

Self Management Café Scientifique
Perth, Ontario
April 18th 2012

Presenters:

Dr. Elaine Wiersma, Associate Professor, Department of Health Sciences; Research Affiliate, CERAH Lakehead University.

Dr. Bruce Sells, Caregiver, Retired Research Scientist in Molecular Biology.

Moderator: Felicia White, Knowledge Broker, Alzheimer Knowledge Exchange

Key Messages from discussion

“The overall mindset around dementia is different than chronic diseases; cancer can happen at any age where dementia usually occurs later in life”

- Dementia is a chronic disease- needs to be acknowledged
- Terminology can create barriers (i.e. be clear about the definitions of Alzheimer’s disease and Dementia and don’t use acronyms)
- Acknowledge the experience and knowledge people already have and focus on building on that
- Should criteria be developed for programs to ensure service providers have the right people in each session?
- How do service providers such as the Alzheimer Society decide where people best fit for programs and what the individuals’ limitations are?
- Programs should respond to each stage of dementia (more services needed for the “in between” phases- not just early and late stage)
- At what stage is it a problem to leave a person with dementia alone? Is there an answer?
- Give a person with dementia freedom and a chance to self manage on their own while taking preventative measures to avoid safety concerns

Self Management Café Scientifique

Ottawa, Ontario

April 19th 2012

Presenters:

Dr. Elaine Wiersma, Associate Professor, Department of Health Sciences; Research Affiliate, CERAH Lakehead University.

Dr. Ken Le Clair, Clinical Director Regional Geriatric Psychiatry, Providence Care

Myra Conway, Caregiver; Volunteer with the Alzheimer Society of Ottawa and Renfrew County

Moderator: Felicia White, Knowledge Broker, Alzheimer Knowledge Exchange

Key Messages from discussion

“Your life does not have to stop”

“Keep making decisions together”

“Always keep the person with dementia in the loop when decisions are being made- including the small stuff” (i.e. which route to take home)

- Co-Management is critical
- Make sure a person’s dignity is respected and good quality care is there.
- Education needed on how to change programs (i.e. support groups) when needed
- How to identify when people should participate in programs- which stages?- Everyone is different; it depends on each individual
- Accommodations must be made for participants of programs
- Self management programs are not flexible enough
- Champlain Dementia Network has established a self management program
- Ask questions- what networks do persons with dementia and their caregivers need?
- Link to those networks and build on them as much as possible- including spiritual ones
- Have an open mind
- Don’t be afraid to change your mind (i.e. going to a support group, even if you never thought you would)
- If support groups are not what you want or need there are others such as music therapy etc.
- Keep life interesting- build links in your community to help support you
- What does early onset mean?
- Are people being taught about self management?
- Dementia is a chronic disease- needs to be acknowledged

- Include the lived experience piece in schooling and training
- Provide education in high schools and post secondary to stand up against stigma and focus on prevention
- Build more partnerships amongst agencies- share records, create system change so everyone can work together and provide more support for persons with dementia and their families



**Self Management Café Scientifique
Thunder Bay, Ontario
December 2012**

Presenters:

Dr. Elaine Wiersma, Associate Professor, Department of Health Sciences; Research Affiliate, CERAH Lakehead University.

Dr. Carrie McAiney, Assistant Professor Psychiatry and Behavioural Neurosciences, McMaster University

Bill Heibein, Personal Advocate and Person Living with Dementia, Alzheimer Society of Thunder Bay

Moderator: Felicia White, Knowledge Broker, Alzheimer Knowledge Exchange

Key Messages from discussion

This event was broadcasted through OTN technology reaching a total of 3 districts in Thunder Bay. Most participants of the Self Management Research Program were present and able to connect with others about their work and the voice they are given as persons with dementia and care partners through the development of the program.

- It is important to build more partnerships amongst community, voices of persons with dementia, care partners and those working in the field. This will have a positive impact on policy, research and care.
- The current self management and dementia community of practice (CoP) through the AKE has representation of persons with dementia, family care partners and dementia care professionals. The CoP can help facilitate some of these relationships and address gaps in information, tools and resources as well as provide an opportunity for people to create new knowledge together.
- We must reduce duplication by partnering with other organizations and keep a tab on what is happening regionally
- Other initiatives include MAREP's education tools (<http://www.marep.uwaterloo.ca/products/>), Age Friendly Communities (<http://afc.uwaterloo.ca/>) and PIDC Alliance (<https://uwaterloo.ca/partnerships-in-dementia-care/>) etc.
- Also look at examples internationally.