

Creating Culture Change in Long Term Care Homes in Canada – a Person Centred Approach

Mary Schulz
Director of Education
Alzheimer Society of Canada

Canadian Dementia Resource And Knowledge Exchange
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The Alzheimer Society of Canada and *in Canada*

- ASC- one of 11 members of a federation of 150 Alzheimer Societies across Canada
- Work together on common initiatives that aim to improve the experience of living with dementia for individuals and families
 - Research program
 - Advocacy
 - Information, support services and education

www.alzheimer.ca



What is Dementia?

Dementia is a syndrome consisting of a number of symptoms that include changes in:

- memory
- judgment and reasoning
- mood and behaviour
- communication abilities
- **ability to function on a day to day basis**

<http://www.alzheimer.ca/english/disease/whatisit-intro.htm>



Dementia in Canada at a glance

- Approximately **500,000** Canadians are living with Alzheimer's disease or a related 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.

Source:

http://www.alzheimer.ca/english/rising_tide/rising_tide.htm



Within a generation (25 years), the number of people living with Alzheimer's disease or a related dementia could reach between **1 million** and **1.3 million**.

What *Rising Tide* says: incidence

Incidence: Number of new cases of dementia per year

The number of new cases of dementia in 2038, among Canadians (65+), is expected to be 2.5 times that for 2008.

Within a generation, we will jump from one new case of dementia every FIVE minutes to one every TWO minutes.

Person Centred Care

What do we mean?

- ❖ First let's discuss...terminology
- ❖ Themes that are common to all these types of 'centredness'

Talking *with* people with dementia – not *to* them.

- As health care professionals, we talk *with* people living with cancer, *with* people living with heart disease, *with* people living with high blood pressure
- Why do we talk *to* people with dementia?

Let's pause and reflect

Who are you?

All the roles you play.

Are you the sum total of these roles?

Getting to know the resident

What typically passes for 'getting to know the resident' in a long term care home setting?



Société Alzheimer Society



If Rembrandt, the famous Dutch artist who lived in the 1660s, was a resident of your long term care home, would your social history say.....

Mr. Rembrandt:

- a) was born in Leiden, Holland
- b) showed early promise as an artist
- c) has had some commercial success
- d) married Saskia, who lost several babies in infancy
- e) had a son, Titus, who lived into adulthood but predeceased him





Culture Change in long term care – What do we mean?

- Understanding there is no ‘quick fix’
- Staff need to be supported in the way that we hope they will support residents
- Ultimate goal: that person centred care of people with dementia is the norm in long term care homes in Canada – not the exception

Why is the Alzheimer Society of Canada focusing on Person Centred Care in Long Term Care Homes?

What *Rising Tide* says: long term care

- The *Rising Tide* report assumes that **the number of long term care beds in Canada will grow from approximately 280,000 in 2008 to 690,000 in 2038.** This leaves a projected shortfall of more than 157,000 beds in 2038.
- This increase in need signals that all the current issues regarding the quality of dementia care in care home settings will only be multiplied with **approximately 260,000 more individuals living in long term care in 2038 than in 2008.**

The *real rationale* why ASC is focusing on this work- Listening to our constituents...

Sent: Wed 02/07/09 3:00 AM

To: Info

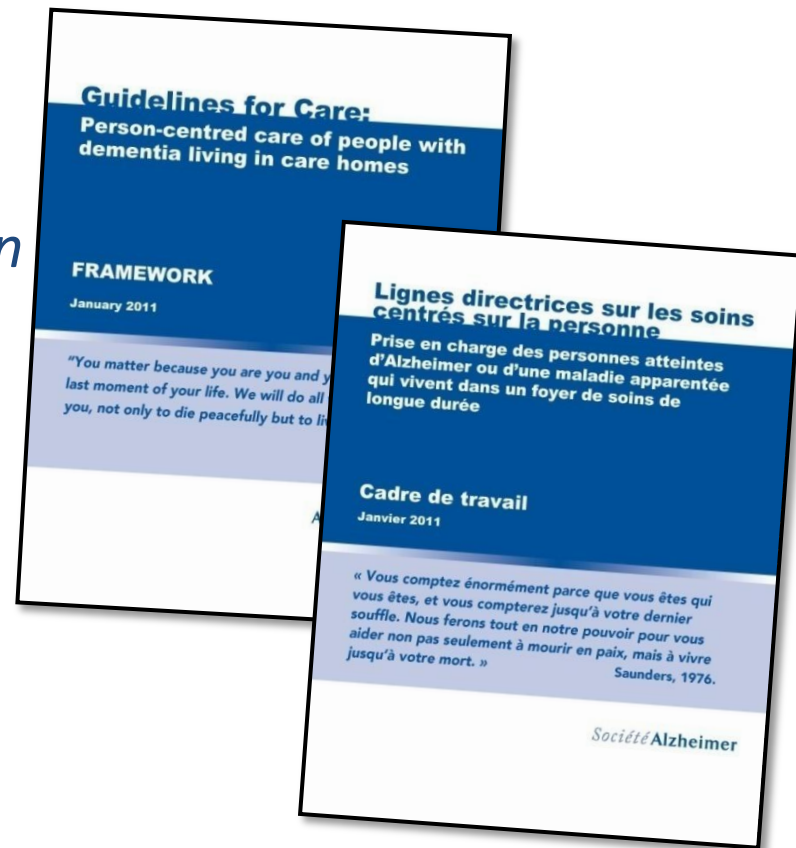
Subject: Request for information

Could you please forward this question.
My family and I are a bit unsure about my
grandmother's current situation and we
were wondering if you could answer a
question for us about her eating habits.



What is the Alzheimer Society in Canada doing to “change the conversation” about long term care in Canada?

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



English - <http://www.alzheimer.ca/english/care/guidelines-care-intro.htm>

French - <http://www.alzheimer.ca/french/care/guidelines-care-intro.htm>

What Does Person-Centred Care Look Like in a Care Home?

- Enjoying Every Day
- Feeling Safe and “Independent”
- Participating in Meaningful Activities
- Anticipating and responding to changes in Mood and Behaviour

Ensuring Family Inclusiveness

- Staff need to ensure that family members are invited, encouraged and supported in being involved and engaged in the life of the person with dementia.
- Staff in a person-centred care home value and include family and friends, involving them actively in the support network and seeking them out, including them as valued members of the care team.

Extending a Person-Centred Philosophy Through End of Life

End of Life Care

The overall goals of palliative and end of life care are to improve the quality of living and dying for people with dementia and to minimize unnecessary suffering through the provision of the following services:

- Psychological, social, emotional and spiritual support
- Support for family members and caregivers
- Bereavement support.

Pain Management

Pain and symptom management

Working with the guidelines, we.....

- Engaged a national/International Steering Committee
http://www.alzheimer.ca/english/care/1_Alz_Society_CC_Steer_Committee_English.pdf
- To steer our *Culture Change in Long Term Care* initiative http://www.alzheimer.ca/english/care/culture_change_initiative.htm
- By listening to people living and working in long term care homes

We want to LEARN and then SHARE

- What makes culture change possible?
- What are the 'essential ingredients'?
- What makes a 'good day'? For the resident? For the staff? For the family?
- What makes families feel that they are TRULY a VALUED member of the care team?
- What are the road blocks that LTC homes feel are 'beyond their control' to change?



- We need to talk
- We need to listen
- But then, we need to...

Standards

**Staff
empowerment**

**Family
involvement**

ACT!

Staff training

Advocacy

Policy

Funding

Let's pause and reflect...

We've talked about:

- *The Rising Tide of Dementia in Canada*
- What we mean by person centred care and 'culture change'
- ASC's rationale for focusing on culture change in long term care through a person centred approach
- The steps that ASC has undertaken and is undertaking to have a 'different conversation' about the experience of living with dementia in long term care

Join us in this conversation!

- Email ASC to be added to our 'list of champions'
mschulz@alzheimer.ca
- Watch our website at
http://www.alzheimer.ca/english/care/culture_change_initiative.htm
- Start your *own* conversation at your *own* organization!
- Don't 'go it alone'. Seek out help – there's lots of expertise out there.
- Feel free to be in touch:

Mary Schulz MSW; RSW
Director of Education
Alzheimer Society of Canada
mschulz@alzheimer.ca

