

# Dementia and End of Life Care

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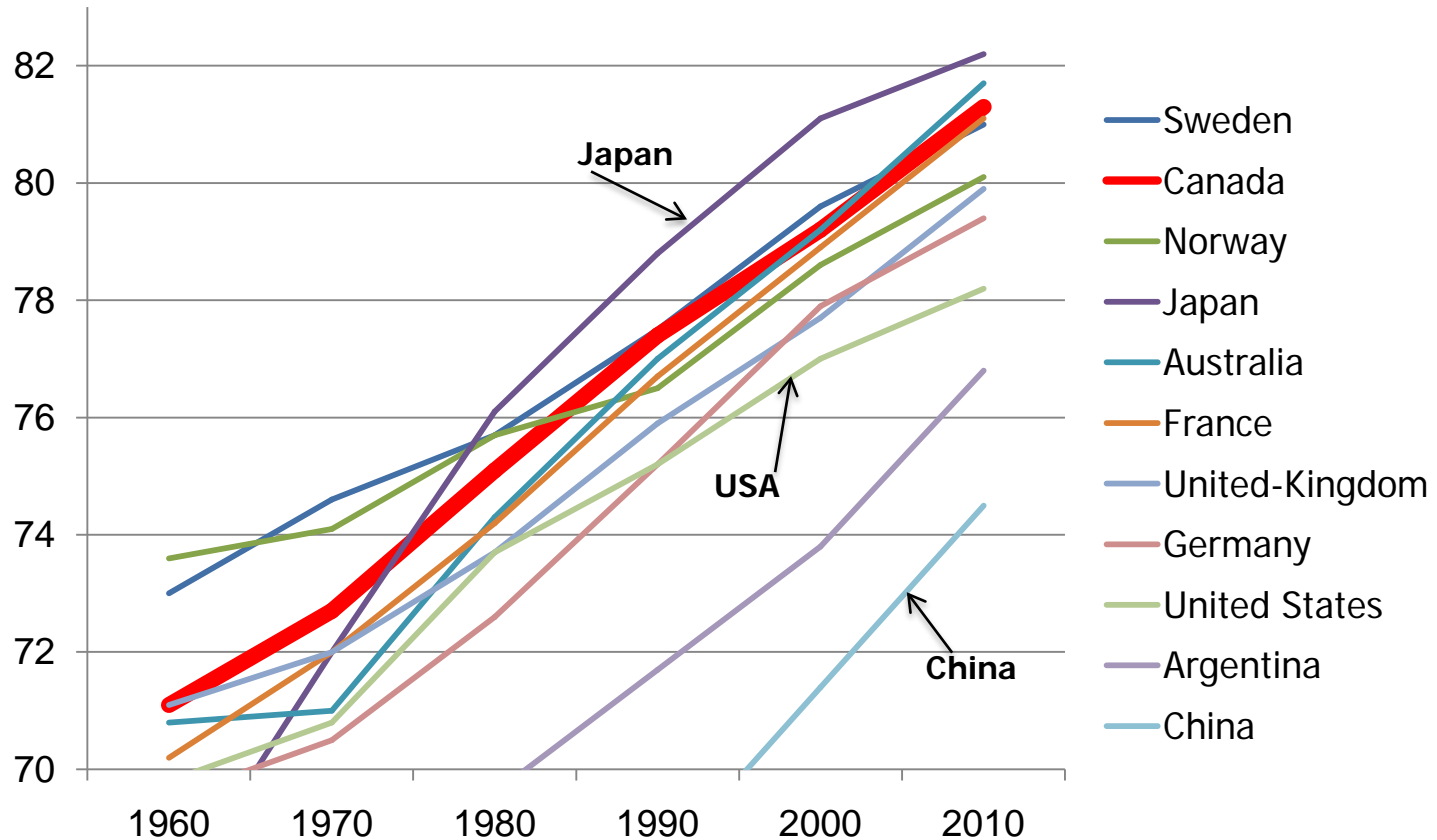
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## Policy Issues

- **Managing transitions well (to and from facilities, emergency department use)**
- **Advanced care planning, including family/caregiver preparedness**
- **Education and training for workforce (symptom management, medication use, psycho-social support)**
- **Access to palliation early in the trajectory**
- **Support systems for the family and other unpaid caregivers during the LTC stay**
- **After death support for caregivers and staff**

# Life expectancy over a half century 1960 – 2010

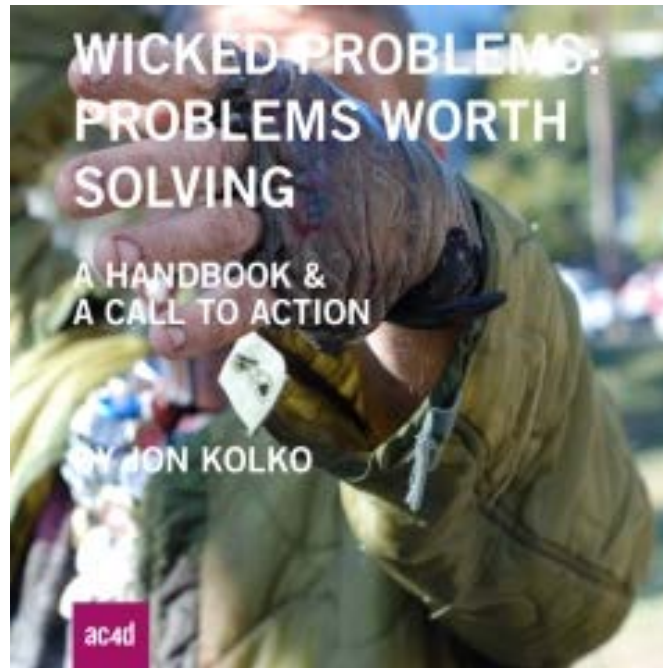


**In 2015 for the first time in Canadian population history the number of people over 65 will exceed the number of children under 15**

## With longer life....

- ✧ Increasing numbers of Canadians with Alzheimer's and other age-related dementias (ARD)
- ✧ One in three Canadians over 85 now has an age-related dementia (over one million by 2038)
- ✧ Currently 36 billion people living with dementia – a new case every 4 seconds

## Dementia is a “wicked” problem



Appropriate end of life care for those with dementia is an “especially wicked” problem, one that demands both health and social innovation

# Residential LTC / Nursing Homes

**Better community and supportive living options delay admission to nursing home**

**Eventually however, care needs overwhelm supports – the most common reason for admission is that caregivers are unable to cope with increasing care demands**

**e.g.,**

- 1. need 24 hr. care**
- 2. safety issues**
- 3. challenging behaviours**
- 4. caregiver has failing health**
- 5. personal care/hygiene issues**

## **Older adults admitted to residential LTC ....**

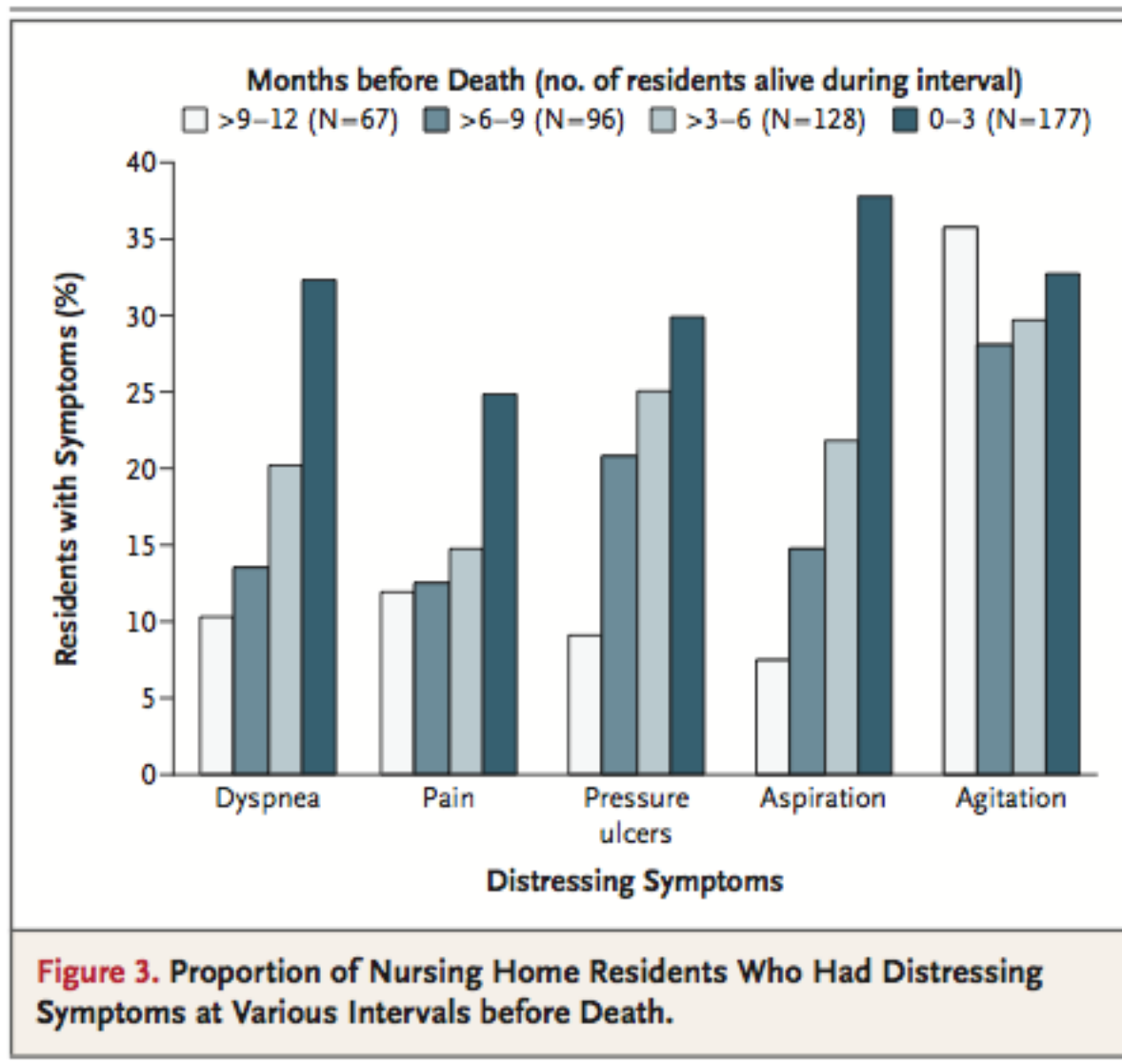
- Arrive late in the course of the dementia, often with multiple other conditions (e.g., diabetes, COPD)
- Are highly complex, highly vulnerable, with heavier care demands
- Stay much shorter periods of time than in the past making LTC increasingly about the end of life care

**The goal of care or a major goal of care in  
nursing homes**

**... must then be optimal end of life care**




## Less than optimal end-of-life care: Distressing symptoms



Mitchell et al., The Clinical Course of Advanced Dementia. NEJM. 2009: 361(16).

**TREC is an applied research program conducted in residential LTC and in partnership with stakeholders.**

**It aims to develop practical solutions for:**

- 
- improving quality of care for residents
  - improving quality of life for residents
  - Improving quality of end of life for residents
  - quality of work-life for caregivers
  - enhancing system effectiveness and efficiencies

# Partnerships help us design

## System Projects



- Early signal system

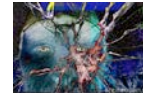


- End of life trajectories



- Responsive behaviours of dementia

## Trainee projects



- Pain



- Depression



- Oral health

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# The faces of dementia

