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First Link®: Reducing the Stigma of Dementia

Carrie A. McAiney
Marg Eisner
Mary E. Schulz
Cathy Conway

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Dementia – what is it?


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

- loss of memory, judgment and reasoning
- changes in mood, behaviour, communication abilities
- a progressive loss of ability to function


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Dementia Defined



Alzheimer's Disease Frontal Temporal Dementia Lewy Body Disease Vascular Dementia Creutzfeldt Jakob Disease


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Dementia is a Mental Health Issue

Dementia has attributes in common with some mental illnesses:


- diminished judgment
- memory deficits
- impaired cognition
- reduced ability to enjoy social interactions

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Dementia Statistics

- **500,000** Canadians are living with Alzheimer's or a related disease
 = **1 in 11 people over the age of 65**
- Within just five years, 250,000 more Canadians will develop this disease
- Within 25 years, the number could reach **1 - 1.3 million** Canadians

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Etiology of Mental Illness and Alzheimer's Disease

Both seem to have multi-factorial etiology including:

- Genetic predisposition
- Biological changes in the brain
- Psychological factors such as levels of self esteem – *growing problem of increasing dependency and reliance on caregivers*
- Complex interplay of risk and protective factors such as environment, diet, exercise and intellectual stimulation



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Depression and Dementia

- Some of the most common co-morbid conditions in people with dementia are psychiatric –most notably *depression*
- Depression is a condition often experienced by family caregivers of people with dementia, leaving them unable to continue to provide care
- Significant impact on physical and emotional wellbeing of caregivers leads to premature death, illness and institutionalization



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Why does it matter? **STIGMA**

- Stigma creates barriers to diagnosis and treatment
- Contributes to isolation and therefore depression
- To reduce the stigma of people living with mental illnesses and *help them to continue to live meaningful lives*, we need to speak out as one voice – and support people with disease in telling their story



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First Link® is....

A new program that:

- recognizes the importance of caregiver support
- is applicable to support of people with other mental health conditions



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Ideal Process

- Diagnosis of the individual
- Referral to the local Alzheimer Society (with consent)
- Early access to counselling, support, education, information, referrals and follow-up



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Why is early access to support important?

- Research has consistently shown that caregivers of persons with dementia have:
 - Poorer physical health
 - Poorer mental health
 - Greater financial burdens
- Despite the availability of education and support services, few individuals with dementia or their caregivers access help early in the course of the disease



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Case Example

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Benefits

- For the person with dementia:
 - Decrease in crisis situations
 - Help with planning
 - Support and information
 - Education
 - Linkage to support services
 - Reduced stigma

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Benefits

- For family members and caregivers:
 - Help with planning
 - Decrease in crisis situations
 - Improve ability to navigate health system
 - Support and information
 - Education
 - Reduced stigma


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Benefits


- For primary care teams:
 - Potential decrease in patient visits / calls
 - Potential reduction in crisis situations
 - Improved access to services for patients
 - Dementia specific expertise
 - Stronger linkage with the local Alzheimer Society

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Video Clip


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First Link Evaluation

- An evaluation of First Link is currently underway
- Funding:
 - Alzheimer Society of Ontario & Ministry of Health & Long-Term Care
 - Alzheimer Society of Canada
- Sites:
 - Ontario: 4 sites (9 Alzheimer Chapters)
 - Saskatchewan: 2 sites

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Evaluation: Objectives

The evaluation aims to measure the impact of First Link® on:

- Connecting family caregivers to the Alzheimer Society and other services earlier in the disease process
- Knowledge & awareness among professionals
- Knowledge & awareness among family caregivers
- Caregiver coping and burnout


Also examining the implementation process (e.g., facilitators, barriers, improvements, sustainability).


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Evaluation: Data Sources


- Data tracking:
 - Ongoing
 - Interim data available
- Surveys:
 - Caregivers - ongoing
 - Primary care providers – Scheduled for Fall 2009
- Interviews:
 - Scheduled for Fall 2009
- Final Report (Ontario):
 - December 2009

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Evaluation: Interim Findings

- Total # of referrals to Chapters (Feb/08 – Aug/09): 2597
 - 46% referred via First Link®
 - 54% were self-referrals
- Among First Link® referrals:
 - 78% from physicians
 - 22% from community services
 - Only 5 individuals declined Alzheimer Society involvement

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Evaluation: Interim Findings

- The demonstration sites have been actively engaged in:
 - accepting referrals
 - distributing information packages
 - facilitating awareness raising activities
 - education events
- Low response rate on Caregiver Survey
 - However, early results suggest that First Link® is having a positive impact on caregivers





Primary Care Feedback

“As a family physician that cares for individuals with a multitude of chronic diseases, I welcome any help I can access to assist my patients and their families. In these days of limited resources, other professionals often have more time and information to share with the public than I have, as I juggle the demands generated by caring for an aging population.”





Conclusions

- First Link is an innovative partnership between primary care, community agencies, and other providers
- Model provides the opportunity to more comprehensively meet the needs of persons living with dementia and their family from the time of diagnosis
- Enables primary care providers to help patients and their families obtain the information and supports they need





For More Information About First Link®...

- Carrie McAiney: mcaineyc@mcmaster.ca
- Marg Eisner: programdirector@alzbrant.ca





Thank you!