

## HEALTH COACHING FOR DEMENTIA CARE: Making Sense of Self Management Strategies

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### Summary of Presentation and Future Resources

#### A. Relevancy/urgency in Addressing the Needs of Alzheimer's and Related Dementias:

***Rising Tide: The Impact of Dementia on Canadian Society*** is a report released by the Alzheimer Society to mark Alzheimer Awareness Month (January 2010). It reveals alarming new statistics about the projected economic and social costs of dementia in Canada.

([http://www.alzheimer.ca/english/rising\\_tide/rising\\_tide.htm](http://www.alzheimer.ca/english/rising_tide/rising_tide.htm))

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

#### B. Core Self Management Skills

Five Core Self-Management Skills

1. Undertaking problem solving (Remember not to immediately label abilities; problem solve taking in to consideration the type of dementia)
2. Decision making (Consider Persons with Dementia (PWD) and Partners in Care as a unit in decision making at care for PWD affects care for partners in care)
3. Locating and using resources (case management/system navigation piece to inform, link and connect)
4. The creation of a partnership between the person and health professional (time intensive but front end saves time in the continuum of care)
5. Making an action plan and taking action (individualizing care plan; avoiding people learning about resources too late—*"I wish I had known about ..."*)

(Adapted from Lorig and Holman, 2004)

#### C. Ontario's Chronic Disease Prevention & Management Framework

An 8 Point Framework that includes *"Personal Skills and Self-Management Supports that empower individuals to build skills for healthy living and coping with disease."* Within this initiative *Self-management Support Services Organized for Clients* is outlined:

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

(Ontario Ministry of Health & Long Term Care, 2007)

#### D. Dementia in a Chronic Disease Model?

As with many conditions more frequently termed chronic, dementia:

1. Affects a diverse group of patients
2. Results in multiple and varied patient needs

3. Is a progressive disease, meaning that patient needs will alter
4. Often has a long duration (15–20 years)
5. Affects and alters insight and decisional capacity
6. Involves unique caregiver needs

(Cohen, 2008)

#### E. Primary Care Plays a Key Role

(Early) Diagnosis is affected by:

1. Access to Primary Care (e.g., urban, rural or remote)
2. Co-morbid conditions
3. Time and ability to screen for dementia
4. Knowledge about dementia
5. Symptom recognition
6. Fear of causing undue stress

(Mcainey et al., 2008)

#### F. How do the principles of self-managed care apply to persons with dementia?

Consider:

1. How might one optimize functional/spared capacity & quality of life ( e.g., leisure/recreation, health & lifestyle)
2. 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.)
3. Address possible triggers for responsive behaviours

#### G. International Initiatives

##### 1. Self-Management in the United Kingdom

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

Key Features: knowing how to recognise and act upon symptoms, making most effective use of medicines & treatments, comprehending the implications of professional advice, accessing social & other services, accessing chosen leisure activities, developing strategies to deal with the psychological consequences of the illness; learning to cope with other people’s response to their chronic illness.

***Don’t Make the Journey Alone: A Message from Fellow Travellers*** written by persons with dementia for persons with dementia available at Alzheimer Scotland – Action on Dementia available at [www.alzscot.org](http://www.alzscot.org)

**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

##### 2. Dementia Advocacy Support Network International (DASNI)

A worldwide organization by and for those diagnosed with dementia working together to improve our quality of life. Purpose: 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.  
(<http://www.dasninternational.org/>)

## H. Local Dementia Self-Management Initiatives

### 1. First Link for Persons with Dementia and their Partners in Care (Alzheimer Society)

Key Features: 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

### 2. Support Groups for Persons with Dementia (Alzheimer Society or Community Agencies)

Key Features: 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)

### 3. By Us For Us Guides© (Self-Help/Advocacy supported by MAREP at the University of Waterloo)

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 (available in hardcopy or downloadable PDF form)

- *Memory Workout, Managing Triggers, Enhancing Communication, Enhancing Wellness, Tips & Strategies, Living and Transforming With Loss & Grief* ([www.marep.waterloo.ca](http://www.marep.waterloo.ca))

### 4. Changing Melody Forums (Various cities)

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)

## I. “Supported” Self Care for Persons with Dementia

Although dementia is not included in Ontario’s Chronic Disease Prevention & Management Framework, supported self care:

1. Compliments care provided by “prepared practice teams” (includes **psychosocial support** and sees **patient as expert and a central team member**)
2. Provides and/or enhances coping strategies and problem solving skills (**coming alongside** of those with chronic disease and their families – not avoiding or shifting responsibility)
3. Empowers people (persons with dementia **want some control**; want to feel have ‘*done all I can*’)

4. Improves well-being & slow progression of disease (diagnosis – especially *early diagnosis* – allows time to integrate coping strategies learned from primary care, case managers, self-learning and/or peer support)
5. Possible avoidance of “**upward substitution**” (failure to access “lower level” supports such as transportation or nutrition) resulting in utilization of “higher level,” more costly, health care such as LTCH bed or hospital bed)
6. Possible enhancement of “**downward substitution**” (appropriate access to “lower level” community supports avoids or delays health care utilization)
7. Possible cost-efficiency or cost-containment (– need both qualitative and quantitative however **measurement can be difficult** i.e. ER/acute usage or ‘near misses’)

#### J. 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

#### K. References

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