Dementia Friendly Policy: Where do we go from here?

Dr. Frances Morton-Chang

Living Well With Dementia: Toward Dementia-Friendly Policy Symposium

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The Issue

- Most older persons – including persons living with dementia (PLWD) wish to age at home as independently and for as long as possible (ASO, 2007; ASUK, 2011)

  however...

- Many end up prematurely or inappropriately in some of the most expensive places in the system because few other options exist (Gill et al., 2011; CIHI, 2010a; CIHI, 2011c,d; Andel et al., 2007)
Why it is Important

- Aging population of individuals living with frailty and/or multiple co-morbidities, all of which may be confounded by the challenges of dementia (Walker, 2011)

- While dementia is impacting upon the “system” (longevity, complexity & #’s) the system is not adapting to the needs of PLWD and informal caregivers with many intersecting only at a point of crisis (ASC, 2010; WHO & ADI, 2012)
Why it is Important (con’t)

- Where institutional care is valuable for those in need of high intensity care, it is ill-suited for those with lower intensity care needs.

- Disconnect between needs and supply not good for the system or for individuals
Growing Gap

- Fragmented system with siloed services focused on episodic, curative/acute care (Walker, 2011; Drummond, 2012)
- H&CC sector stretched/inadequate including ethnic/linguistic/cultural challenges (Williams et al., 2016; Morton, 2010)
- No dementia care standards/standardized education
- Navigation/care coordination challenges for PLWD (WHO, 2012; ASC, 2010; ASO, 2010; McAiney et al., 2008)
- Informal caregiving concerns – (inconsistent, intrusive) (Smale & Dupuis, 2004b,c,d; Fast, 2015; Williams et al., 2015 and 2016);
- LTCH or hospital care often become default (e.g. crisis)
Influence of Historical Legacies

- Ontario had a $68.4 million 10-Initiative Strategy
  - 3 decades ago recognized need to improve dementia care through a continuum
  - Incremental change in a positive direction

however

- Strategy was allowed to lapse
- Continues to be a growing mismatch between demand and supply
- History repeating itself
National/Provincial Strategy Achievable?

- Transformative change is difficult
  - Dementia strategies may be more or less comprehensive
  - Difficult to achieve and sustain politically particularly in the face of competing demands from dominant bed-based systems of care

- Incremental change more likely and not veering far from historical pathways
Window of Opportunity

- Federally
  - Bill C-233 – sentiment dementia transcends partisanship
  - Primarily coordination and dissemination of EBPs
  - Senate Report: *Dementia in Canada: A National Strategy for Dementia-Friendly Communities*

- Provincially
  - *Developing Ontario’s Dementia Strategy: Discussion Paper*

Do they open Pandora's box?
Provincial Strategies in Canada

- Existing strategies focus on three broad themes
  - Enhance awareness, information, education, research
  - Improve and coordinate “person-centred” care
  - Acknowledge and support informal caregivers
What Should a Dementia Strategy Aim To Do?

- Where does the money go?
  - Health Care? Or Health?
  - Challenges in hospitals and residential care?
  - Building supportive neighborhoods
  - Integrated health and social care over full continuum
What Could Happen: Interventions

- **Care practices** (e.g., early diagnosis, ongoing case management/education, consistent routines/support staff/volunteers, flexible eligibility criteria, hours)

- **Programs** (e.g., research, supportive housing/assisted living, adult day programs, transportation, MedicAlert® Safely Home®)

- **Clinical and non-clinical services** (e.g., First Link™, memory clinics, respite care, homemaking, meal preparation, monitoring, counselling, education)

- **Built Environment** (e.g., inclusive dementia-friendly communities, campuses of care, small scale design, access to nature, lighting, orientation aids, falls prevention techniques)  
  
  (Morton-Chang, 2015)
Learning From Elsewhere

- The Netherlands
- Germany
- Japan
- England

- Many have been adapted to Ontario
Promising Local Approaches

- Changing Melody Conferences (for PLWD)
- Memory Clinics (in family health teams)
- First Link™ (supporting at point of diagnosis)
- Community Hubs in LTC homes
- Behavioural Support Ontario (LTCH, community)
- Demetria Friendly Built Environment (small-scale)
- Finding Your Way (wandering, safety)
- Taking Control of Our Lives (self-management)
- Dementia Friendly Communities (Blue Umbrella)
- Dementia Friends (broad scale public engagement)
How Might One Build Support?

- Promising Initiatives internationally
- Promising Local Initiatives

So how do you do this?

Three things are crucial…
Future Policy Guiding Pillars

Pillar 1:
Engage PLWD to the extent possible in decisions around their own care and the use of available health resources

Morton-Chang et al., Healthcare Papers Vol. 16 No. 2 (In Press)
Future Policy Guiding Pillars

Pillar 2:
Engage and support informal caregivers as essential partners in care

Morton-Chang et al., Healthcare Papers Vol. 16 No. 2 (In Press)
Future Policy Guiding Pillars

Pillar 3:
Move toward an integrated formal continuum of care aimed at assisting PLWD and caregivers though an enabling policy framework

Morton-Chang et al., Healthcare Papers Vol. 16 No. 2 (In Press)
Enable Promising Local Innovation

- Set clear goals with sustainable funding
- Reduce institutional constraints: funding, legislation, regulations, bureaucratic hurdles
- Address formal system constraints: human resources, community support services, voluntary organizations
- Facilitate inter-sectoral policy development and at different levels (federal, provincial, municipal) across a full continuum of care
- Support inclusive equitable societies where people prosper to their fullest extent
Conclusions

- Dementia is a “game changer”
- In the absence of proactive and preventative policy in H&CC, default to institutional care entrenched
- While difficult to change long standing institutional structures, interests and investments one can build on “points of light”
- 3 overarching pillars crucial to guide coherent strategy
  - person-centred care
  - support for informal caregivers
  - an enabling framework across
Everyone Friendly Strategy

- A dementia-friendly strategy does not strand others – it is a doorway to an everyone friendly strategy

For more information please refer to:

Towards a Community-Based Dementia Care Strategy: How Do We Get There from Here?
Healthcare Papers Special Issue Vol. 16 No. 2 (In Press)
THANK YOU
QUESTIONS?

frances.morton@utoronto.ca
Local Resources

- **Dementia Strategy and Policy:**
  Lauren Rettinger [lrettinger@alzheimeront.org](mailto:lrettinger@alzheimeront.org) & Gagan Gill [ggill@alzheimeront.org](mailto:ggill@alzheimeront.org)

- **Education and Finding Your Way:**
  Cathy Conway: [cconway@alzheimeront.org](mailto:cconway@alzheimeront.org)

- **Taking Control of Our Lives and First Link:**
  Kathy Hickman [khickman@alzheimeront.org](mailto:khickman@alzheimeront.org)

- **Dementia Friendly Communities and Programs:**
  Felicia White [fwhite@alzheimeront.org](mailto:fwhite@alzheimeront.org)
Local Resources

- Ontario Dementia Advisory Group:
  ontariodementia@gmail.com

- Murray Alzheimer Research and Education Program (MAREP)
  Lisa Loiselle loisele@uwaterloo.ca