



# Meaningful connections in dementia end of life care in long term care homes

## Lead Author

Lynn McCleary, Brock University

## Co-authors

Genevieve Thompson, University of Manitoba  
Lorraine Venturato, University of Calgary  
Abigail Wickson-Griffiths, University of Regina  
Paulette V. Hunter, University of Saskatchewan  
Tamara Sussman, McGill University  
Sharon Kaasalainen, McMaster University

This project was funded by the Canadian Institutes of Health Research.



**CIHR IRSC**  
Canadian Institutes of Health Research Institut de recherche en santé du Canada

## SUMMARY POINTS

- Although individuals with cancer and dementia arguably experience a similar burden of suffering, persons with dementia are less likely than people with cancer to be referred, and thus have less access, to palliative care
- The purpose of this study is to examine and compare family and staff perspectives on end of life care for people with dementia, as well as their family caregivers, who live in long-term care (LTC) homes
- We explored how end of life care is currently being provided to those with dementia, what facilitates the provision of care, and what challenges are experienced by staff and family caregivers

## HOW WAS THIS STUDY DONE?

- This descriptive qualitative study was conducted during baseline data collection for a larger, multi-site investigation of a program geared towards enhancing end-of-life care in LTC homes
- Multiple focus groups were conducted at each LTC home
  - At each LTC site, one focus group at each site consisting of relatives of residents enrolled at the LTC home
  - Additionally, thirteen focus groups consistently of staff were held (approximately 3 or 4 were led in each of the four LTC homes)

## KEY FINDINGS

- Three themes emerged from the focus groups that were conducted: (1) the importance of knowing the resident, (2) they are all human beings, and (3) the long, slow decline and death in dementia
- Existing rituals for marking deaths in LTC homes may not fit the ends of individuals dementia after the death of another resident
- Our research highlighted the need to support staff in answering questions asked by residents' relatives in order to comfortably inform them about the trajectory of their family member's dementia and eventual death