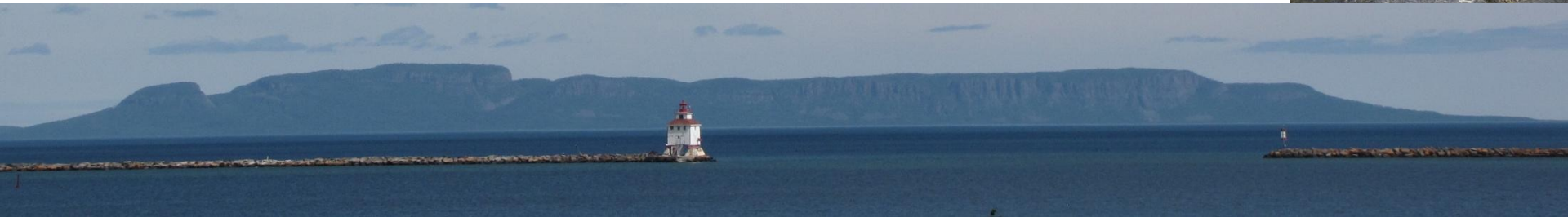
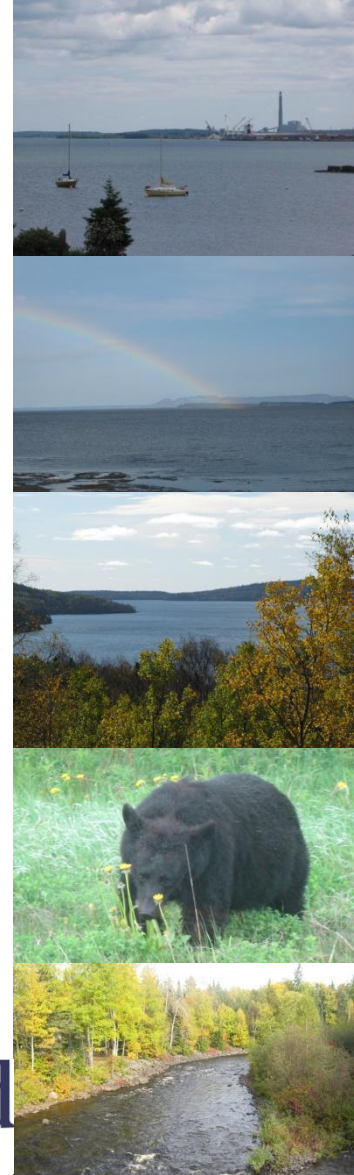


# Self-Management and Dementia

Elaine Wiersma, PhD  
Associate Professor  
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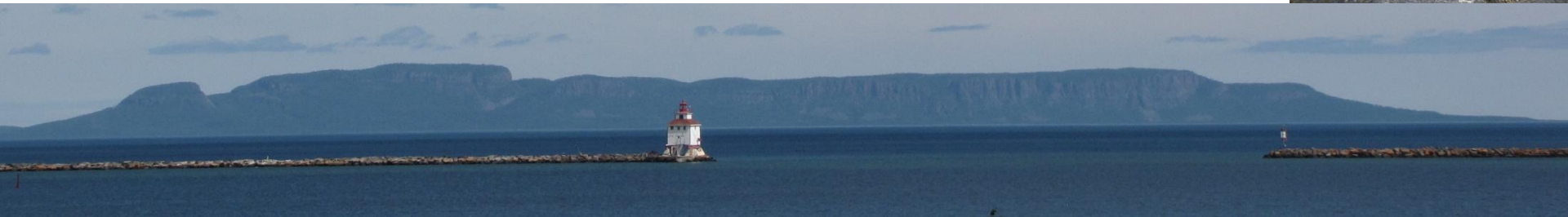
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# Outline

- What is self-management?
- How is self-management used in chronic disease management?
- Can self-management be used in the dementia context?
- What does self-management look like in the dementia context?
- What benefits and challenges does self-management bring for dementia care?

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# Research Team

- Centre for Education and Research on Aging and Health (CERAH), Lakehead University
  - Dr. Elaine Wiersma, Dr. Mary Lou Kelley, Ruth Wilford
- Murray Alzheimer Research and Education Program (MAREP), division of the Research Institute for Aging (RIA), University of Waterloo
  - Dr. Sherry Dupuis
- Centre for Studies in Aging & Health at Providence Care, Queen's University
  - Dr. Kenneth LeClair, Dr. John Puxty

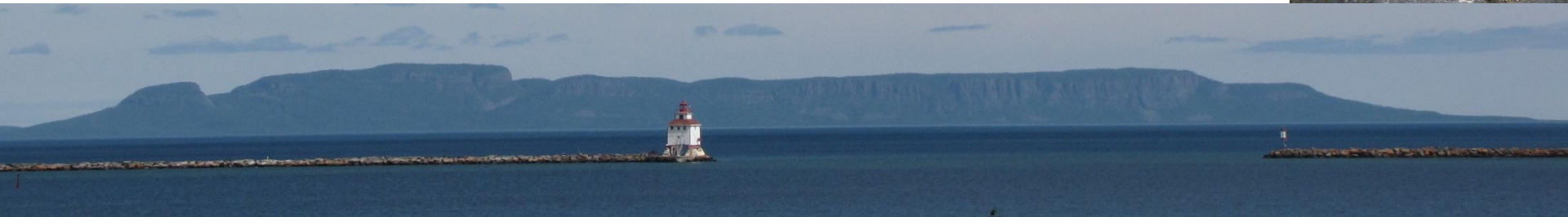


# What is self-management?

•“...learning and practicing the skills necessary *[and having the supports]* to carry on an active and emotionally satisfying life in the face of a chronic condition...”

•Adapted from Lorig, K. (1993). Self-management of chronic illness: A model for the future. *Generations XVII(3)*, 11-14. [p. 11]

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# The CDSMP

- Stanford Patient Education Research Center`s *Chronic Disease Self Management Program*
- based on self-efficacy theory

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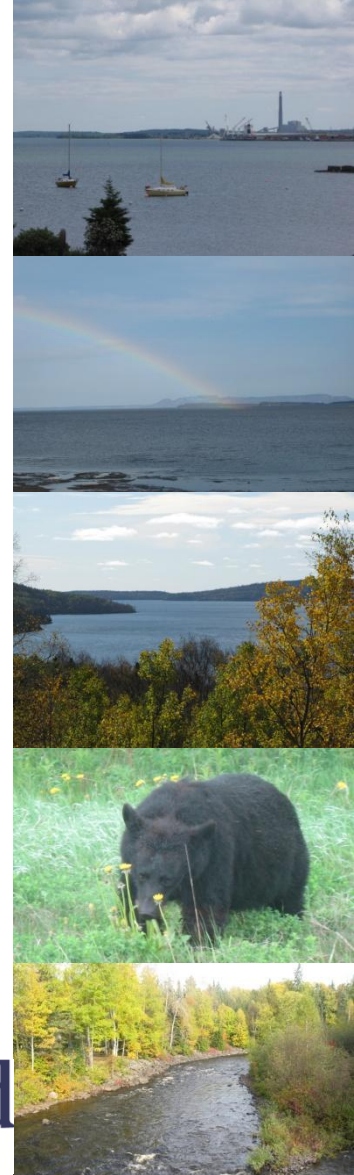


# Characteristics of Self-Management Programs

- Problem solving
- Decision-making
- Finding and utilizing resources
- Helping to form partnerships with health care providers
- Taking action

Lorig, K.R., & Holman, H.R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1-7.

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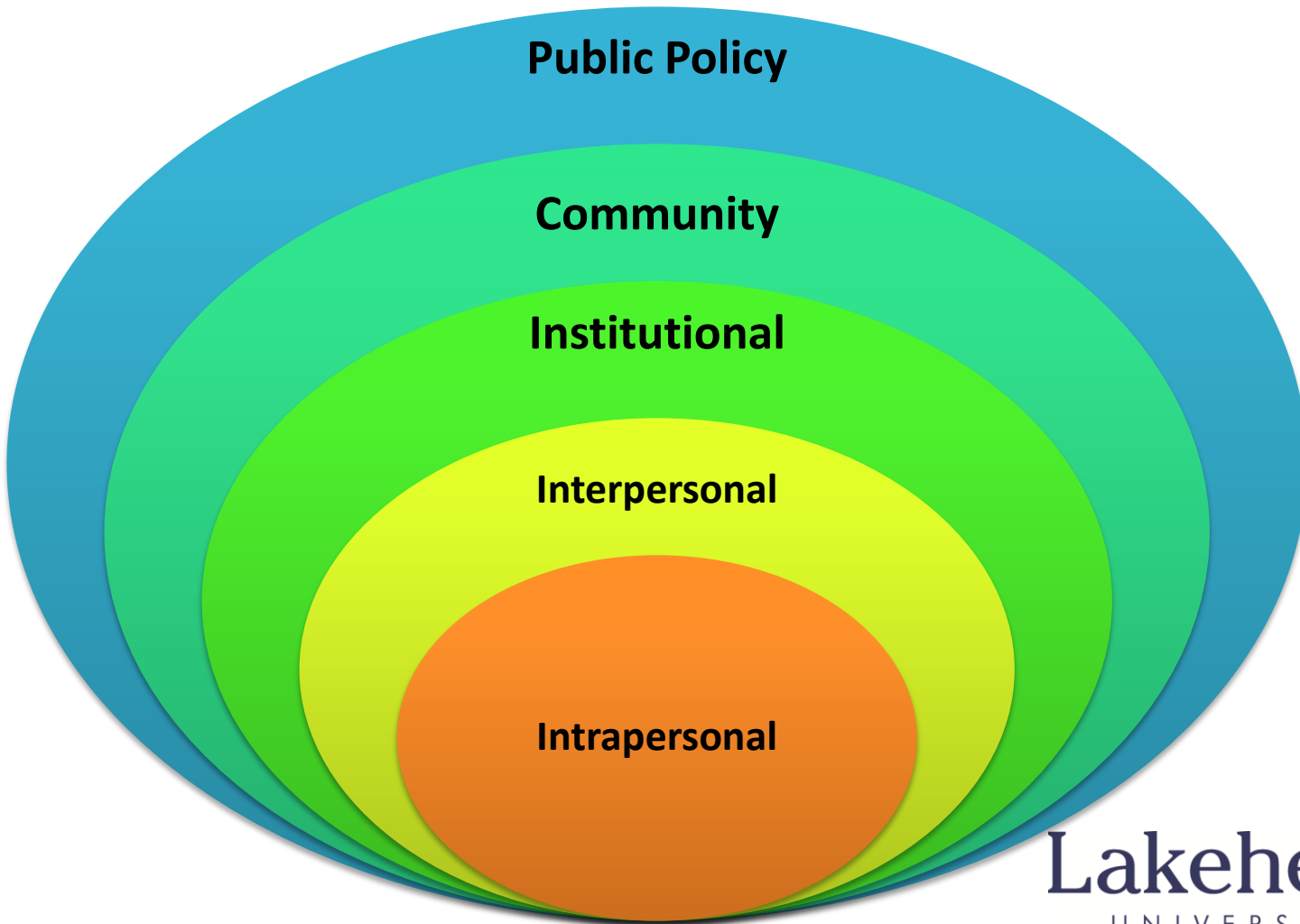
# Should we be using self-management approaches in dementia?

- Desires of people with dementia to manage their own lives and care
- Underpinned by notions of empowerment, control, and partnerships
- Political value of positioning dementia within chronic disease prevention and management

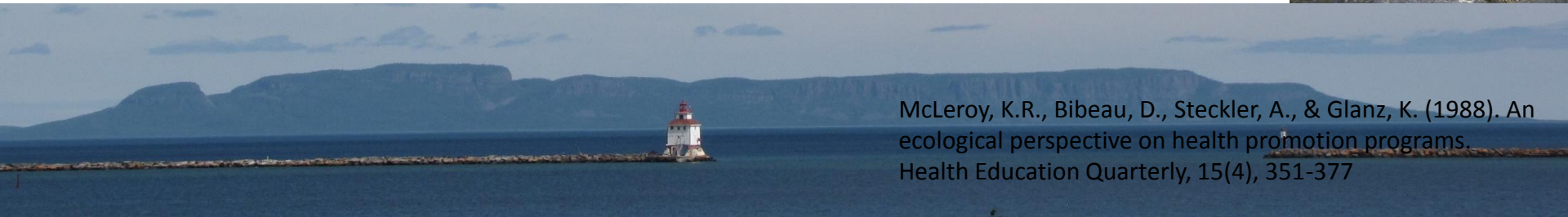
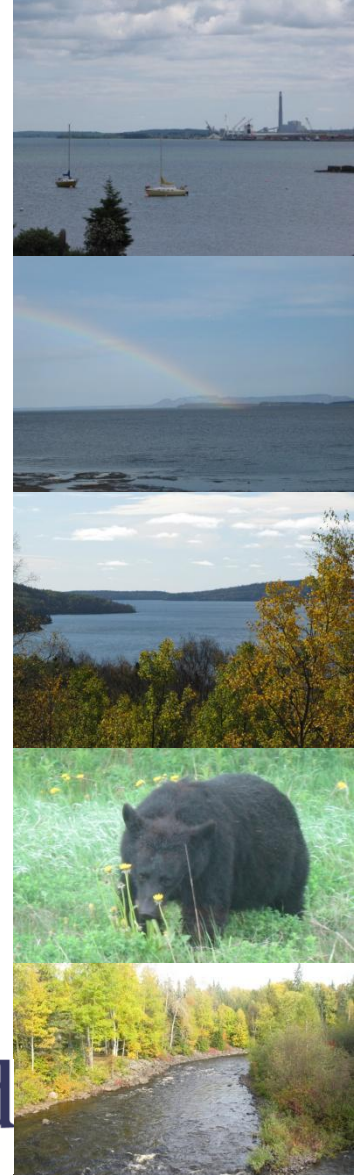
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# Social Ecological Model



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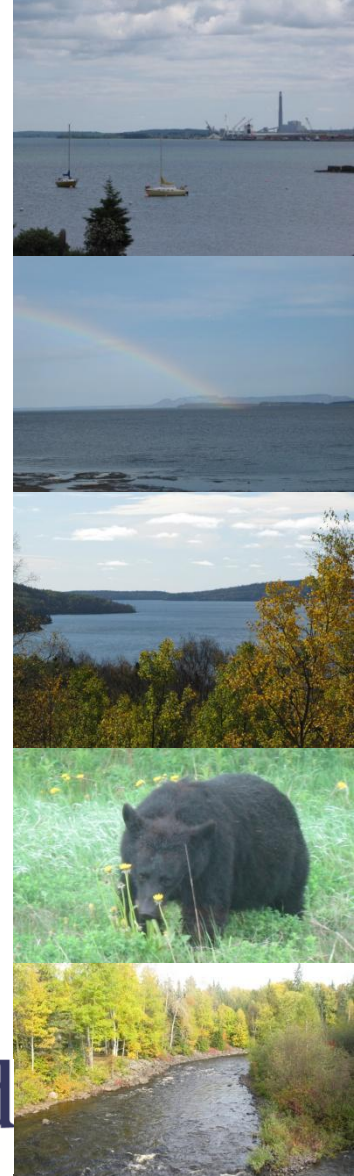


McLeroy, K.R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, 15(4), 351-377



- Research purpose: To explore the meaning of self-management from various perspectives—people with dementia, care partners, and health care providers
- Methodology: Open-ended questionnaire (90 responses)
- Focus groups and individual interviews (40 participants in total)
  - 17 people living with dementia
  - 9 care partners/family members
  - 14 health care providers

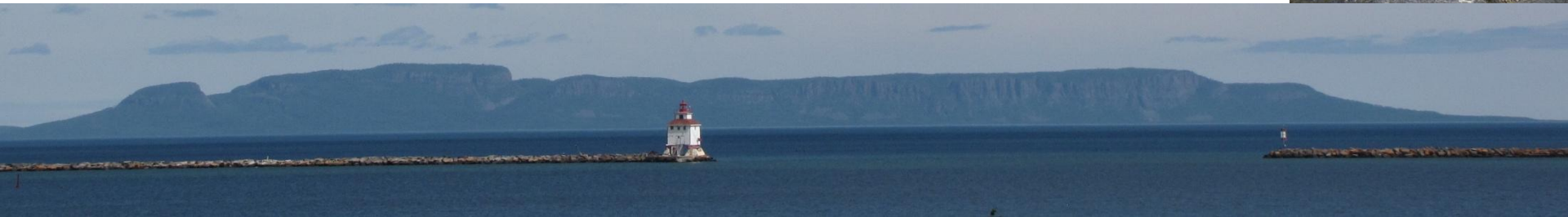
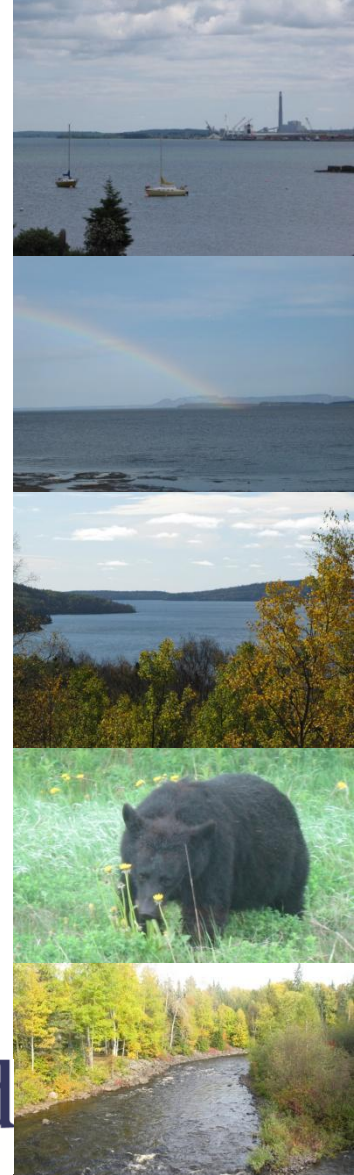
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# Self-Management of Dementia is:

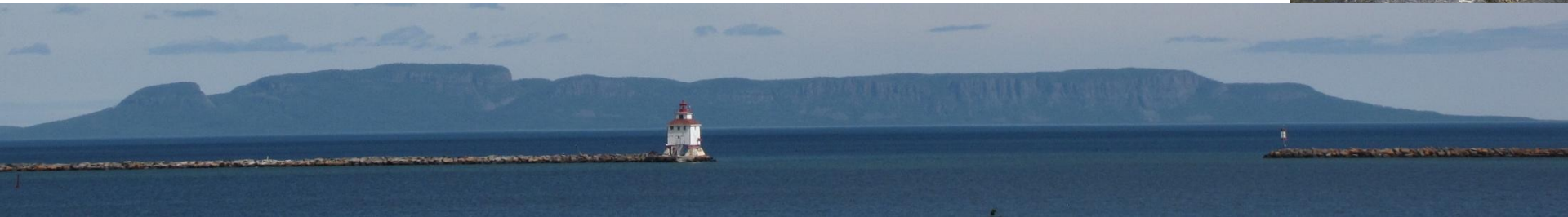
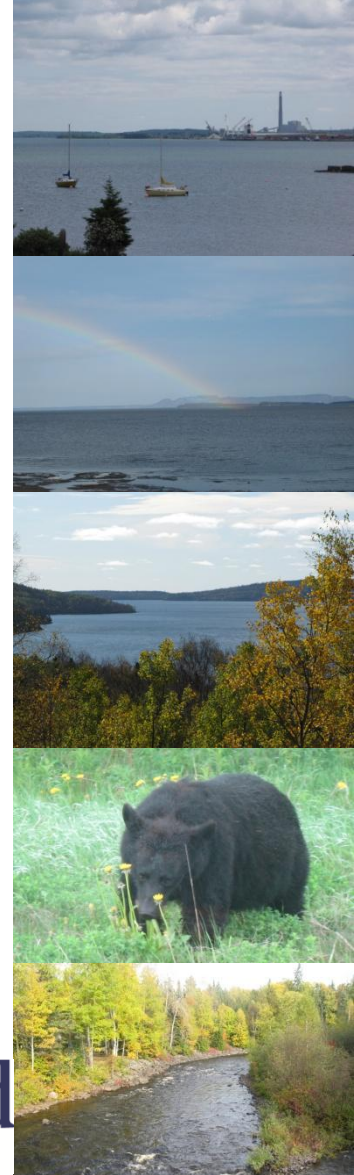
- *“...self-management is the skills, tools, strategies, connections that people with early-stage dementia and their families can garner in order to maintain their independence and maintain quality of life.” (health service provider)*
- *“It might mean how do you make the best of what situation you’re in.” (family)*

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- ***“...Self-management is the true, blunt concept of it. We have to learn to manage ourselves...and what other term can you use? Sometimes in our journey it has to be the truth, and that’s maybe a bit blunt for some folks. But it’s the truth. To get the best out of life, we have to manage ourselves in the most productive manner...self-management—it’s managing yourself to give yourself the best that life can give you...”***

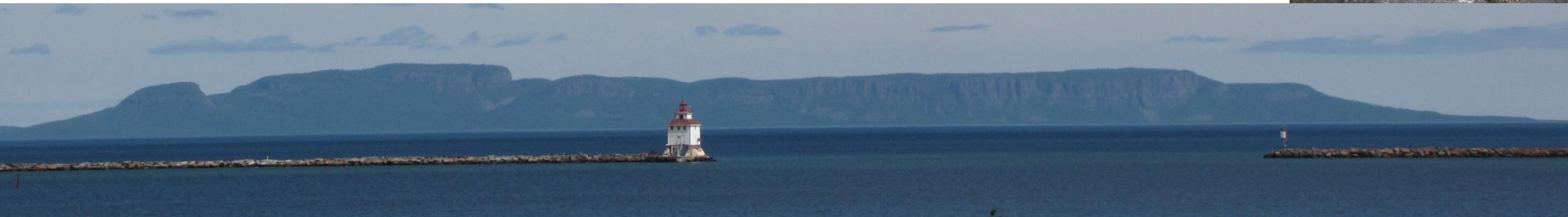
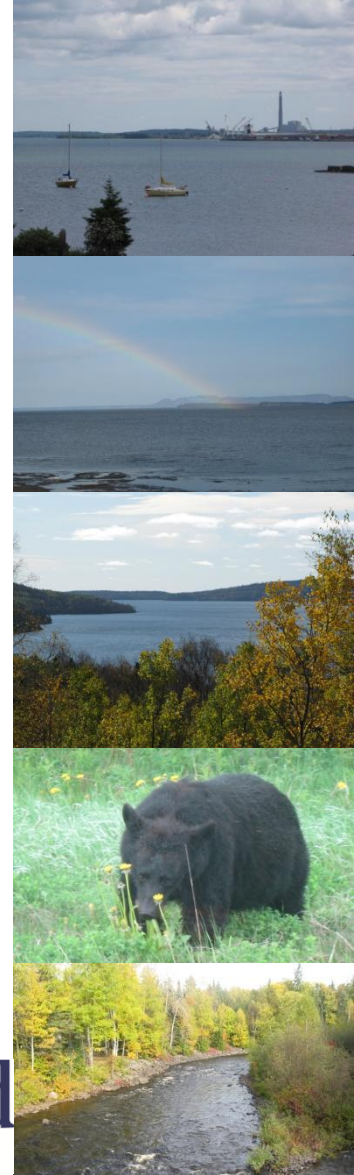
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# What is self-management to people with dementia and their partners in care?

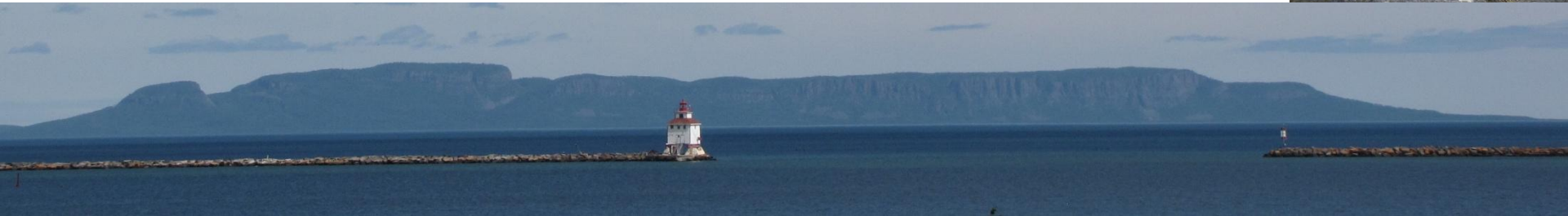
- Managing the physical (and cognitive) aspects of the disease: strategies to compensate for memory loss and cognitive stimulation, physical activity
- Emotional management, including a positive attitude and a day-by-day approach
- Role management, including social support
- System support, including the Alzheimer Society

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- *“Hang in there. As one of my peers said, at least I’m still on the right side of the grass... think of the little things that you still can enjoy and enhance that... so we need to celebrate the little moment, and if we have one little moment where we think that’s great, then usually the rest of the day will be good.” (person with dementia)*

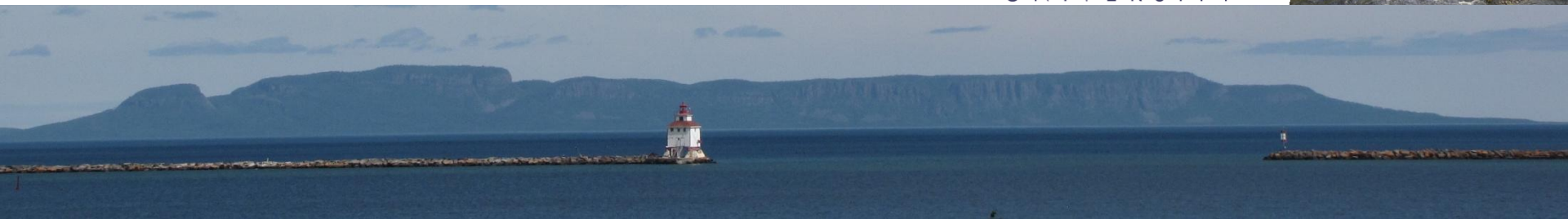
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- *“The camaraderie that we’ve formed between us here, we’re just one big happy family. It’s been fun and it’s helped through a lot of rough spots.”*
  
- *“That’s one of the things I would encourage someone, even if they don’t consider themselves joiners. And I did not. The whole group idea kind of made me a little bit nuts... and you have to remember that this is a club that nobody wants to join. But once you’re in it, it has benefits that you just can’t even begin to imagine.” (person with dementia)*

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# Self-Management Support

- Health care system
- Obtaining a clear diagnosis
- Necessary information about the diagnosis
- Available resources
- Supportive health care providers

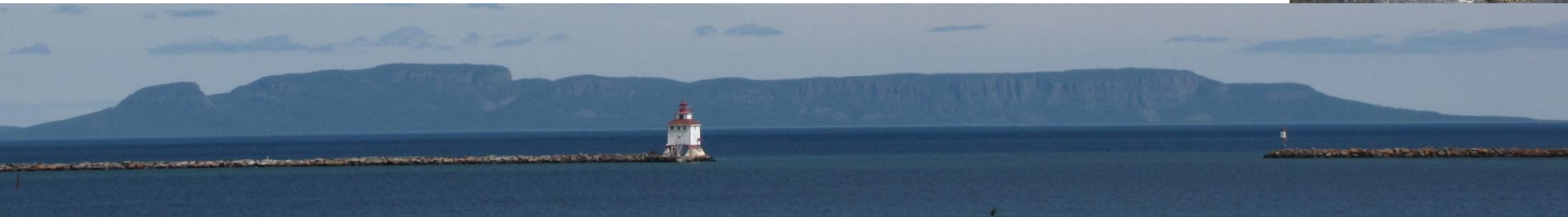
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# Questions and Challenges

- A philosophy, framework or program?
- Balancing the problem focus in self-management with strengths-based approaches
- Setting people up for success and not failure
- Varying types of dementias and co-morbidities
- Flexible approaches
- Balancing “living in the moment” with planning for the future
- Roles of care partners
- Transitioning into “co-management” throughout the dementia journey
- Self-management for care partners

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# Thank you!

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