dementia may help conversations between

health care providers, patients and their families, according to new research in *CMAJ (Canadian Medical Association Journal)*.

The recent tragic outbreaks of COVID-19 in long-term care homes highlight the need to have care discussions with residents and their caregivers.

"The majority of residents in long-term care homes have been diagnosed with dementia. Our study shows that the survival of many people with dementia is poor. It may be that many would choose care that focuses on comfort care and [quality of life](#) should they become acutely ill," says Dr. Peter Tanuseputro, a [family physician](#) and researcher with the Bruyère Research Institute, the Ottawa Hospital Research Institute and ICES, Ottawa, Ontario.

"We have developed a tool that asks simple questions about a person at the time of dementia diagnosis and translates it to the chance of dying and of entering a nursing home over the next 5 years. This information can be used in conversations about what to expect," says Dr. Tanuseputro. "For newly diagnosed dementia patients and their families, personalized information about their trajectory may be helpful to plan for the future, including [advance care planning](#) and planning for additional supports."

The study used linked data from ICES on more than 108 000 people living in the community in Ontario who were newly diagnosed with dementia from 2010 through 2012.

Researchers found that more than half of individuals (55%) died within 5 years—comparable to many cancers—and almost half of those who died (28%) lived in institutions. Only 1 in 4 people were still alive and living in the community 5 years after diagnosis.

Older age, male sex and presence of chronic obstructive pulmonary disease (COPD), [congestive heart failure](#) and [kidney failure](#) at the time of diagnosis of dementia were the most important factors that predicted death and admission to long-term care. The impact of organ failure on prognosis in people with dementia has not been well documented in other studies.

The researchers used data from the paper to develop an online dementia calculator <https://www.individualizedhealth.ca/dementia-tool>.

Dementia is a progressive, life-limiting illness, and personalized information about survival and potential transition into long-term care facilities like nursing homes can help patients and care providers with prognosis and planning. This is, however, not always done, perhaps partly because easily accessible tools have not been available. The global prevalence of dementia is increasing and is expected to triple by 2050.

"For patients, families and caregivers, these conversations can be difficult and too often they don't happen at all," says Dr. Tanuseputro. "If we can help patients and families understand what is likely to happen to their health, and what the next few years may hold, it can help with planning, perhaps provide some peace of mind, and ensure they maximize the quality of life remaining."

A related ICES infographic will be available on publication here <https://www.ices.on.ca/Publications/Infographics>.

"Five-year risk of admission to long-term care home and death for [older adults](#) given a new diagnosis of [dementia](#): a population-based retrospective cohort study" is published April 20, 2020.

More information: *Canadian Medical Association Journal* (2020). www.cmaj.ca/lookup/doi/10.1503/cmaj.190999

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