

Forward with Dementia

Enhancing post-diagnostic supports using co-design

Carrie McAiney, PhD

Associate Professor, School of Public Health Sciences, University of Waterloo
Schlegel Research Chair in Dementia, Schlegel-UW Research Institute for Aging
KTE Co-Lead, Canadian Consortium on Neurodegeneration in Aging

UNIVERSITY OF
WATERLOO



RIA RESEARCH
INSTITUTE
for AGING

Schlegel • UWaterloo • Conestoga

Enhancing Life

Forward
with dementia ●●●

A guide to living with dementia

Land Acknowledgement

I am joining you from Dundas, Ontario. Dundas is on the traditional territory of the Haudenosaunee and Anishinabe nations. The territory was the subject of the Dish with One Spoon Wampum Belt Covenant, an agreement between the Iroquois Confederacy and the Ojibwe and allied nations to peaceably share and care for the resources around the Great Lakes.

Background

According to ASC's Landmark Report:

	2020	2030
Number of Canadians living with dementia	~600,000	

Alzheimer Society of Canada (2022). Navigating the path forward for dementia in Canada: The Landmark Report Study #1.

Background

According to ASC's Landmark Report:

	2020	2030
Number of Canadians living with dementia	~600,000	Almost 1,000,000

Alzheimer Society of Canada (2022). Navigating the path forward for dementia in Canada: The Landmark Report Study #1.

Background

According to ASC's Landmark Report:

	2020	2030
Number of Canadians living with dementia	~600,000	Almost 1,000,000
Number of new cases of dementia	124,000 / yr (348 / day)	

Alzheimer Society of Canada (2022). Navigating the path forward for dementia in Canada: The Landmark Report Study #1.

Background

According to ASC's Landmark Report:

	2020	2030
Number of Canadians living with dementia	~600,000	Almost 1,000,000
Number of new cases of dementia	124,000 / yr (348 / day)	187,000 / yr (512 / day)

Alzheimer Society of Canada (2022). Navigating the path forward for dementia in Canada: The Landmark Report Study #1.

Background

- Clinical guidelines (e.g., CCCDTD) exist in many countries on how to diagnose dementia. However, dementia diagnosis is still suboptimal.
- Rates of undiagnosed dementia in developed countries ranges from ~43% - 70%

Even when a diagnosis is made, it is not always communicated, or not communicated appropriately:

- 89% of family physicians and 97% of specialists usually/routinely tell the family
- 34% of family physicians & 48% of specialists usually/routinely tell the person with dementia

Lang, L., et al., Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis. *BMJ Open*, 2017. 7(2).; Low, L.F., et al., Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners. *Dementia (London)*, 2018, (7-8):2856-2905. doi:10.1177/1471301218761911

Background

Many reasons why dementia diagnostic practices may be suboptimal:

- Stigma & reluctance to seek help
- Physicians feel they lack time, knowledge, and/or skills
- Concern about worrying their patients
- Belief that there is nothing that can help

Milby, E., G. Murphy, and A. Winthrop, Diagnosis disclosure in dementia: Understanding the experiences of clinicians and patients who have recently given or received a diagnosis. *Dementia (London)*, 2017. 16(5): p. 611-628.; Phillips, J., et al., Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *The British Journal of General Practice*, 2012. 62(601): p. e546-e553.; Foley, T., et al., "We're certainly not in our comfort zone": a qualitative study of GPs' dementia-care educational needs. *BMC Family Practice*, 2017. 18(1): 66.

Background

- When a diagnosis of dementia is made, people living with dementia & family care partners:
 - ◆ Are often not given a sense of hope about living with dementia
 - ◆ Need more supports following the diagnosis
- **Project aims:**
 - ◆ To enhance the supports provided following a diagnosis (primary goal)
 - ◆ To promote the communication of a dementia diagnosis that is sensitive, supportive and empowering (secondary goal)

Robinson, L., et al., The transition to dementia – individual and family experiences of receiving a diagnosis: a review. *International Psychogeriatrics*, 2011. 23(7): 1026-1043; Brodaty, H., et al. A survey of dementia carers: doctors' communications, problem behaviours and institutional care. *Aust N Z J Psychiatry*, 1990. 24(3): 362-70; Swaffer, K., Dementia and Prescribed Disengagement™. *Dementia*, 2015. 14(1): 3-6; Wang, K., et al., Perceived provider stigma as a predictor of mental health service users' internalized stigma and disempowerment. *Psychiatry Research*, 2018. 259: 526-531.

Forward with Dementia

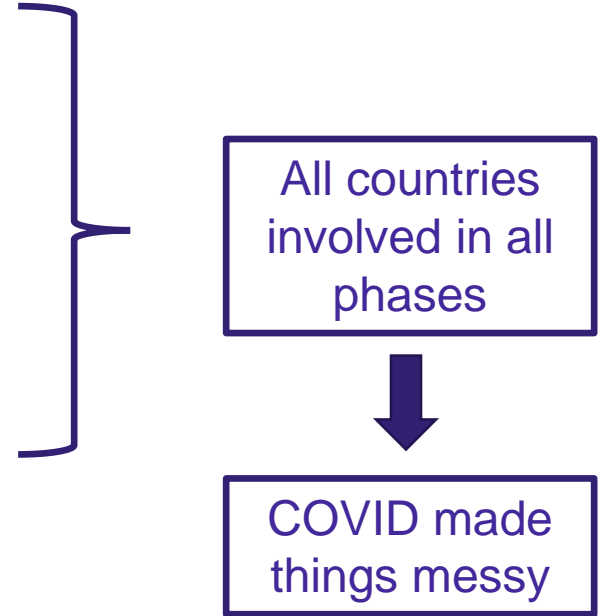
● International study:

- ◆ Australia
- ◆ Netherlands
- ◆ UK
- ◆ Poland
- ◆ Canada (Waterloo Wellington, New Brunswick, Quebec)



Forward with Dementia

- Work Package 1: Surveys & focus groups (Lead: Netherlands)
- Work Package 2: Website development (Lead: UK)
- Work Package 3: Campaign development (Lead: Australia)
- Work Package 4: Evaluation (Lead: Canada)
- Work Package 5: Playbook development (Lead: Poland)



Approach to Developing 'Forward with Dementia'

Participatory (co-design):

- People living with dementia
- Family/friend care partners
- Health care providers
- Social care providers
- Decision makers



Forward with Dementia: Website Development (Work Pkg 2)

- 4 co-design meetings:

- ◆ Included: people with dementia, care partners, providers
- ◆ Held in other countries within a one-week period
- ◆ Specific goals, common resources used – marketing company
- ◆ Findings summarized

Forward with Dementia: Website Development (Work Pkg 2)

● 4 co-design meetings:

- ◆ Included: people with dementia, care partners, providers
- ◆ Held in other countries within a one-week period
- ◆ Specific goals, common resources used – marketing company
- ◆ Findings summarized

● Focus of co-design meetings:

- #1: Understanding experiences (motivations to learn; hopes/needs/fears)
- #2: Campaign messaging ideas
- #3: Website: name & visual brand
- #4: Website design: imagery, type, colours

Forward with Dementia: Website Development (Work Pkg 2)

- Website content:

- ◆ All countries contributed ideas
- ◆ Content written from the perspective of one country
- ◆ Adapted by other countries (language, terminology, services)
- ◆ Pilot tested with people living with dementia and care partner (content, navigation)



Forward with Dementia: Campaign Development (Work Pkg 3)

- Campaign expertise in Australia
- Campaign planning documents
 - ◆ Campaign goals
 - ◆ Determining target audience(s)
 - ◆ Identifying stakeholders
 - ◆ Determining promotional materials and activities



The 'Forward with Dementia' intervention

- Target audience:
 - ◆ People living with dementia & family care partners
 - ◆ Health & social care providers
- Complements existing resources & supports
 - ◆ Alzheimer Society has been an important partner
- Key messages:
 - ◆ Provide hope
 - ◆ Share information on living well with dementia
 - ◆ Share practical resources
 - ◆ Opportunities to learn from others



The 'Forward with Dementia' intervention

The **Forward with Dementia** intervention includes:

- A **website** that has:
 - ◆ Information and practical resources
- A **campaign** that may include:
 - ◆ Webinars & presentations
 - ◆ Media & social media
 - ◆ Promotional materials (pamphlets, postcards, business cards)

forwardwithdementia.ca or **forward-avancer.ca**



Forward with Dementia

Forward
with dementia ●●●

A guide to living with dementia

[Home](#)

[Articles](#) ▾

[Stories](#)

[News](#)

[Get involved](#) ▾



Search



Languages

Please help us improve the site. [Take our quick survey](#) >



[For people with dementia](#) >



[For carers](#) >



[For healthcare professionals](#) >

us
w
at you

Forward with Dementia

For people living with dementia

The categories below contain information, tools, links and stories from other's experiences with dementia

Hearing (or giving) a diagnosis

Coming to terms with dementia

Managing symptoms and changes

Supporting health and wellbeing

Making plans and decisions

Forward with Dementia website – Example of Content

2.8 Share your diagnosis, your way

You are in control of who you tell your diagnosis to, how you tell them, and when you tell them.



There is no right or best way to share your diagnosis

- Many people chose to tell others face to face, or by telephone.
- Some people chose to share the news in letters or by email. One person told us she announced her diagnosis through her annual Christmas card.

Forward with Dementia website – Practical Resource

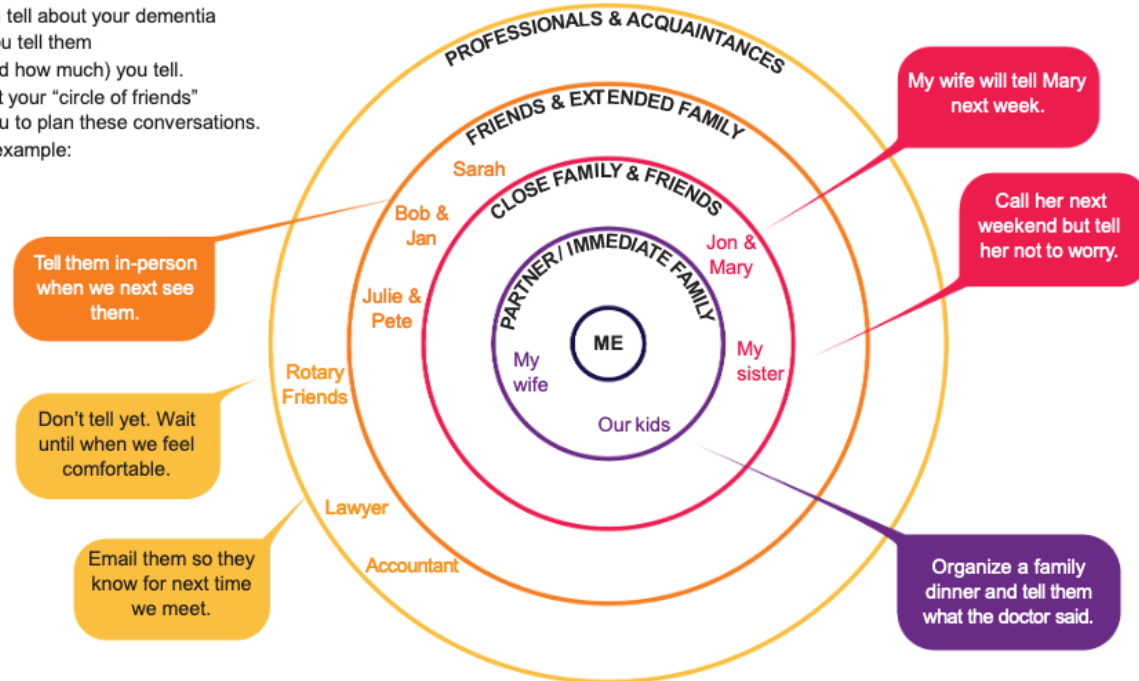
When, and with whom, do I share my dementia diagnosis?

You are in control of:

- who you tell about your dementia
- when you tell them
- how (and how much) you tell.

Drawing out your “circle of friends” can help you to plan these conversations.

Here is an example:



Forward with Dementia



Sharing information to make everyone more comfortable

Fiona was diagnosed with posterior cortical atrophy (PCA) in 2017. Inspired by a suggestion in an online PCA support group, Fiona's daughter wrote a simple document that explained the challenges Fiona was facing.

[> read more](#)

dementia.org/ca-en/news/you-can-still-have-joy-in-your-life/



You can still have joy in your life

Myrna came to realize that just because you are diagnosed with dementia doesn't mean life is over. Somewhere along the line she got permission to be happy, and she sees that as a pivotal moment in her life after diagnosis.

[> read more](#)

Evaluation

- RE-AIM framework, case-study design
- Quantitative data:
 - ◆ web analytics
 - ◆ website & webinar surveys
 - ◆ surveys of people living with dementia & care partners
- Qualitative data:
 - ◆ interviews – people living with dementia, care partners, providers, key informants



Evaluation Highlights: RE-AIM

Reach - # of people willing to participate & characteristics of these individuals

- Total website views (November 2021 – May 2022):
 - English = 24,476
 - French = 11,716
- Newsletter subscribers: 400
- Social media (November 2021 – May 2022):
 - Facebook: 197 followers, 2800+ engagements, 40,000+ total reach
 - Twitter: 195 followers, 17,800 page profile views, 37,000+ tweets viewed
 - YouTube: 8 videos posted, 404 video views
- Personal stories reported to be most impactful

Note: Limited information
on characteristics of
people reached

Evaluation Highlights: RE-AIM

Effectiveness – impact of intervention on important outcomes

- Helpfulness of information on the website, helpfulness of information presented in webinars
 - ‘moderately’ to ‘very’ helpful for people living with dementia and care partners
- Qualitative findings:
 - Interview participants highlighted that the website and campaign activities supported the concept of living well with dementia

Evaluation Highlights: RE-AIM

Adoption – Organizations (& people within organizations) willing to support and/or use the intervention

Individuals within:

- Alzheimer's Society
- Community support services
- Primary care providers

Evaluation Highlights: RE-AIM

Implementation – fidelity, adaptations, facilitators, barriers

- Resources (posters, pamphlets) to raise awareness
- 7 webinars
- 7 newsletters

● Facilitators

- International collaboration
- Use of social media & print resources to raise awareness of website
- Recording webinars

● Barriers

- Limited number of French webinars
- Length of some videos
- Limited information for providers who are not physicians or nurses

Challenges & Next Steps

Challenges:

- COVID
- “Finding” people to engage in the evaluation (COVID)

Next Steps:

- Continue to analyze evaluation data; cross-case analysis
- Continue to add content; expand to other parts of Canada
- Development of a playbook to support implementation in other countries & regions



Thank you!

carrie.mcainey@uwaterloo.ca

Visit us:

forwardwithdementia.ca

or

forward-avancer.ca

Team Canada:

Carrie McAiney
Emma Conway
Evgeny Neiterman

Shelley Doucet
Amy Reid
Luke MacNeill

Alison Luke
Pam Jarrett

Isabelle Vedel
Laura Rojas Rozo

