Women and Dementia

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Lived Experience Panel:

Maggie Weidmark

Vicki Ballentine

Susan Bithrey

Speakers:

Juanita Dobson, Assistant Deputy Minister, Ontario Seniors' Secretariat and the Ontario Women's Directorate
(Opening Remarks)

Elaine Wiersma, PhD, Lakehead University (facilitator)

ONTARIO SENIORS’ SECRETARIAT

ONTARIO’S ACTION PLAN FOR SENIORS:

Women and Dementia

brainXchange Event

Overview

Contents

1. Context
2. Women and Dementia
3. Government Initiatives
4. Finding Your Way (Wandering) Program

Context

- Many Ontarians are affected by Alzheimer’s disease and other dementias. We want Ontario seniors living with brain health conditions to remain healthy and independent for as long as possible, and to feel safe and supported.
- The effects of Alzheimer’s disease, other dementias and neurological conditions can cause serious and alarming safety concerns that society cannot ignore.
- Dementias are progressive, degenerative and irreversible conditions. They affect memory, emotions, and language resulting in a decline in cognitive functions.
- Alzheimer’s is the most common form of dementia, representing up to 60–80% of all cases.
- According to the Alzheimer Society of Ontario (ASO), the current direct and indirect annual cost of dementia in Ontario is over $5 billion and is expected to increase by $770 million per year through 2020.

Women and Dementia

- There are more than 200,000 (one out of every 10) Ontarians over the age of 65 with dementia, and this number is expected to increase to 300,000 by 2017.

- Women represent 72% of all Canadians living with Alzheimer's disease and are doubly affected by this disease (Alzheimer Society).

- Women tend to live longer than men and age is a significant risk factor that contributes to Alzheimer's disease.

- In January 2015, The Alzheimer Society launched a nationwide campaign called The 72%.
  - The Campaign's goal was to inform women in their forties and older about the warning signs of Alzheimer's disease and how the Alzheimer Society can assist those living with dementia, their family and caregivers.

Government Initiatives

- Government recognizes challenges that individuals with dementia face in living with the effects of this disease and understands the importance of supporting those living with dementia and their families. Ministry of Health and Long-term Care (MOHLTC) has made substantial investments in improving the lives of Ontarians with Alzheimer's disease and related dementias and their caregivers. Examples include:

Initiative	**Funding**	**Who**	**Details**
Alzheimer Society of Ontario (ASO) deliver services	Nearly $24 million in funding	Alzheimer Society of Ontario	Funding given to various chapters of the (ASO) to deliver a range of services to improve treatment and management of Alzheimer's disease.
Long-Term Care homes (LTCHs) receive funding for staff training and development opportunities.	In January 2013 and January 2014, MOHLTC provided $10 million and $10.06 million, respectively, in one-time funding to Long-Term Care homes (LTCHs)	Long-Term Care homes	Investments focused on improving resident safety, preventing abuse and neglect, and advancing quality of care for residents with responsive behaviours or other specialized care needs, including residents with palliative care needs.
BSO receives funding to help meet needs of individuals with challenging and complex behaviours wherever they live (e.g. homes, LTCHs)	Between 2011/12 and 2012/13, Ontario invested approximately $59 million in Behavioural Supports Ontario (BSO)	Behavioural Supports Ontario	(BSO) to support the redesign of service delivery and hiring of new staff to meet the needs of individuals with challenging and complex behaviours wherever they live, at home, in long-term care homes, or elsewhere.
LHINs receive annual funding to sustain BSO staffing capacity.	Annual funding of $44 million	Health Integration Networks (LHINs)	MOHLTC is providing Local Health Integration Networks (LHINs) $44 million annually to sustain BSO staffing capacity.
Ontario Neurodegenerative Disease Research Initiative (ONDRI) through Ontario Brain Institute (OBI)	$19 million investment	Ontario Brain Institute (OBI)	In January 2015, MOHLTC provided OBI with funding, which includes a $19 million investment over five years in the Ontario Neurodegenerative Disease Research Initiative (ONDRI). This study will foster new understanding in diagnosis and treatment for Alzheimer's, Parkinson's, ALS and other neurodegenerative diseases.

Finding Your Way (Wandering Prevention) Program

- In 2013, the government launched Ontario's Action Plan for Seniors. Through the plan, Ontario invested over $2 million in the Finding Your Way Program (FYW) in partnership with the Alzheimer Society of Ontario.

- This is a ground-breaking multicultural program offering practical advice on how people with dementia, their families and communities can recognize and reduce the risk of going missing, while supporting a quick and safe return should a wandering incident occur.

- Program offers public awareness materials (i.e. TV, radio and print ads, and caregiver videos) and safety kits that include tip sheets, an identification kit, and information on locating technologies.
  - To reach as many individuals as possible, materials are available in twelve different languages: English, French, Cantonese, Mandarin, Punjabi, Italian, Portuguese, Spanish, Tagalog, Arabic, Tamil and Urdu.

- Program also provides educational sessions (through local Alzheimer Societies across the province) related to FYW and dementia for community groups, seniors and caregivers - resulting in greater awareness about wandering prevention.

Panel Discussion

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Maggie Weidmark

My story living with dementia

- Education: Masters in Applied Science in Nursing
- Still working in public health management when diagnosed 5 years ago
- Started having memory problems that affected work and was asked to leave
- Went to doctor and had testing (family doctor, gerontologist, therapist, specialists) – diagnosed with Frontal Temporal Dementia
- Very emotional, felt lost and sad – “now what”
- Although it was very unsettling and hard to cope, still tried to stay involved
- Got connected to the Alzheimer Society and joined a support group
- Very independent person – still drives around town

Family & support relationships

- Family (husband Mark, daughters Laura and Kathleen)
- Mother-in-law – lives close and attend seniors’ centre together (carpet bowling)
- Visit parents often
- Maintain connections with friends
- Attends Alzheimer Society support group
- Medical practitioners
- Involved in research and education through MAREP

Sense of self

What is the same:

- Still very aware – know what I like and what I want to do
- Think about others before myself
- Helping nature – get involved
- Very much a people person

What is different:

- Very emotional

Women & dementia

- There seems to be more men with younger onset than women (more men than women in support groups) – need to have choices of women only, men only and co-ed support groups
- A lot of care and support systems feed into the stereotyping of women (and men) – functional assessments are based on traditional role of “homemaker”; but a lot more women work outside the home now

Advice to other women

- Diagnosis can be very isolating – need to stay involved
- Need to accept it and away you go
- Be who you are; do the things that you want
- Be an advocate for yourself – do not allow people to treat you like you are less of a person, or are invisible

Vicki Ballentine

My Dementia Journey

- Others in my life noticed signs early on, but I didn’t realize what was happening at first.
- I received a diagnosis in November of 2013 after many tests and appointments with a specialist. It was a shock at first to me.
- I was referred to the local Alzheimer Society and attend some of their programs.
- I am living with dementia and coping with it, I try to live day by day and moment by moment.

Family and Support

- My husband George is a great support.
- Two wonderful sons; our son and his wife live close by, and our other son lives further away.
- Group of friends I get together regularly with to visit, and do social activities with.
- Friends and family who live further away, and we visit as often as we can.
- I attend a group at the Alzheimer Society as well.

Sense of Self

- I’m still me, but sometimes I am hard on myself when I see a change in my abilities.
- I still do the activities I enjoy, and travel.
- I question ‘what if’ sometimes.
- It is an up and down journey, but mostly I feel good.

Being a Woman with Dementia

- Personal connection: my mother and grandmother.
- I used to do everything for the household and my family, and now my husband does much more.
- Notice that more men with dementia attend programs and services.

My Advice

- Developed tips and tricks so I can do all the things I like.
- Be kind to myself.
- Focus on today.
- Its important how you approach someone with dementia.
- I need to do something a few times to feel comfortable .
- I tell people my diagnosis as needed when I am out and about, so that I can be helped where/when I need it.

Panel Discussion

Questions?

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