New Care Models: Creating Dementia Friendly Environments in Long Term Care

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Presentation to the Newfoundland & Labrador Centre for Applied Health Research (NLCAHR) Research Exchange Group on Aging
Overview of Presentation

• My background
• Overview of Dementia
• Strengthening Seniors Care – recommendations on seniors care particularly on dementia
• Dementia Care Models
• Dementia Friendly Care Homes
My Background

• Born in Calgary, Alberta
• Policy Work – close to 20 years in health policy
• Graduate of University of Alberta (Bachelors); MPA (Queen’s)
• Ontario Ministry of Health and Long Term Care – Policy Analyst Intern
• BC Medical Association (now Doctors of BC) – Research Analyst
• Alberta Health (Senior IGR Analyst)
My Background

- BC Ministry of Health – Senior Policy Analyst
  - Intergovernmental Relations
  - Seniors Directorate (in response to Ombudsperson report on seniors care)
- Director of Policy and Research at BC Care Providers Association (BCCPA)
  - Industry association for non-government care continuing care providers (LTC, AL, HC and IL)
  - Policy Documents on BCCPA Website ([https://bccare.ca/policy/](https://bccare.ca/policy/))
Facts on Dementia

• Alzheimer’s disease is most common form of dementia — approximately 64 per cent of Canadians who have dementia have Alzheimer’s

• Currently there are 747,000 Canadians living with Alzheimer's disease and other forms of dementia. Number expected to increase to 1.4M by 2031.

• BC Dementia Guide (2016): dementia impacts roughly 62,000 British Columbians and is expected to rise to 87,000 by 2024

• In 2014/15, 47% of those with dementia were aged 85 or older, followed by 45% aged 65 to 84, and 8% with early onset under the age of 65
Facts on Dementia

• Dementia currently costs Canada roughly $33 billion per year, both in direct health care expenses and in indirect costs, such as lost earnings of the person’s caregivers. Costs are expected to total $293 billion by 2040.  
  (Alzheimer’s Society of Canada)
  • Majority of care and support for people is provided by caregivers such as family members, friends and/or neighbors.

• USC Leonard D. Schaeffer Centre for Health Policy and Economics (2014): annual per-person cost of the disease (including direct and indirect costs) was $71,000 (US) in 2010 and is expected to double by 2050

• US: age-adjusted death rates for dementia have doubled (30.5 deaths per 100,000 in 2000 to 66.7 in 2017)
Facts on Dementia

• BC Dementia Guide: While the majority of people with dementia continue to live at home (~60 per cent), the other roughly 40% live in long term care

• High rates of patients in Alternate Level of Care (ALC) also have dementia
  • New Brunswick study: one third of hospital beds in two hospitals were occupied by ALC patients (63% had been diagnosed with dementia)

• CIHI Data: Over 60% of residents in long term care have dementia (BC has highest rate at about 65%). About 30% of home care clients have dementia
Acuity Levels of Long Term Care Residents by Province, 2016-17

Figure 5 – Acuity Levels of Long Term Care Residents by Province, 2016-17

Source: CIHI, CCRS (2016-17)
CALTC – Increasing levels of acuity

<table>
<thead>
<tr>
<th>Condition</th>
<th>Prevalence as of 2015-2016</th>
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<tbody>
<tr>
<td>Dementia, including Alzheimer's</td>
<td>61.5%</td>
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<tr>
<td>Diabetes</td>
<td>25.5%</td>
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<tr>
<td>Arthritis</td>
<td>39%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>58.3%</td>
</tr>
<tr>
<td>Heart/Circulation Disease</td>
<td>70.8%</td>
</tr>
<tr>
<td>Gastrointestinal Disease</td>
<td>20.9%</td>
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</tbody>
</table>

% of assessed long-term care residents
Dementia issues in long term care

• High rates overall (CIHI data: 60%+)
• High rates of antipsychotic use (has been some decline over past years)
  • BCCPA has released a couple of best practice guides on ways to reduce antipsychotics
  • Backgrounder on polypharmacy
• High rates of resident on resident aggression (resident to staff – violence prevention)
BCCPA: Care for the Facts

RESIDENT ON RESIDENT AGGRESSION IN RESIDENTIAL CARE

**DEFINITION:**
An act of physical aggression that causes severe harm to another resident in a residential care home.

In 2015, 1% of older adults in Residential Care in British Columbia experienced an act of "Resident on Resident" aggression.

Residential Care Homes by Number of Incidents

<table>
<thead>
<tr>
<th>Number of Incidents</th>
<th>Homes</th>
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<tr>
<td>0</td>
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<tr>
<td>1</td>
<td>48</td>
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<tr>
<td>2</td>
<td>32</td>
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<tr>
<td>3</td>
<td>11</td>
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<tr>
<td>4</td>
<td>22</td>
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</tbody>
</table>

Residential Care Homes with 4 or more incidents had:
- Residents with Behavioral Issues
- Residents with Psychiatric Disorders
- Residents with Poor Cognitive Performance
- Mobile Residents
- Residents who use Wheelchairs
- Staffing Hours per Resident

Severe Aggressive Behaviour
- Personal History
- Nonmedical Factors
- Situational Triggers
- Physical Environment
- Staffing Quality

Reducing Polypharmacy in Residential Care

31% of seniors in Residential Care in British Columbia are prescribed anti-psychotics without a diagnosis of psychosis.

According to the BC Ministry of Health, seniors in residential care are prescribed 9 medications on average.

70% of Canadian seniors use 5 or more medications.

**CURRENT INITIATIVES**

01 **DE-PRESCRIBING BY PHYSICIANS**
Physicians are working with the BC Government to safely reduce the number of medications seniors take through the BC Shared Care Initiative.

02 **BCCPA 2013 BEST PRACTICE GUIDE**
Outlines how to safely reduce anti-psychotic drug use in residential care. Access here. The BCCPA is updating and refreshing this resources for 2017.

03 **CALL FOR LESS ANTI-PSYCHOTICS IN RESIDENTIAL CARE**
Government-Care Home Partnership to reduce the use of anti-psychotics in Residential Care

https://bccare.ca/care-for-the-facts/
Use of antipsychotics in long term care

<table>
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<tr>
<th></th>
<th>Ontario</th>
<th>Alberta</th>
<th>British Columbia</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>With dementia</td>
<td>With dementia</td>
<td>With dementia</td>
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<tr>
<td></td>
<td>Without dementia</td>
<td>Without dementia</td>
<td>Without dementia</td>
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<tr>
<td>2011</td>
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<td>40%</td>
</tr>
<tr>
<td>2012</td>
<td>35%</td>
<td>33.5%</td>
<td>35%</td>
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<tr>
<td>2013</td>
<td>32%</td>
<td>31%</td>
<td>32%</td>
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<tr>
<td>2014</td>
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<tr>
<td>2015</td>
<td>30%</td>
<td>29%</td>
<td>30%</td>
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BCCPA: Strengthening Seniors Care

• Released in January 2017
• 30 recommendations to Strengthen Seniors Care in British Columbia
  • Based on two earlier White Papers (new Care Models and funding / financing of seniors care) – issues around staffing, funding, improving quality of life, EOL care, dementia, etc.
  • 180+ pages
Dementia recommendations

• Establish Residential Care Infrastructure Fund (RCIF)
  • Enhancements for improving dementia friendly environments
• Support development of Continuing Care Hubs to reduce acute care congestion, ER visits but also provide better care for frail elderly and seniors with chronic conditions and dementia
  • Model first advocated in 2015 (integrating long term care)
Accommodation
Development and maintenance of resident’s Care Plan
Clinical Support Services
Ongoing, Planned Physical, Social and Recreational Activities
Meals, Meal Replacements and Nutrition Supplements
Laundry Service
General Hygiene Supplies
Routine Medical Supplies
Medication supervision
24-hour surveillance
Professional nursing care and/or supervision
Incontinence Management
Any other specialized services

* All services currently provided in 24/7 long term care model
* Could be physically co-located (i.e. Continuing Care Campus or Campus of Care) or provided as part of virtual affiliated network of care homes
* No one size fits all – services provided will differ based on expertise and needs of the community

**New Services Offered**

* Expanded adult day programs
* Use of physical infrastructure to provide community services for seniors
* Respite care for frail elderly
* Physical co-location of urgent care or sub-acute
* Expanded sub-acute care and paramedic services (i.e. wound care, dialysis and IV care)
* Greater preventative and health promotion services (i.e. CDM and frailty screening)
* Expansion and integration of end-of-life care as well as palliative / hospice care
* Expanded pharmacy services and medication management
* Expanded mental health services for seniors including dementia care
* Provision of some diagnostic and laboratory services (X-rays, blood tests etc.)
* Provision of supplemental care services (i.e. dental, oral, optical and foot care, etc.)
* Expanded rehabilitation and recovery care (i.e. OT/PT and post-operative care)
* Use of technologies to link with care homes particularly to rural areas
* New funding models (outcome-based funding)
* New roles for care providers (creation of new care aide roles and multidisciplinary LTC team)
* Integration of health professionals (Nurse Practitioners, Physician Assistants / Paramedics and family in seniors care)
Dementia recommendations

• Funding for BC Behavioral Supports program to provide training and resources to improve dementia care
  • Based on Behavioral Supports Ontario (BSO)
• BSO program hires and trains specialized staff teams to help reduce behavioural symptoms and improve QoL of residents with dementia in LTC (OLTCA, 2018)
• BSO teams support frontline staff at designated care homes by engaging them in dementia education, training, and problem-solving to manage challenging behaviours
• Training and education offered by BSO teams have been reported by care home staff as contributor to feeling significantly more supported (less use of antipsychotics, etc.)
Dementia recommendations

• Advancement of National Dementia Strategy with fed. participation

  • BCCPA and CALTC CEO on national dementia panel
  • CALTC – fed government invest in construction, renovation and retrofit of 400 long-term care homes to meet current design standards and needs of today’s seniors, especially those with dementia, by 2023

• Seniors Quality of Life Fund

• Development of a National Seniors Health Promotion Strategy (promote senior health and well being)

  • Health promotion and prevention is critical (smoking, diabetes and hypertension can increase risk of dementia)
  • Seniors Isolation
Pro-active / preventative dementia focus can reduce demand for LTC

- UCLA Alzheimer's and Dementia Care Program (*JAMA Internal Medicine*, Dec 21, 2018)

- Comprehensive, coordinated care program for PWD and their caregivers significantly decreased likelihood individuals would enter nursing home – ~40% reduction (reduced Medicare costs)

- UCLA program – PWD and caregivers meet with a nurse practitioner specializing in dementia care for a 90-minute in-person assessment and receive personalized dementia care plan to address medical, mental health and social needs

- BC First Link Program – Alzheimer Society of BC
Dementia recommendations

National or Provincial Dementia strategy

• Explore where appropriate new care models or initiatives to support seniors with dementia including but not limited to dementia villages, butterfly care homes and dementia friendly communities

• Advocate using RCIF to support retrofitting existing care homes (dementia friendly care homes)
Senate Committee report on dementia (2016)

- Recommends that the federal government invest $540 million in continuing care infrastructure to increase the capacity for long-term care.

- Training and professional development with respect to aging and dementia care.

- Models of dementia care that integrate healthcare delivery, such as the Dementia-plus Care Model; integration of social services into dementia care.
Priorities for National Dementia Strategy

- Engaging persons living with dementia
- Prevention, awareness and living well with dementia
- Improving health and social care for persons living with dementia
- Education and support for caregivers
- Building and supporting the health and social care workforce
- Creating and translating knowledge on dementia
- Supporting research and innovation in all stages of dementia

Models of Dementia Care: Dementia Villages

- Village of Hogeweyk (20km from Amsterdam, Netherlands)
  - Opened 2007; first established Dementia Village; over 150 seniors living with severe cases of dementia
  - Creates an alternate reality for seniors who are encouraged to roam around the confines of the village

- 20+ residential units shared by 6-8 seniors each, home-like environment for seniors (seven options available such as artisan, Indonesian, and cultural)

- Caregivers and Geriatric nurses monitor and provide seniors with care as “villagers” in street clothes, administering medicine, cooking meals and planning activities

- High staff numbers: one health-care worker on site at all times to help with cleaning and other necessary tasks
Models of Dementia Care: Dementia Villages

- Each resident has own bedroom and is free to stroll through the village, and visit the stores and cafés.
- Attempts to create sense of normalcy as well as reduce the confusion and sadness (clinical settings).
- Positive outcomes: administered less medication; more active lifestyle, increased lifespan, etc.
- Antipsychotics: 50% of residents in 1993 were given antipsychotic drugs compared to 8% in 2015.
Dementia Village

• Hogeweyk (Dementia Village) received over 1,400 visitors in 2017

• May not be mainstream model for dementia care

• High costs: €6,000 ($9,100 CAD) monthly cost for each resident; Netherlands: 4.3% of its GDP on long-term care (highest OECD)

• BC is also developing several dementia villages – two in Vancouver Lower Mainland and one on the Island

• In January 2019 - Providence Health Care announced development of second dementia village [http://thedailyscan.providencehealthcare.org/2019/01/dementia-village/]
Models of Dementia Care: Dementia Villages (Videos)

**Dementia Care by Design**

http://dementiacarebydesign.com/

A special ‘neighborhood’ for people with dementia

https://globalnews.ca/news/2362492/a-special-neighbourhood-for-people-with-dementia/

**Ted Talk: Yvonne van Amerongen**

https://www.ted.com/talks/yvonne_van_amerongen_the_dementia_village_that_s_redefining_elder_care
Models of Dementia Care: Butterfly Care Homes

- Uses many of same care approaches as the dementia village
- Initial introduction at Merevale House in Atherstone, UK in 1995 (care home for 36 people living with a dementia)
- Founder: David Sheard, Dementia Care Matters
- Spread across UK but other countries including Ireland, Australia and most recently Canada
- November 2018: 30+ care homes adopting this model - 24 in the UK, seven in Canada (Alberta and Ontario), three in Australia and one in the US
Models of Dementia Care: Butterfly Care Homes

• Model of Care rests on belief that for people experiencing dementia, feelings matter most, that emotional intelligence is the core competency

• That “people living with a dementia can thrive well in a nurturing environment where those living and working together know how to “be” person centred together
Butterfly Care Homes

- Home is split into a number of small living spaces for people experiencing dementia, instead of being one ‘unit’
- Workers are trained to express empathy and spend time with people, rather than rushing from one task to the next
- Bright living environment (i.e. walls painted in fuchsia, tangerine and neon green to help people feel their spirit is alive)
Butterfly Care Homes

• Removing barriers between residents and staff: no uniforms, no nursing stations, no drug trolleys, residents and staff eat together

• Hiring right staff: Emotional Intelligence

• Fill the place with life: from sterile clinical environment to one with energy and more home-like feeling
Butterfly Care Homes

• Removing ‘us and them’ – no uniforms, no separate staff toilets, no nursing stations
• Creating family-like household living – where House Leaders and Housekeepers are the real heart of each household home
• Joining people in their reality – helping people to be who they were in their past experiences
• Home-like administration of medication – with individual drug cabinets in people’s own bathrooms
Butterfly Care Homes

• Matching – grouping people together in ‘houses’ at a similar point of dementia experience
• Relaxing routines – freeing up the staff team, by giving them permission to be with people
• Fostering team work to still flexibly achieve the discreet running of the home
• Turning all staff into butterflies - all staff see their role as a butterfly, creating moments fleeting between people, adding colour to people’s lives
Butterfly Care Homes

• Initial evidence has shown Butterfly Care model has improved quality of care for those with dementia, increased health and safety outcomes

• Falls – 43% reduction in incidents
• Expressions of behavior – 58% reduction in incidents
• Weight gain – 15-18% increase
• Positive interactions – 81% increase
• Use of PRN (as needed) medication – 100% decrease
• Use of PRN pain relief – 100% decrease
• Sustainability – 90% achievement
Models of Dementia Care: Butterfly Care Homes (Videos)

We are Family
• [https://www.youtube.com/watch?v=4gcaElkEFFfE&app=desktop](https://www.youtube.com/watch?v=4gcaElkEFFfE&app=desktop)

Transformation of Peel Region's Redstone dementia unit
• [https://www.youtube.com/watch?v=aYrMu3ujs-Y](https://www.youtube.com/watch?v=aYrMu3ujs-Y)

Interview with BCCPA
• [https://bccare.ca/2016/06/bccpa-interview-dr-david-sheard/](https://bccare.ca/2016/06/bccpa-interview-dr-david-sheard/)
City of Toronto Report

Nursing homes could get big benefit from emotion focused care home models

(March 8, 2019 Toronto Star)

Household Model of Care

• Various models: dementia village, butterfly care homes, etc.

• Literature has shown that people living with dementia experience better quality of care in home-like, clustered accommodation models

• Home-like, clustered domestic models of care are associated with better quality of care, specifically in regards to providing access to the outdoors and flexibility of care

• Research from Australia: home-like models (smaller groups of up to 15 residents) are delivering better outcomes for a comparable cost
  • Less likely admitted to hospital or transferred to and ED
  • 52% less likely to be prescribed a potentially inappropriate medication
Challenges implementing new models

- Funding (minimal extra funds to support change)
- Regulation (excessive or inflexible regulations)
- Staffing challenges (lack of providers)
- Resistance to fundamental change (status quo)
- Education and training
- Need better evidence
- Better define person-centred care / quality of life
Dementia Friendly Care Homes

Creating Dementia-Friendly Care Homes in B.C. (December 2018)
Dementia Friendly Care Homes

Builds on idea of dementia friendly communities

• Alzheimer Society works closely with municipalities, professional groups, corporations and individuals to reduce stigma and remove barriers to support PLWD to participate fully in communities and continue to enjoy activities that are meaningful

BCCPA White Papers and Strengthening Seniors Care

• In partnership with relevant stakeholders including care providers, health authorities and the Alzheimer Society of B.C., the provincial government explore establishing a dementia-friendly program in which a designation could be provided to care homes that have made specific redesign changes to accommodate people living with dementia and/or where dementia training has been provided to staff

• Investments in physical infrastructure as well as training and education
Dementia Friendly Care Homes

• Research partnership between BCCPA, Alzheimer Society of BC and Simon Fraser University (SFU)
• Examine what other jurisdictions in Canada and internationally have done, or are doing, to develop dementia-friendly criteria or guidelines in long-term care
• Three key features or elements of DFCH: 1) intentionally utilize dementia-friendly design, 2) put emphasis on ensuring staff have appropriate dementia education and training, & 3) intended to feel home-like, rather than institutional
• A 2017 study noted that supportive environments can have a number of positive effects PLWD in LTC
  • Helping people stay oriented, improving daily activities, promoting autonomy and meaningful activity, reducing anxiety, agitation and falls as well as providing better person-centred care
Dementia Friendly Care Homes

• Study is largely focusing on two areas: 1) physical infrastructure / living environment and 2) staffing (including education and training)

• **Physical infrastructure**: create environments that are distinctive, safe, and familiar to seniors (i.e. as are well-lit, avoiding reflective and slippery floor surfaces, and providing easy-to-use furniture and distinctive landmarks to assist with navigation).

• Many care homes are outdated and need to be update (dementia friendly designs, larger living spaces, increased privacy, etc.)

• **Staff education and training**
  • Butterfly care approaches
  • Ontario: Behavioral Supports Ontario
  • Gentle Persuasive Approaches (Safe Care BC and ASBC – Creating Connections, P.I.E.C.E.S)
Dementia Friendly Care Homes

• Extensive literature review
• Consultation process to include a DFCH forum event which will bring stakeholders together to inform the development of criteria and principles for B.C (late April)
• May also explore the challenges as well as pros and cons of developing a DFCH program or designation in B.C. context
• Assist current and future care homes in using or implementing promising practices to become more dementia-friendly
• Workshop at BCCPA Conference (late May); release paper in summer or fall of 2019
Dementia Friendly Care Homes: Initial Findings

• Grey literature search of relevant documents (UK, Australia, Canada – Ontario and Alberta)
  • 156 documents identified (86 for final review)
  • Focusing on: 1) staffing, education and training and 2) physical infrastructure
  • SALTY Project (Dr. Janice Keefe, Nova Scotia)

• Key highlights:
  • Need to better clarify what is meant by person-centred care, needs to be evidence based
  • Training and education programs are critical (all staff, not just those involved with direct care)
  • Cultural competency
  • Involvement of family members
Dementia Friendly Care Homes:
Key Highlights from staffing perspective

- Involvement of direct care staff in care planning and decision-making
- Use of innovative teaching techniques (virtual reality) and online decision support tools
- Dementia champions in care settings was considered as valuable
- Increasing staff levels including minimizing turnover
- Delivery of outcome-focussed care rather than task-focused care
Dementia Friendly Care Homes: Key Highlights from physical infrastructure / environment perspective

• While designing within larger buildings, strategies to create small groupings of residents should be adopted.

• Signage should contain least possible amount of information thus preventing cognitive overload.

• Consistent colours of doors and signs for spaces with similar functions across units and bays.

• Circular hallways, free of clutter, may be more effective than long, narrow corridors, for less confusion and better wayfinding.
Dementia Friendly Care Homes: Key Highlights from physical infrastructure / environment perspective

- Common spaces like kitchen, dining, and activity areas should be located in close proximity
- Avoid multi-purpose rooms as may be difficult for PLWD to cope with changes that may occur in space with differing functions
- Interior elements should convey domestic character. (i.e. use of warm colour schemes, favouring material finishes such as carpeting, wood, upholstery, and different styles of furniture, lighting, as well as an abundance of details, artwork, and accessories)
- Access to outdoors provides residents opportunity for physical exercise and exposure to sunlight, which in turn helps regulate residents’ sleep cycle
Dementia Friendly Care Homes: Baby Steps

• Small changes (baby steps) can make a difference

• Long-term care home (Mt. Cartier Court) in Revelstoke, B.C., helping residents with dementia avoid getting confused by identical-looking doors

• Doors covered with made-to-measure vinyl decals to look like made of different materials (i.e. antique wood, wrought iron or stained glass)

• Cost of $150 per door ($6500)
Summary

• Dementia rates are increasing and significant portion are entering long term care
• Preventative / pro-active (i.e. UCLA program) focus can potentially reduce LTC demand
• Need to look at variety of approaches (including prevention, etc.) but also new care models
• Need to improve dementia care (and quality of life) in LTC
• Variety of different dementia care models
  • Butterfly Care Homes
  • Dementia Villages
  • Other models: Green House models and Eden Alternative
Summary

- Focus less on models as opposed to how care is organized and delivered
- Focus on physical environment and staffing (including training and education)
- Physical environment: modifications to layout (dementia friendly) and household model approach
- Staffing, training and education
  - Necessary skill set (GPA)
  - Emotional Intelligence
- Focus on person-centred care / quality of life
- Dementia Friendly Care Homes (gradual change or baby steps)
Gradual change: Baby Steps

Baby Steps
Small Steps
Equal Sure
Success

Baby steps count, as long as you are going forward. You add them all up, and one day you look back and you’ll be surprised at where you might get to.
Resources

- Senate Committee report on dementia
- Butterfly Care Homes bring humanity to those living with dementia
- Study shows dementia care program delays nursing home admissions, cuts Medicare costs
- CIHI Dementia in Canada: https://www.cihi.ca/en/dementia-in-canada
- CAHS Report:
Resources – BCCPA Website

• BCCPA Papers (Strengthening Seniors Care, etc.)
  https://bccare.ca/policy/

• The Butterfly Effect: Changing Dementia Care in British Columbia

• Dementia care: changing philosophies and a health social movement

• Creating Dementia-Friendly Care Homes in B.C.
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