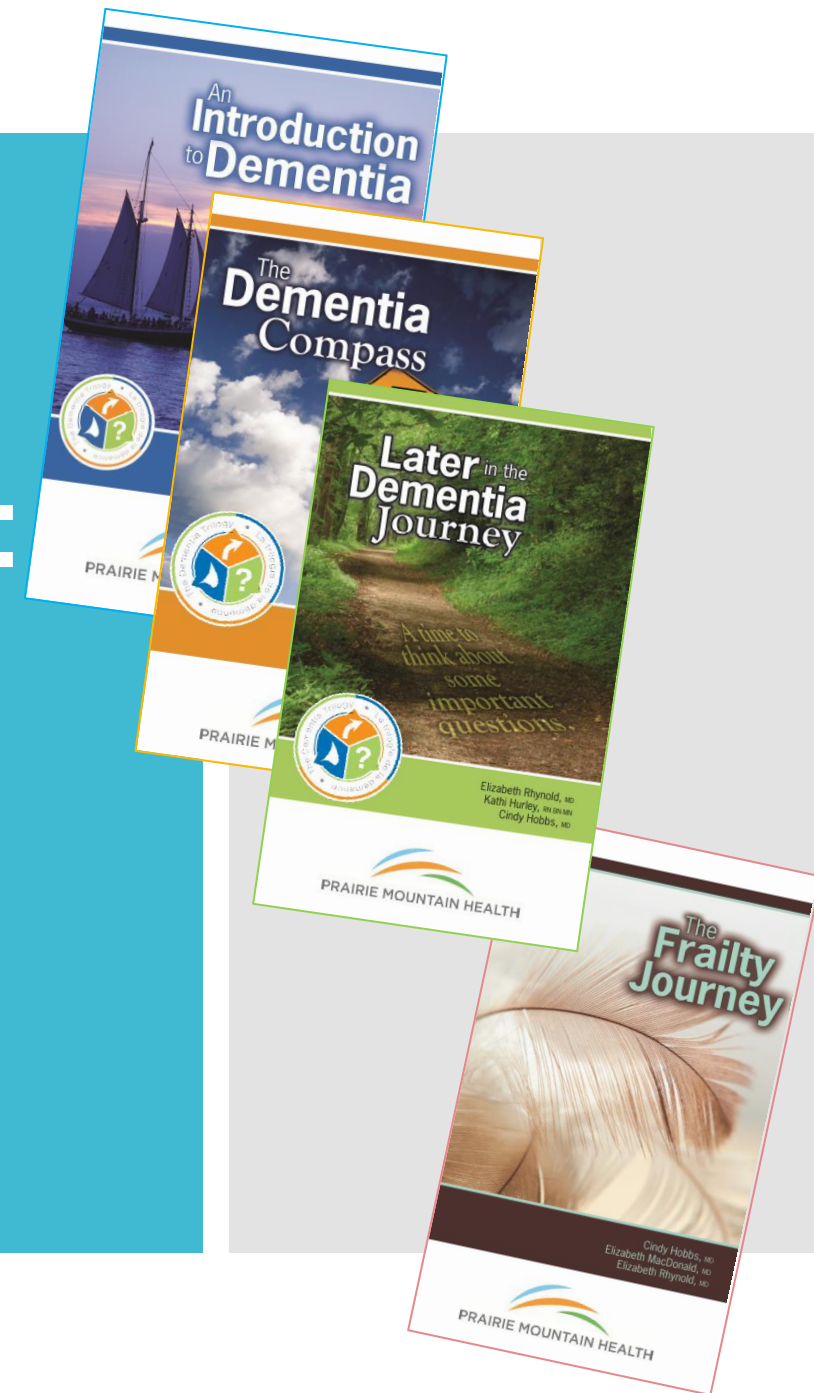


“The Dementia Trilogy”: Development of Patient/Family/Staff Education Materials about Dementia and Frailty

Elizabeth Rhynold, MD FRCPC

Geriatrician working in Prairie Mountain Health since 2016



Faculty/ Presenter Disclosure



- **Faculty:** Elizabeth Rhynold
- **Relationships with commercial interests:**
 - **Grants/Research Support:** nil
 - **Speakers Bureau/Honoraria:** nil.
 - **Consulting Fees:** nil
 - **Other:** Work is supported by Prairie Mountain Health. The copy right specifically states that no profit can be made from the use of the educational materials for the education of patients, caregivers and staff

Mitigating Potential Bias



- Not applicable

Objectives



- Summarize evidence to support supplementing education with written material
- Highlight content in the Dementia Trilogy and the Frailty Journey
- List some contexts in which the booklets have been used in my clinical practice
- Describe some feedback both positive and negative
- Advocate for copies of written resources to supplement education available from the Alzheimer Society

The Origin Story of *"The Dementia Trilogy"*



- 2008 Saskatoon, SK

Remembering medical information



- Kessels, R. Patient's memory for medical information. *Journal of the Royal Society of Medicine* 2003
 - 40 – 80% of medical information provided by health care practitioners is forgotten immediately
 - Half of the information remembered is incorrect
 - Medical information that confirmed existing beliefs was better remembered. Acquiring totally new information is easier than correcting preexisting knowledge
 - Recall is worse when medical information is related to the participant's own illness and has personal relevance
 - Written information is better remembered and leads to better treatment adherence

The Handout Bandit

- Too much of a good thing:



The Dementia Compass

*"Getting you
going in the right
direction!"*



Introduction

- Communication

Part 1: Day-to-day routine

- Getting ready in the morning, Bathing, Toileting, Eating,

Part 2: Personality changes

- Lack of motivation, Depression, Pacing/Restlessness, Changes in sleep, Agitation & aggression, Altered reality (Suspicious, Hallucinations), Changes in sex drive, Violence

An Introduction to Dementia

*"Helping you
chart a course"*



- What is dementia?
- Domains of cognition: memory, language, recognition...
- What's the difference between dementia and Alzheimer's disease? Lewy body dementia, Parkinson's dementia, Vascular dementia, Mixed dementia frontotemporal dementia
- Diagnosis
- Treatment
- Safety issues: driving, getting lost, supervision
- Powers of attorney, advanced care directives and wills
- Stages of dementia

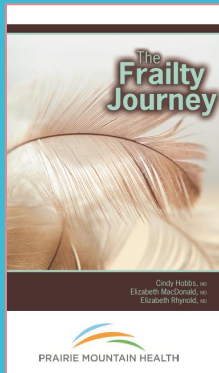
Later in the Dementia Journey

*"A time to think
about some
important
questions"*



- Introduction: What to expect in the later stages of dementia
- Part 1:
 - Where people with late stage dementia live
- Part 2:
 - Making comfort the priority
- Part 3:
 - Decision-making
- Part 4
 - How life changes for the caregiver

The Frailty Journey



- Part 1
 - Why is frailty important
 - How do you know if someone is frail
- Part 2
 - Health priorities, targets & guidelines, DM, HTN, major decisions
 - What to expect as frailty progresses
- Part 3: Supporting a Frail Adult
 - How plans change over time, 24 hour care, moving to a nursing home

Common to the booklets



- Additional information
- The Dementia Compass, Later in the Dementia Journey and The Frailty Journey
 - Life story
 - Sensory preferences

Use of the booklets



- Loosely, the Dementia Trilogy aligns with the stages of dementia
- I would feel comfortable having all the booklets except Later in the Dementia Journey out on my wall of information
- I challenge us as health care providers to recognize the need to proactively start the conversation about dementia diagnosis, late stage dementia and frailty
 - For discussion, could there be a goal to provide education at 3 months into a personal care home admission
- Often I am giving 2 or 3 of the Dementia Trilogy booklets at one time
- I offer that they are available online (Horizonnb.ca) and give one copy on paper
- I provide copies to staff or direct them to the Intranet site

Feedback

- **Language used was clear and understandable**
- **Information included was helpful and beneficial**
- **There was interest in sharing the booklets with others**
- **Readers expressed an improved outlook towards the future**
- **Benefits extended to caregivers, family members, health care professionals and dementia advocates.**



- In New Brunswick we did a satisfaction survey in our ambulatory clinic
 - “Most noteworthy is the manner in which they were written” in simple language made easy to understand...the information provided has given us the power we need to face the future together.” Maric C.
 - >9/10 with 10 being very helpful
- A quality improvement project in the same clinic alternated colour covers and black & white covers on our wall of information
 - 37 black & white cover booklets (421 patients)
 - 64 colour cover booklets (422 patients)

Feedback: Controversy regarding *Later in the Dementia Journey*



Email Feedback July 2017

“In the ‘Later in the Dementia Journey’ booklet, there is some phrasing that the staff are taking offense to. **The booklet references acute care sites and states they have rigid times for eating/bathing/medications, give sleeping pills, and tie residents/clients up so they don’t walk around the unit. This isn’t the kind of environment we promote** in either our acute care centers or our personal care homes, and don’t want to be giving staff or families that impression. Is there any possibility that this language can be softened?”

PMH1358 Pages 14 and 15 “Avoiding crisis: The Risks of admission to the hospital

In many provinces there are long waiting lists for getting assessed for help at home and for moving to a nursing home. If there is not enough help at home or if the people providing that help “burns out” the only option may be a trip to the local hospital.

Visits to the hospital are particularly hard on people with dementia. Of course sometimes trips to hospital can not be avoided. Some of the challenges to providing care to people with dementia in the hospital include:

- Changes in their day-to-day routine
- Rigid times for bathing, eating and taking medications
- Loud rooms with multiple strangers
- Less access to water which can lead to dehydration
- Being given sleeping pills or being tied down so that they don’t walk around the unit”

Concluding thoughts



- Education is one of the most important interventions we do in our work. There are opportunities to be more consistent providing information.
- We can't assume people have already been provided with, encoded and retained introductory information.
- Having your favorite written materials at your finger-tips when you need them improves education
- There is room for improvement in funding of print copies on written material for patients and families
- I see these booklets as opening the door to the excellent education and support available from the Alzheimer Society of Canada and the provincial Societies. I use them in tandem with referral to the Alzheimer Society of Manitoba First Link Referral Program

Acknowledgements



- Co-authors Dementia Trilogy: Cindy Hobbs and Kathi Hurley
- Co-authors The Frailty Journey: Cindy Hobbs and Elizabeth MacDonald
- Cover & Interior Design: Sheena Dougan
- A single copy of each booklet is available for you to have at a booth... somewhere here
- Feel free to contact me: erhynold@pmh-mb.ca

Questions???