

Improving the Experience of living in Long  
Term Care for people with dementia:

*“Do I really have to move to the  
Netherlands??”*

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**Saskatchewan Seniors Mechanism**  
**Annual Conference**  
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## Take home messages:

From my earlier conversation with you all:

- Person centred care recognizes each individual as a unique, whole person.
- LTC homes have been built as “mini hospitals”. It is time to move away from a task-focused to a person centred approach.
- Evidence is mounting; there are benefits for everyone from a person centred approach.
- The Alzheimer Society has developed several initiatives to help YOU become more person centred in your approach.



## Take home messages Part II

- Dementia is a set of symptoms that accompanies a disease. Alzheimer’s disease (AD) is the most common form of progressive dementia.
- AD eventually affects all aspects of a person’s ability to function. A LTC home will likely be needed at some point.
- Providing person centred care in LTC requires a “culture change”. There are 7 key elements to providing this care – PC P.E.A.R.L.S.™



## **A Refresher: What is a person centred approach or philosophy?**

- Recognizes that individuals have unique values, personal history and personality.
- Each person has an equal right to dignity, respect, and to participate fully in their environment.
- The ultimate goal of a person-centred approach is to create partnerships among staff, individuals and their families to enhance quality of life and quality of care.
- Services and supports are designed and delivered in a way that is integrated, collaborative, and mutually respectful of all persons involved.



## **Dementia in Canada at a glance**

- Approximately **747,000** Canadians are living with Alzheimer's disease or other dementia.
- More than **70,000** Canadians living with Alzheimer's disease or a related dementia are **under the age of 65**.
- Women make up **72 per cent** of Canadians with Alzheimer's disease.



Within a generation (25 years), the number of people living with Alzheimer's disease or other dementia could reach **1.4 million.**

## **Dementia in Saskatchewan at a glance**

- Today in Saskatchewan, approximately **18,884** people have dementia.
- **By 2038**, over **28,099** Saskatchewan residents will be living with dementia, accounting for 2.3% of the population.
- **65% of people** in Saskatchewan with dementia will be **women**.



## Setting the stage...

- What is **dementia**?
- What is the **difference** between **Alzheimer's disease** and **dementia**?



## **What Is The Difference Between Alzheimer's Disease And Dementia?**

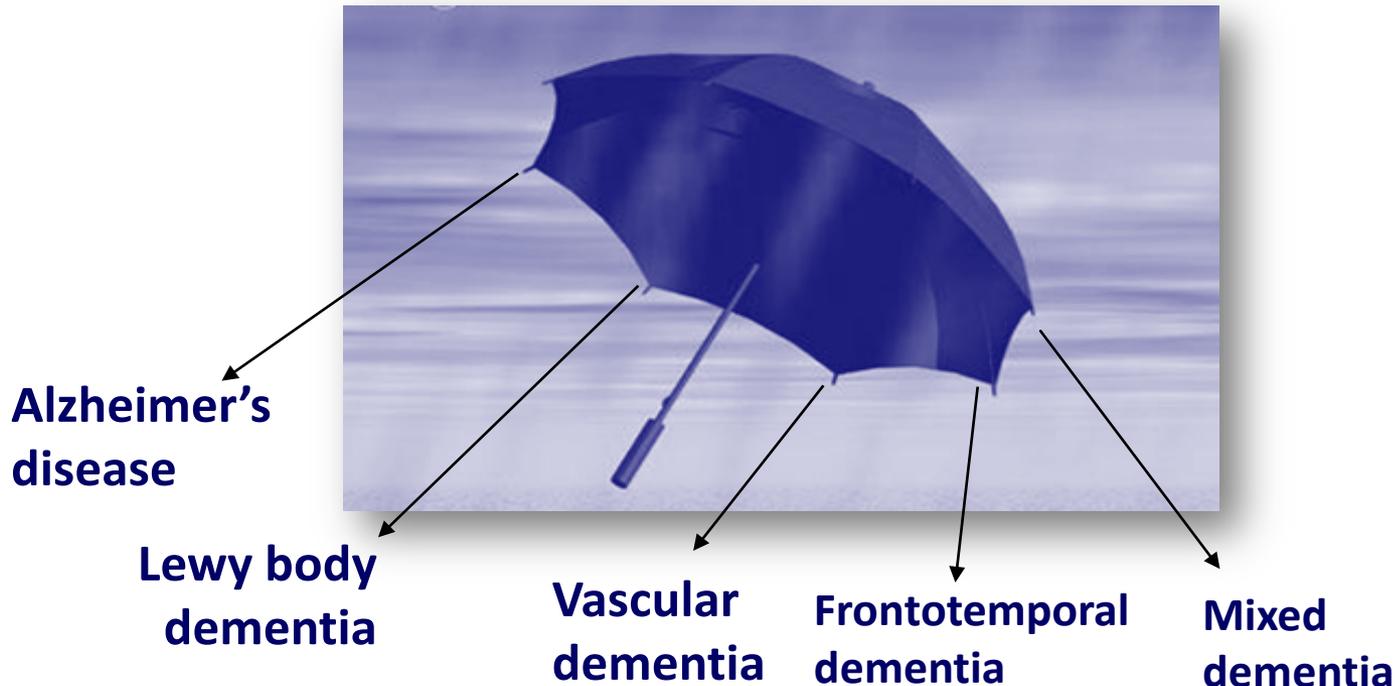
FreeDem Films from the NEIL Programme at Trinity College Dublin

<https://www.youtube.com/watch?v=jBT5FW4qM2U>



# What is Dementia?

Not a disease, but a set of symptoms that accompanies a disease.



# Alzheimer's disease is...

## Progressive

- damage from the disease increases over time

## Degenerative

- brain cells degenerate or break down

## Irreversible

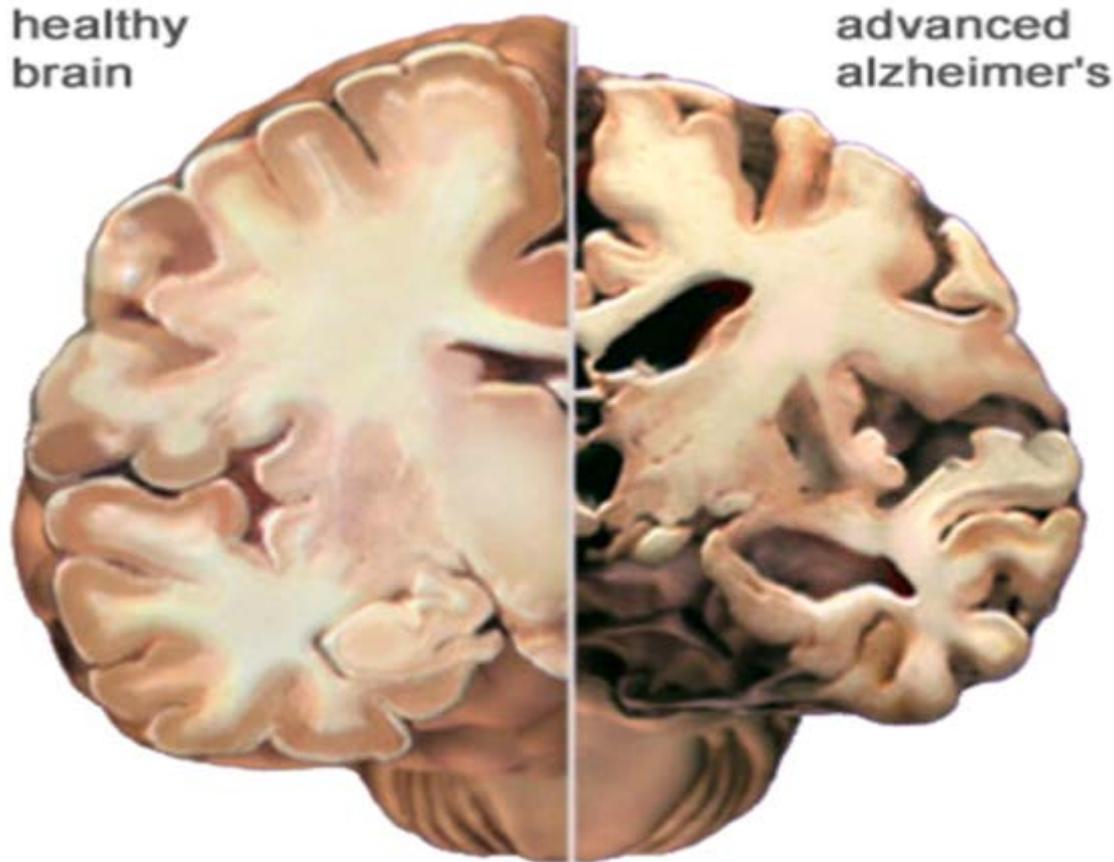
- damage cannot be repaired;
- at present there is no known cure

## More than just memory

- Affects a person's ability to function on a day to day basis



## Healthy Brain vs. Brain with Alzheimer's disease



# Stages of Alzheimer's Disease

Early

Middle

Late

End of Life



## What tends to happen as a person with dementia nears the end of life?

- Profound memory loss, loss of ability to communicate with words
- Loss of facial expressions
- Loss of mobility, inability to sit up or hold up one's head without assistance
- Poor blood circulation (colder hands and feet), blood pressure drops
- Less interested in taking food and drink, weight loss
- Increased sleepiness or agitation/ restlessness
- Increased phlegm and mucus/ secretions
- Senses decrease (vision, hearing)
- Irregular/congested breathing
- Irregular pulse
- Prone to infections



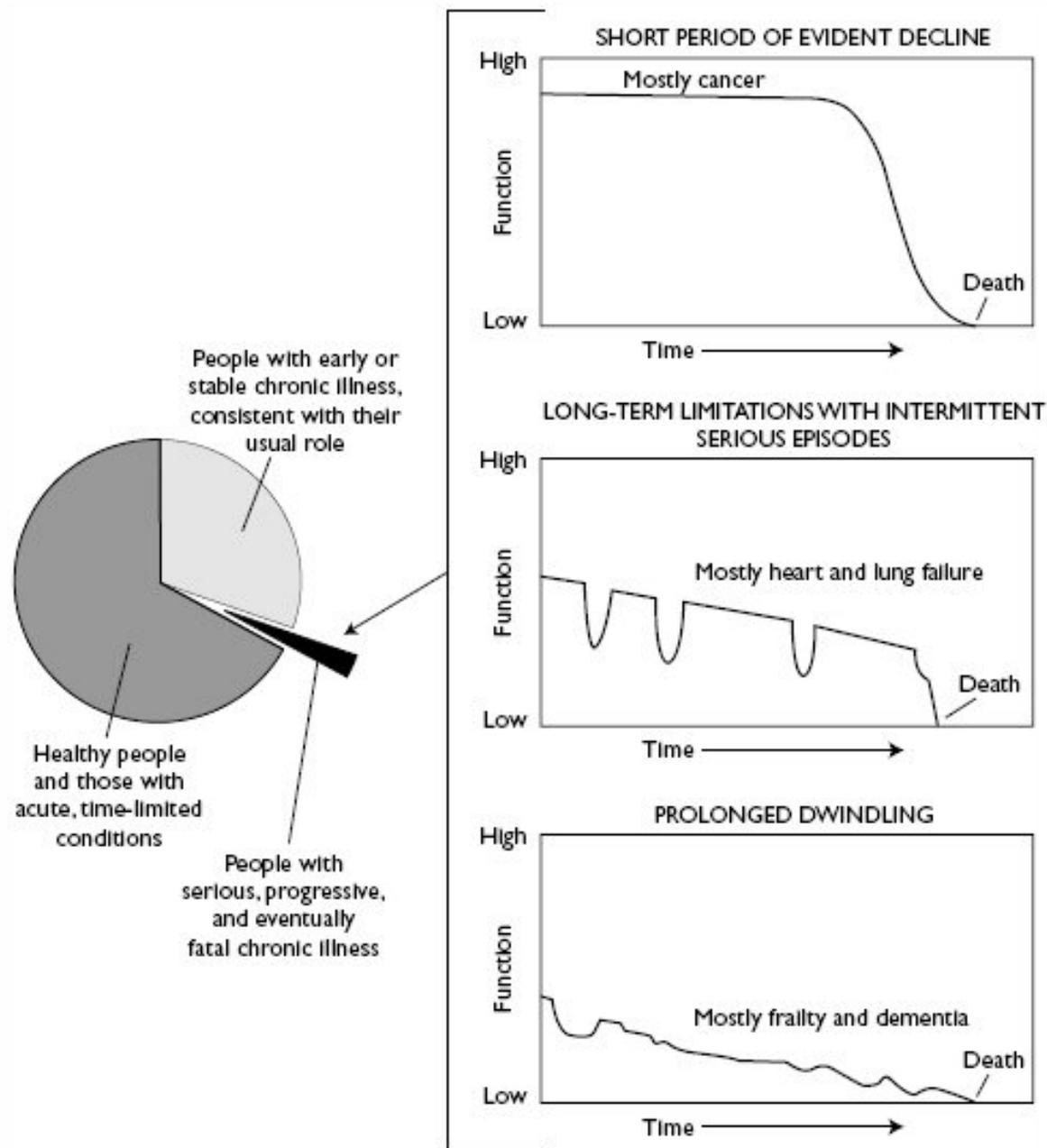


Figure 5. Trajectories of eventually fatal chronic illnesses. Source: Lynn and Adamson 2003.



## What would be a **DIFFERENT** conversation?

- What kind of conversations tend to take up your day?
- How focused on the person are they - really?
- What would you **rather** be talking about to make your resident's day better?



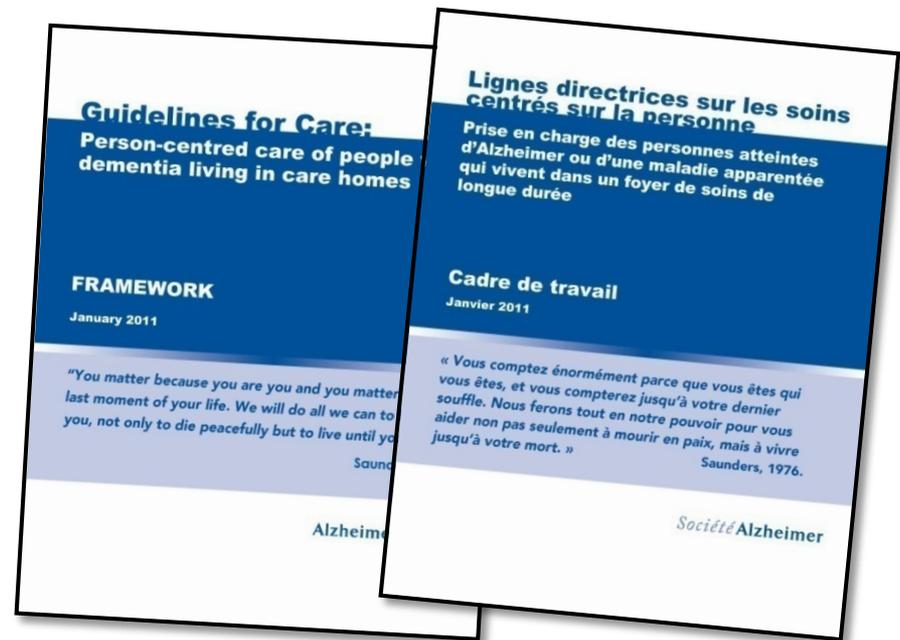
## ASC's Ultimate Goal

That a person-centred approach to care of people with dementia is the **norm** in long term care homes in Canada – not the exception.



# Phase 1: Guidelines for Care

Alzheimer Society of Canada  
***Guidelines for Care:  
Person-centred care of  
people with dementia  
living in care homes***



Full document available for download from the health care professionals section of the Alzheimer Society's website [www.alzheimer.ca/culturechange](http://www.alzheimer.ca/culturechange).



## **Phase 2: Exploratory Qualitative Research in 6 LTC homes**

- Each trying approaches to person-centred care that other LTC homes could duplicate
- Be fairly “typical”
- Representative of
  - geography
  - funding
  - unionized and non
  - urban/rural
  - chains and independently run
  - number of residents



## **7 Essential Elements in Person Centred Care in LTC: PC P.E.A.R.L.S.™**

- **Person and family engagement**
- **Care**
- **Processes**
- **Environment**
- **Activity/Recreation**
- **Leadership**
- **Staffing**





## Person and Family Engagement

Creating and maintaining meaningful and respectful relationships among care home staff, people with dementia and their families can improve the quality of life for all.

- ✓ “tune in” to their reality
- ✓ Use ASC’s “All About Me”
- ✓ Redesign Care conferences to *start* with resident and family concerns – directed by them
- ✓ Family volunteers lead tours



## **2** Care

Effective care planning focuses on each resident's abilities and includes routine pain assessment and management to help the person enjoy an improved quality of life.

- ✓ Use "All About Me"
- ✓ Meaningful engagement in the development of care plans ongoing
- ✓ Innovations in end of life care (dignity shrouds; honour guard; acknowledge staff grief)



## **3** ▶ **Processes**

Embed person-centred care principles into the strategic plan and operational processes to begin and sustain culture change.

- ✓ Decide on PCC initiatives – evaluate with help of researchers
- ✓ Nursing staff involved in non-medical day to day lives
- ✓ Never: “It’s not my job”; “I am going on break now”



## 4 Environment

Working within current regulations and legislation, promote a physical and social environment that supports the resident's abilities, strengths and personal interests and enhances the daily life of people with dementia.

- ✓ More intimate living spaces; remove bumpers from hallways
- ✓ Open, accessible 'nursing stations' – do you really need them?
- ✓ Restraint free
- ✓ Culture of learning

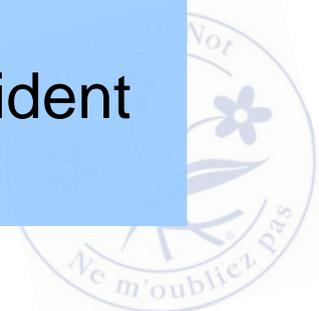


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## Activity/Recreation

Engage each resident in stimulating and meaningful activities, tailoring recreational plans to the person's interests, preferences and abilities.

- ✓ Meaningful activities!
- ✓ Wandering artist program
- ✓ Staffing weekends and evenings
- ✓ Resident driven activities
- ✓ Assess/review/reassess/review constantly in partnership with resident and family





## **Leadership**

Person-centred care can only happen with strong leaders who are champions of person-centred care, ingrain it in their organizational philosophy and values, and model the actions expected of staff in their own interactions with residents, families and staff.



## Leadership Examples:

- ✓ Commitment to PCC everywhere in different media (logos- e.g., sunflower; public statements designed in accessible/readable/interesting ways; staff orientation and ongoing performance review; resident and family orientation)
- ✓ Leaders embrace a person centred approach and if they are not committed to this, seek employment elsewhere
- ✓ Teach and model PCC language (*located under the Culture Change section at [www.alzheimer.ca/culturechange](http://www.alzheimer.ca/culturechange) )*
- ✓ Staff meaningfully involved in decision making (have you asked them what this might look like?)





## **Staffing**

Staff training and support, continuity of care, and the fostering of intimate and trusting relationships between families, residents and staff are key factors in optimizing person-centred care and the well-being of residents.



## Staffing Examples:

- ✓ Hire for attitude- unions engaged
- ✓ Invite a resident to be a coach for staff on how to improve care
- ✓ Consistent staff assignments
- ✓ Extensive ongoing staff orientation to PCC
- ✓ Mandatory ongoing dementia training on all of dementia's impacts on individual and family; demonstrating empathy for the journey they are on



## I'm still not sure...

### Common Misbeliefs:

Person centred care is...

- A nice idea in theory but **not practical** to put into practice
- **Costly** and labour intensive
- Person centred care is a feel-good, “nice to do” – not a “must do”. There is **little compelling evidence** in support of it.



# Commitment to Change

- **P**erson and family engagement
- **C**are
- **P**rocesses
- **E**nvironment
- **A**ctivity/**R**ecreation
- **L**eadership
- **S**taffing



**As a result of what you  
have learned today,  
what are you going to...**

- Start doing?
- Stop doing?
- Continue doing?



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**Culture Change:** [www.alzheimer.ca/culturechange](http://www.alzheimer.ca/culturechange)

**All About Me booklet:** [www.alzheimer.ca/allaboutme](http://www.alzheimer.ca/allaboutme)

**Ambiguous loss and grief:** [www.alzheimer.ca/healthcareprofessionals](http://www.alzheimer.ca/healthcareprofessionals)

**A best-evidence review of intervention studies for minimizing resistance-to-care behaviours for older adults with dementia in nursing homes,** Konno, R. et al, Journal of Advanced Nursing. 70 (10), (2014) 2167-2180.

**Review: Resident outcomes of person-centred care in long term care: A narrative review of international research,** Li, Junxin and D. Porock. International Journal of Nursing Studies. SI (2014) 1395-1415

**Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience,** Edvardsson, D. et al. International Psychogeriatric Association (2014) 1-9

**Using the Newcastle Model to understand people whose behaviour challenges in dementia care.** Jackman L, Beatty A. Nursing older people (2015) Mar 2;27(2):32-39



If I have one message about dementia-related behaviour...it is:

**Assume people are scared. They live in a world that doesn't make sense to them.** They don't know whom to trust and **they are looking for reassurance** that they are in the right place, doing the right thing, and that someone knows how to find them.

**That explains a lot of the behaviours.** If you think about that each time you see someone who looks like they are behaving uncharacteristically or aggressively, you'll do fine.”

– **Professor Lisa Gwyther**, Alzheimer's Research Center, Duke University  
*Source: HealthCare Interactive: Online Dementia Training*



To close, I would like to show you a video of Ms Naomi Feil, the developer of validation therapy. She is an American Social Worker who in this video works with Gladys, a lady living in a LTC home in late stage dementia.

<https://www.youtube.com/watch?v=CrZXz10FcVM>



**Thank you!**

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