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
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

Dementia Defined

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

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

500,000 Canadians are living with Alzheimer’s or a related disease
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

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

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
First Link® is…

A new program that:
• recognizes the importance of caregiver support
• is applicable to support of people with other mental health conditions

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

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
Case Example

Benefits

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

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
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

Video Clip

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
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).

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

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
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®…

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Thank you!