



# Dementia in Primary Care- practical and..

Good, Bad, and Ugly

Chris Frank, Queen's University  
MD, CCFP, FCFP (COE, PC)

“How would you want diagnosis disclosed to a loved one?”

# Consider

What are your thoughts on advance directives for MAiD?

Which condition do you fear the most: ALS, PSP, Alzheimer's?

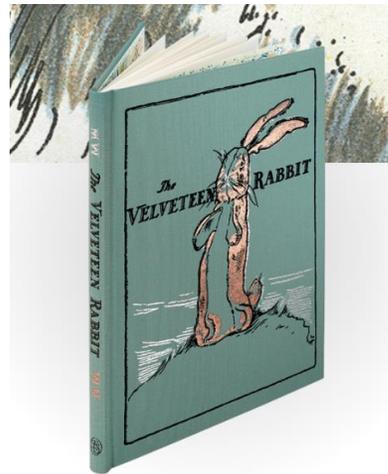
What makes a person a person?

A musician and artist gives us advice

<https://www.facebook.com/granville.johnson>

# The Lived Experience

- *“Once you are real you can’t become unreal again. It lasts for always.”*
- *“Generally, by the time you are Real, most of your hair has been loved off, and your eyes drop out and you get loose in the joints and very shabby. But these things don’t matter at all, because once you are Real you can’t be ugly, except to people who don’t understand.”*



# Relevant medical literature

- “Dementia, in a sense, is a disease of autonomy, and the lives of persons with it are in extended conversation over a question: What’s a good life when you’re losing your ability to determine that life for yourself?”
- “She’s happy, most of the time; it’s me who’s suffering.” *Caregiver*

# Pathophysiology paradigms

- *“Whenever a theory appears to you as the only possible one, take this as a sign that you have neither understood the theory nor the problem which it was intended to solve.”*

*Karl Popper*





Lived Experience

Review Article | Practice

# A patient's experience in dementia care

**Using the “lived experience” to improve care**

Christopher Frank and Rev Faye Forbes

Canadian Family Physician January 2017, 63 (1) 22-26;

# Family physicians and dementia in Canada

## Part 2. Understanding the challenges of dementia care

Nicholas J.G. Pimlott, Malini Persaud, Neil Drummond, Carole A. Cohen, James L. Silviu, Karen Seigel, Gary R. Hollingworth and William B. Dalziel  
Canadian Family Physician May 2009, 55 (5) 508-509.e7;

[Home](#)

[Articles](#)

[Intro to](#)

[About CFP](#)

[Feedback](#)

[Blog](#)

[Article Commentary](#) | [Commentary](#)

# Role of the family physician in dementia care

Ainsley Moore, Christopher Frank and Larry W. Chambers

Canadian Family Physician October 2018, 64 (10) 717-719;

\_\_\_\_\_

# Quality Care

**Figure 1.** Framework of primary care quality indicators for patients with dementia

Access	Integration	Effective care	Efficient care	Population health	Safety	Patient-centred care
Access to a regular primary care provider	Continuity of care	Diagnosis at an early stage of disease	Annual cost of health services	Yearly flu shot (immunization for influenza)	Having a high number of medications	Access to counseling for patients
After-hours access to the regular primary care provider	Telephone calls between the regular primary care provider and specialists	Dementia diagnosed by the regular primary care provider	Duplicate medical tests	Other recommended immunizations	Potentially inappropriate prescriptions for medications associated with serious side effects prescribed by the regular primary care provider	Access to counseling for caregivers
Access to an interprofessional primary care team	Length of time spent in hospital in the year following diagnosis of dementia	Requests for blood tests originating from the regular primary care provider				Access to home care
Visits to the regular primary care provider	Potentially avoidable hospitalizations	Medications prescribed for dementia				Access to long-term care
Nonurgent visits to the emergency department	Visit to the regular primary care provider within 7 days following a hospitalization	First medication for dementia prescribed by the regular primary care provider				Number of days spent in long-term care
	Readmission to the hospital within 30 days following a hospitalization	Annual visit to the regular primary care provider				Access to palliative end-of-life care provided by the regular primary care provider
		Referrals to specialists in dementia originating from the regular primary care provider				Number of days spent in hospital in last 3 months of life
		Referrals to other specialists originating from the regular primary care provider				Support for dying at home
<b>Equity</b>						
Equitable care across all patients						

# Sharing the diagnosis of dementia

## Conclusions

1. Disclosing/sharing the diagnosis of dementia is **important**
2. It is **possible** to do it badly
3. Supporting people with dementia, and their families, after the diagnosis is **essential**

## [Gold Standard article](#)

### Diagnosing Dementia – What to Tell the Patient and Family

Geriatrics and Aging 2005; 8,48-51

“No more than 50% of physicians  
regularly disclose the diagnosis  
to patients with dementia

**WHY?**

# Failing to plan.....

## **EDITORIAL**

HOSPITALS “FAILING TO PLAN FOR DEMENTIA IS PLANNING TO FAIL”: ALL CANADIAN HOSPITALS MUST LAUNCH ACUTE CARE DEMENTIA STRATEGIES IF THEY ARE SERIOUS ABOUT DECREASING HOSPITAL OVERCROWDING, DECREASING ALTERNATE LEVEL OF CARE (ALC), AND THEREBY INCREASING HOSPITAL CAPACITY TO PERMIT PANDEMIC RECOVERY AND TO MEET FUTURE ESCALATING NEEDS

# Acute Care-Important components



Surname \_\_\_\_\_ MRN \_\_\_\_\_  
Given Names \_\_\_\_\_  
Date of Birth \_\_\_\_\_ Sex \_\_\_\_\_  
(Affix Patient Label here)

**Strategies to Support Care and Communication**  
Place this form on top of the patient bed chart notes

- 1.
- 2.
- 3.
- 4.
- 5.

Carer Name: \_\_\_\_\_ Date: \_\_\_\_\_  
Staff Member: \_\_\_\_\_ Date: \_\_\_\_\_

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF Health and Medical Research Foundation.

2012 Version 2

- Hospital- level data
- Corporate commitment
- Detection and documentation
- Value and support families as Essential Care partners
- Person-centred care to meet physical needs (cannot be expressed)
- Training and staff support
- Dementia care expertise
- Non-pharmacological interventions
- Individualized discharge planning
- Supportive physical environments

# My clinic template

- Dear Dr. Smith , thank you for referring [] to Geriatric Clinic.
- Onset and progression-
- Functional status: Phone/ Transportation/ Medication adherence/ Finances/ Other
- Other-
- PH&Medications:
  - Social history/Lifestyle and environment factors-
  - Family history-
- Safety issues: Driving/ Wandering/Home-
- Advance care planning
- Imaging/Labs/Physical Examination
- **Formulation and plan:**