HEALTH COACHING FOR DEMENTIA CARE

Making Sense of Self Management Strategies

Presented by Frances Morton • Wednesday February 17, 2010
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?

Frances Morton • Wednesday, February 17, 2010
Adult Day Programs for Persons with Dementia

Enablers

• Ethno-cultural-linguistic specific programs
• Allowing people with ethno-cultural-linguistic backgrounds outside of catchment areas to attend
• Flexible and/or extended hours
• Assistance with toileting (trained staff & equipment)
• Transportation (have own bus/van, escorts/2 staff on bus)
• Helps to expand access to more programs
• Subsidies
• Social Workers on-site

Frances Morton  •  Toronto Dementia Care Project •  Thursday, January 28, 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.

From Rising Tide, January 2010
Impact of Dementia

Personal

- Long term 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

From 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

From 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 \textit{one new case every 5 minutes}

2038: 257,800 new dementia cases per year or \textit{one new case every 2 minutes}

From 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

Canadians with Alzheimer’s disease or a related dementia

500,000

1,100,000

Now

Within a Generation
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

Rising Tide Report can be found at 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)
Might Dementia Fit 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)
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
- Memory clinics mushrooming
- National dementia strategy

(Gail Mountain, 2006)
What Persons with Dementia Have to Say

Pre-Diagnosis

Diagnosis and Stigma

Ways of Coping

Supporting Old & New Potential
Application Using Balance of Care
Application Using Balance of Care

What determines whether older persons 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

<table>
<thead>
<tr>
<th></th>
<th>Waterloo</th>
<th>Toronto</th>
<th>Central West</th>
<th>Central</th>
<th>NSM</th>
<th>NE (Oct. 2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low Difficulty</strong></td>
<td>53%</td>
<td>43%</td>
<td>34%</td>
<td>41%</td>
<td>52%</td>
<td>62%</td>
</tr>
<tr>
<td><strong>Medium Difficulty</strong></td>
<td>28%</td>
<td>28%</td>
<td>25%</td>
<td>29%</td>
<td>27%</td>
<td>17%</td>
</tr>
<tr>
<td><strong>High Difficulty</strong></td>
<td>19%</td>
<td>29%</td>
<td>41%</td>
<td>30%</td>
<td>21%</td>
<td>21%</td>
</tr>
</tbody>
</table>
People on LTC Wait Lists

Instrumental Activities of Living (IADL)

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

<table>
<thead>
<tr>
<th></th>
<th>Waterloo</th>
<th>Toronto</th>
<th>Central West</th>
<th>Central</th>
<th>NSM</th>
<th>NE (Oct. 2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Low Difficulty</strong></td>
<td>2%</td>
<td>3%</td>
<td>1%</td>
<td>1%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Medium Difficulty</strong></td>
<td>32%</td>
<td>32%</td>
<td>26%</td>
<td>25%</td>
<td>32%</td>
<td>41%</td>
</tr>
<tr>
<td><strong>High Difficulty</strong></td>
<td>66%</td>
<td>65%</td>
<td>73%</td>
<td>74%</td>
<td>66%</td>
<td>57%</td>
</tr>
</tbody>
</table>
# People on LTC Wait Lists

## Caregiver Living with Client?

<table>
<thead>
<tr>
<th></th>
<th>Waterloo</th>
<th>Toronto</th>
<th>Central West</th>
<th>Central</th>
<th>NSM</th>
<th>NE (Oct. 2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>46%</td>
<td>35%</td>
<td>56%</td>
<td>55%</td>
<td>45%</td>
<td>43%</td>
</tr>
<tr>
<td>No</td>
<td>54%</td>
<td>65%</td>
<td>44%</td>
<td>45%</td>
<td>55%</td>
<td>57%</td>
</tr>
</tbody>
</table>
People on LTC Wait Lists

Cognition

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

<table>
<thead>
<tr>
<th></th>
<th>Waterloo</th>
<th>Toronto</th>
<th>Central West</th>
<th>Central</th>
<th>NSM</th>
<th>NE (2007)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intact</td>
<td>43%</td>
<td>48%</td>
<td>33%</td>
<td>38%</td>
<td>43%</td>
<td>48%</td>
</tr>
<tr>
<td>Not Intact</td>
<td>57%</td>
<td>52%</td>
<td>67%</td>
<td>62%</td>
<td>57%</td>
<td>52%</td>
</tr>
<tr>
<td>Total</td>
<td>1100</td>
<td>1684</td>
<td>725</td>
<td>2631</td>
<td>1768</td>
<td>1500</td>
</tr>
</tbody>
</table>
### Divert Rates Compared: Family Residence & Supportive Housing

<table>
<thead>
<tr>
<th>Region</th>
<th>Family Residence</th>
<th>Supportive Housing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central</td>
<td>21%</td>
<td>27-43%</td>
</tr>
<tr>
<td>Central West</td>
<td>30%</td>
<td>40-57%</td>
</tr>
<tr>
<td>Champlain</td>
<td>14%</td>
<td>14-33%</td>
</tr>
<tr>
<td>Toronto Central</td>
<td>37%</td>
<td>46-53%</td>
</tr>
<tr>
<td>North East</td>
<td>28%</td>
<td>32-69%</td>
</tr>
</tbody>
</table>
Remembering Core Skills

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 Dementia Self-Managed Care

How might the principles of self-managed care apply to persons with dementia?
Dementia Self-Management Initiatives

• First Link (Alzheimer Society of Canada)
• Support Groups for Persons with Dementia
• By Us For Us Guides (MAREP, University of Waterloo)
• Changing Melody Forums
• Dementia Advocacy & Support Network International (DASNI)
• Other…
Exercise
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, managing medications and preparing meals and **great difficulty** with transportation and housekeeping
- **Has a live-in caregiver.** This live-in caregiver provides advice/emotional support and assistance with IADLs. (note: 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
Now - *Let’s Make It So*

Frances Morton
Elder Coaching
(416) 422 – 1292
elder.coach@hotmail.com
or
frances@eldercoach.org