



Understanding Health Care Trajectories of People Living With Dementia

Summary based on: Canadian Institute for Health Information. (2024). A Step Toward Understanding Health Care Trajectories of People Living With Dementia. Ottawa, ON: CIHI. ISBN 978-1-77479-250-6. Available at: <http://www.cihi.ca>

Overview

This report, published in 2024 by the Canadian Institute for Health Information (CIHI) in collaboration with the Public Health Agency of Canada (PHAC), examines the health care trajectories of people living with dementia across several Canadian provinces. It builds on the 2018 CIHI report 'Dementia in Canada' and supports the implementation of Canada's national dementia strategy through the Enhanced Dementia Surveillance Initiative. The analysis uses CIHI data to follow individuals for five years after their first recorded dementia diagnosis, focusing on home care and long-term care data.

The report identifies key patterns in health care usage, caregiver experiences, and socio-demographic influences on care pathways. It highlights that dementia trajectories are not uniform but vary depending on health needs, available supports, and systemic factors. By providing insights into diagnosis, home care, long-term care transitions, and hospitalizations, the report informs service planning, policy development, and caregiver support initiatives.

Key Points

- Two-thirds of people living with dementia (67%) had their first record of dementia during an encounter with a family doctor/general practitioner.
- Family doctors play a crucial role in diagnosis and ongoing dementia care, but many report feeling under-resourced.
- Four main health care trajectories were identified: living at home with home care, moving to long-term care after home care, moving to long-term care without home care, and living at home without home care.
- 58% of individuals received publicly funded home care, with almost half of them later transitioning to long-term care.

- Caregivers of people with dementia are more likely to experience distress, anger, or depression compared with caregivers of individuals without dementia.
- Hospitalizations frequently precede both home care initiation and long-term care admissions.
- People living with dementia and concurrent mental health or substance use disorders face greater barriers in accessing appropriate services.
- Excess health care costs attributable to dementia are significant, especially in the year prior to death, with hospital admissions and long-term care being the largest contributors.

Health Care Trajectories of People Living With Dementia

Overview

CIHI & PHAC 2024 report on dementia care in Canada
 Analyzes 5-year trajectories after dementia diagnosis
 Focus on home care, long-term care, and hospital use

Key Findings

67% first diagnosed by family doctors
 4 main trajectories: home care, LTC after home care, LTC without home care, at home without care
 58% received home care; nearly half later moved to LTC
 Caregivers experience higher distress and burnout
 Hospitalizations often precede care transitions
 Mental health & substance use disorders add barriers
 Excess health care costs highest in year before death

Implications

Family doctors play central role in dementia care
 Need for stronger caregiver support
 Support systems need to match each family's unique situation.

This brochure is part of ClarityPath's commitment to supporting caregivers and healthcare professionals with accessible, evidence-informed resources.

Visit <https://claritypath.ca/> for more tools and resources.
