

# HEALTH COACHING FOR DEMENTIA CARE



## **Making Sense of Self Management Strategies**

# Objectives

- Discuss the relevancy of proactive self-care strategies for persons with dementia
- Challenge popular misconceptions about persons with dementia's ability to manage their own care
- Provide examples and insight regarding current self-management strategies for persons with dementia
- Explore opportunities and strategies to better support and empower persons with dementia to manage and accommodate changes associated with dementia

# Workshop Agenda

- “*Rising Tide*” of dementia (Jan. 4, 2010)
- What is self-managed care and where might dementia fit in a Chronic Disease Model?
- What do people with dementia have to say?
- “*Balance of Care*” considerations
- How might this be applied in my role/practice?

# **Rising Tide:** **The Impact of Dementia** **on Canadian Society**

A study commissioned by the Alzheimer Society

**Released January 4, 2010**

# Review of Dementia

- Term “dementia” refers to disorders of the brain that slowly destroy memory and reasoning, erode independence and eventually, take life
- Alzheimer’s disease is the most common form, accounting for 64% of all dementias
- Other **irreversible** dementias include Vascular dementia, Frontotemporal dementia (including Picks disease), Lewy body disease and Creutzfeldt-Jakob (mad cow) disease

**(Rising Tide, January 2010)**

# Impact of Dementia

## Personal

- Long-term (chronic) disease burdens both person with disease and caregivers
- Causes more years with disability than any other chronic disease
- Severe financial burden for people living with disease
- Erodes health of caregivers

## Systemic

- For the past decade, dementia and its impact on national economies have been the subject of increasing focus around the globe

**(Rising Tide, January 2010)**

# Dementia in Canada at a Glance

- **500,000** Canadians are now living with Alzheimer's disease or a related dementia
- Within a generation (25 years), that number could reach between **1 million** and **1.3 million**
- More than **71,000** Canadians living with dementia are **under the age of 65**
- Women make up **72 per cent** of Canadians with Alzheimer's disease

**(Rising Tide, January 2010)**

# What the Report 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.

**Projected incidence:**

2008: 103,700 new dementia cases per year or ***one new case every 5 minutes***

2038: 257,800 new dementia cases per year or ***one new case every 2 minutes***

**(Rising Tide, January 2010)**

# What the Report Says: Prevalence

## Prevalence: Number of People with Dementia

By 2038, the number of Canadians (of all ages) with dementia expected to increase to 2.3 times the 2008 level.

### Projected Prevalence:

2008: 480,600 people, or **1.5% of the Canadian population**

2038: 1,125,200 people, or **2.8% of the Canadian population**

Now

500,000

Within a Generation

1,100,000

**Canadians with Alzheimer's disease or a related dementia**

# Rising Tide 5 Recommendations for a Comprehensive National Dementia Strategy:

1. Accelerated investment in all areas of dementia research
2. Clear recognition of the role of informal caregivers
3. Increased recognition of the importance of prevention and early intervention
4. **Greater integration of care and increased use of chronic disease prevention and management**
5. Strengthening Canada's dementia workforce

**The Rising Tide Report** can be found at [www.alzheimer.ca](http://www.alzheimer.ca)

# What is Self-Managed Care?

## Five Core Self-Management Skills

1. Undertaking problem solving
2. Decision making
3. Locating and using resources
4. The creation of a partnership between the person and health professional
5. Making an action plan and taking action

(Lorig and Holman, 2004)

## “Supported” Self-Care

- Compliments care provided by “prepared practice teams” (includes **psychosocial support** and sees **patient as expert/central team member**)
- Provides and/or enhances coping strategies and problem solving skills (**coming alongside** of those with chronic disease and their families – not shifting /shirking responsibility)
- Empowering to people (want some **control**; ‘done all I can’)
- Improve well-being & slow progression of disease
- Possible cost-efficiency or cost-containment (measurement can be difficult without **evidence** – i.e. ER/acute usage)

# Ontario's Chronic Disease Prevention & Management Framework

- Health Care Organizations (prevention & management of chronic disease efforts; prepared, proactive practice teams)
- Delivery System Design (prevention & system improvements)
- Provider Decision Supports (*easily understood/applied* EBPs )
- Information Systems (enhanced, e-ready & integrated)
- **Personal Skills and Self-Management Supports** (empower skills building & coping strategies)
- Healthy Public Policies (health improvements & health inequities)
- Supportive Environments (living & working conditions)
- Community Action (local health)

(MOHLTC, 2007)

# MoHLTC Personal Skills & Self-Management Supports

- Clients are part of the Care Team & Engaged in Shared Decision Making
- Individuals Empowered to be Self-Managers
- Self-management Support Services Organized for Clients
- Shared Clinical Guidelines
- Follow-up
- Personal Skills for Health & Wellness

(MOHLTC, 2007)

# Dementia in a Chronic Disease Model?

**As with many conditions more frequently termed chronic, dementia:**

- Affects a diverse group of patients
- Results in multiple and varied patient needs
- Is a progressive disease, meaning that patient needs will alter
- Often has a long duration (15–20 years)
- Affects and alters insight and decisional capacity
- Involves unique caregiver needs

**(Cohen, 2008)**

# Primary Care Plays a Key Role

(Early) Diagnosis is affected by:

- Access to Primary Care (e.g., urban, rural or remote)
- Comorbid conditions
- Time and ability to screen for dementia
- Knowledge about dementia
- Symptom recognition
- Fear of causing undue stress

(Mcainey et al., 2008)

# Self Management in the United Kingdom

*“Whilst benefits of self-management in other conditions have long been recognised, developments in field of dementia have been slower”*

*Changed focus the result of:*

- *Unexpected side effects of memory enhancing medication (even though coverage ltd to moderate stage)*
- *Memory clinics mushrooming (in the UK)*
- *National dementia strategy*

(Gail Mountain, 2006)

# Self-Management in the United Kingdom

2002 – **Expert Patient Program** integrated into the National Health Service

2005 – **Supporting People with Long Term Conditions: An NHS and Social Care Model** to support local innovation and Integration

2009 – **National Dementia Strategy** published in February  
And implementation framework outlined in July 2009

# International Self-Management Initiatives

## Dementia Advocacy Support Network International (DASNI)

*A world wide organization by and for those diagnosed with dementia working together to improve our quality of life*

*Our purpose is to promote respect and dignity for persons with dementia, provide a forum for the exchange of information, encourage support mechanisms such as local groups, counselling, and internet linkages, and to advocate for services.*

- Chat rooms
- Blogs,
- Resources

# Local Dementia Self-Management Initiatives

- First Link for Persons with Dementia and their Partners in Care (Alzheimer Society of Canada)
- Support Groups for Persons with Dementia (Alzheimer Society or Community Agencies)
- By Us For Us Guides© (Self-Help/Advocacy supported by MAREP at the University of Waterloo)
- Changing Melody Forums (Various cities)
- Every Door is the Right Door? (MOHLTC, 2009)
- Other...

# First Link (Alzheimer Society)

- Direct referrals from primary care
- Collaborations to enhance diagnostic capacity and offer self-management education and strategies
- Early intervention and on-going support (both persons with dementia & partners in care)
- Progressive 4-stage learning series
- Increased care coordination with community services
- Building a broader base of experts in ADRD

# Support Groups

- Education and support in learning how to cope functionally and emotionally with their condition
- Facilitated and/or peer-led groups
- Safe and non-judgemental places
- Targeted populations (persons with dementia, spouses, children, language, culture, ethnicity, faith-based)

# By Us For Us Guides©

- A series of guides created *By* persons with dementia *For* persons with dementia
- Designed to equip people with the necessary tools to enhance their well being and manage daily challenges
  - *Memory Workout*
  - *Managing Triggers*
  - *Enhancing Communication*
  - *Enhancing Wellness*
  - *Tips & Strategies*
  - *Living and Transforming With Loss & Grief*

# *A Changing Melody Forums*

- Learning and sharing forums specifically designed for persons with early stage dementia and their partners in care – originally sponsored by the Murray Alzheimer Research and Education Program (MAREP) in partnership with the Alzheimer Society of Canada (ASC), the Alzheimer Society of Ontario (ASO), and DASNI
  - **April 10, 2010** (St. Catharines, ON)
  - **April 10, 2010** (Kingston, ON)
  - **June 3, 2010** (tentatively in Durham, ON)
  - **September 22, 2010** (Stratford, ON)

# Application Using Balance of Care

What determines whether older persons (*with dementia*) can age successfully at home?

## **Demand side**

- People's needs and characteristics

## **Supply side**

- System capacity – access to safe, appropriate cost-effective community-based care

**Both demand and supply vary considerably**

# Upward & Downward Substitution

## Upward substitution

- Failure to access “lower level” supports (e.g., transportation or nutrition) results in utilization of “higher level,” more costly, health care (e.g., LTC or hospital bed)

## Downward substitution

- Appropriate access to “lower level” community supports avoids or delays health care utilization

# LTC Wait Lists

|                        |      |
|------------------------|------|
| • Waterloo             | 811  |
| • Toronto Central      | 1684 |
| • Central              | 2631 |
| • North West           | 860  |
| • North East           | 1500 |
| • South West           | 2876 |
| • Central West         | 725  |
| • North Simcoe Muskoka | 1758 |
| • Champlain            | 3724 |

# People on LTC Wait Lists

## Activities of Daily Living (ADLs)

*Self-Performance Hierarchy Scale*: eating, personal hygiene, locomotion, toilet use

|                          | <b>Waterloo</b> | <b>Toronto</b> | <b>Central West</b> | <b>Central</b> | <b>NSM</b> | <b>NE<br/>(Oct. 2007)</b> |
|--------------------------|-----------------|----------------|---------------------|----------------|------------|---------------------------|
| <b>Low Difficulty</b>    | <b>53%</b>      | <b>43%</b>     | <b>34%</b>          | <b>41%</b>     | <b>52%</b> | <b>62%</b>                |
| <b>Medium Difficulty</b> | <b>28%</b>      | <b>28%</b>     | <b>25%</b>          | <b>29%</b>     | <b>27%</b> | <b>17%</b>                |
| <b>High Difficulty</b>   | <b>19%</b>      | <b>29%</b>     | <b>41%</b>          | <b>30%</b>     | <b>21%</b> | <b>21%</b>                |

# People on LTC Wait Lists

## Instrumental Activities of Living (IADL)

*IADL Difficulty Scale*: meal preparation, housekeeping, phone use, medication management

|                          | <b>Waterloo</b> | <b>Toronto</b> | <b>Central West</b> | <b>Central</b> | <b>NSM</b> | <b>NE<br/>(Oct. 2007)</b> |
|--------------------------|-----------------|----------------|---------------------|----------------|------------|---------------------------|
| <b>Low Difficulty</b>    | <b>2%</b>       | <b>3%</b>      | <b>1%</b>           | <b>1%</b>      | <b>2%</b>  | <b>2%</b>                 |
| <b>Medium Difficulty</b> | <b>32%</b>      | <b>32%</b>     | <b>26%</b>          | <b>25%</b>     | <b>32%</b> | <b>41%</b>                |
| <b>High Difficulty</b>   | <b>66%</b>      | <b>65%</b>     | <b>73%</b>          | <b>74%</b>     | <b>66%</b> | <b>57%</b>                |

# People on LTC Wait Lists

## Caregiver Living with Client?

|            | <b>Waterloo</b> | <b>Toronto</b> | <b>Central West</b> | <b>Central</b> | <b>NSM</b> | <b>NE<br/>(Oct. 2007)</b> |
|------------|-----------------|----------------|---------------------|----------------|------------|---------------------------|
| <b>Yes</b> | <b>46%</b>      | <b>35%</b>     | <b>56%</b>          | <b>55%</b>     | <b>45%</b> | <b>43%</b>                |
| <b>No</b>  | <b>54%</b>      | <b>65%</b>     | <b>44%</b>          | <b>45%</b>     | <b>55%</b> | <b>57%</b>                |

# People on LTC Wait Lists

## Cognition

*Cognitive Performance Scale*: short term memory, cognitive skills for decision-making, expressive communication, eating self-performance

|                   | <b>Waterloo</b> | <b>Toronto</b> | <b>Central West</b> | <b>Central</b> | <b>NSM</b>  | <b>NE (2007)</b> |
|-------------------|-----------------|----------------|---------------------|----------------|-------------|------------------|
| <b>Intact</b>     | <b>43%</b>      | <b>48%</b>     | <b>33%</b>          | <b>38%</b>     | <b>43%</b>  | <b>48%</b>       |
| <b>Not Intact</b> | <b>57%</b>      | <b>52%</b>     | <b>67%</b>          | <b>62%</b>     | <b>57%</b>  | <b>52%</b>       |
| <b>Total</b>      | <b>1100</b>     | <b>1684</b>    | <b>725</b>          | <b>2631</b>    | <b>1768</b> | <b>1500</b>      |

# Divert Rates Compared: Family Residence & Supportive Housing

|                        | <b>Family Residence</b> | <b>Supportive Housing</b> |
|------------------------|-------------------------|---------------------------|
| <b>Central</b>         | <b>21%</b>              | <b>27-43%</b>             |
| <b>Central West</b>    | <b>30%</b>              | <b>40-57%</b>             |
| <b>Champlain</b>       | <b>14%</b>              | <b>14-33%</b>             |
| <b>Toronto Central</b> | <b>37%</b>              | <b>46-53%</b>             |
| <b>North East</b>      | <b>28%</b>              | <b>32-69%</b>             |

# Remember Core Skills

## Five Core Self-Management Skills

1. Undertaking problem solving (remember type of dementia)
2. Decision making (care for PWD affects care for partners in care)
3. Locating and using resources (case management)
4. The creation of a partnership between the person and health professional (time intensive but front end saves back end)
5. Making an action plan and taking action (individualizing care plan; avoiding “*I wish I had known about ...*”)

(Lorig and Holman, 2004)

# Supported Dementia Self-Managed Care

How do the principles of self-managed care apply to persons with dementia? Consider:

- How might one optimize functional/spared capacity & quality of life (leisure/recreation, health & lifestyle)
- Address progressive nature of cognitive impairment (e.g., short term-memory, aphasia, psychosocial issues, supporting prompts and reminders, consistent carers & in-person case management, etc.)
- Address possible triggers for responsive behaviours

# Sample Vignette for Upperton

- *Not cognitively intact*
- *Functionally independent in all ADLs with the exception of bathing (limited assistance is required).*
- *Experiences (some) difficulty using the phone, some difficulty with meal preparation, and managing medications and great difficulty with transportation and housekeeping.*
- *Has a live-in caregiver. The caregiver provides advice/emotional support & assistance with IADLs and more than half provide assistance with ADLs).*

# Sample Vignette for Vega

- *Not cognitively intact*
- *Functionally independent in all ADLs with the exception of bathing (limited assistance is required).*
- *Experiences **no** difficulty using the phone, some difficulty with meal preparation, and managing medications and **great** difficulty with transportation and housekeeping.*
- *Not have a live-in caregiver. The caregiver is an adult-child who lives outside of the home (provides advice/emotional support & assistance with IADLs).*

## Sample Vignette for Xavier

- *Not cognitively intact.*
- *Requires **some** assistance with ADLs (independent in locomotion in the home, eating, personal hygiene and toileting; **extensive** assistance required with bathing).*
- *Experiences **some** difficulty using the phone and **great** difficulty with housekeeping, meal preparation, managing medications, and transportation.*
- ***Not** have a live-in caregiver. Xavier's caregiver is an adult child who lives outside the home (provides advice/emotional support & assistance with IADLs).*

# Review

- Proactive self-care strategies for persons with dementia are both relevant and important
- Negative misconceptions about persons with dementia and their ability to manage their own care has limited self-managed care initiatives
- Core self-management skills need to be applied and expanded to better support and empower persons with dementia in managing and accommodating the dementia journey

Thank You for Your Valuable  
Time  
*Let's Make It So*

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## References

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