

AN ETHICAL DECISION-MAKING ROADMAP: SUPPORTING PERSONS WITH DEMENTIA

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*Empty-handed I entered the world.
Barefoot I leave it.
My coming, my going
Two simple happenings
That got entangled.*

—Kozan Ichikyo (d. 1360).

AGING

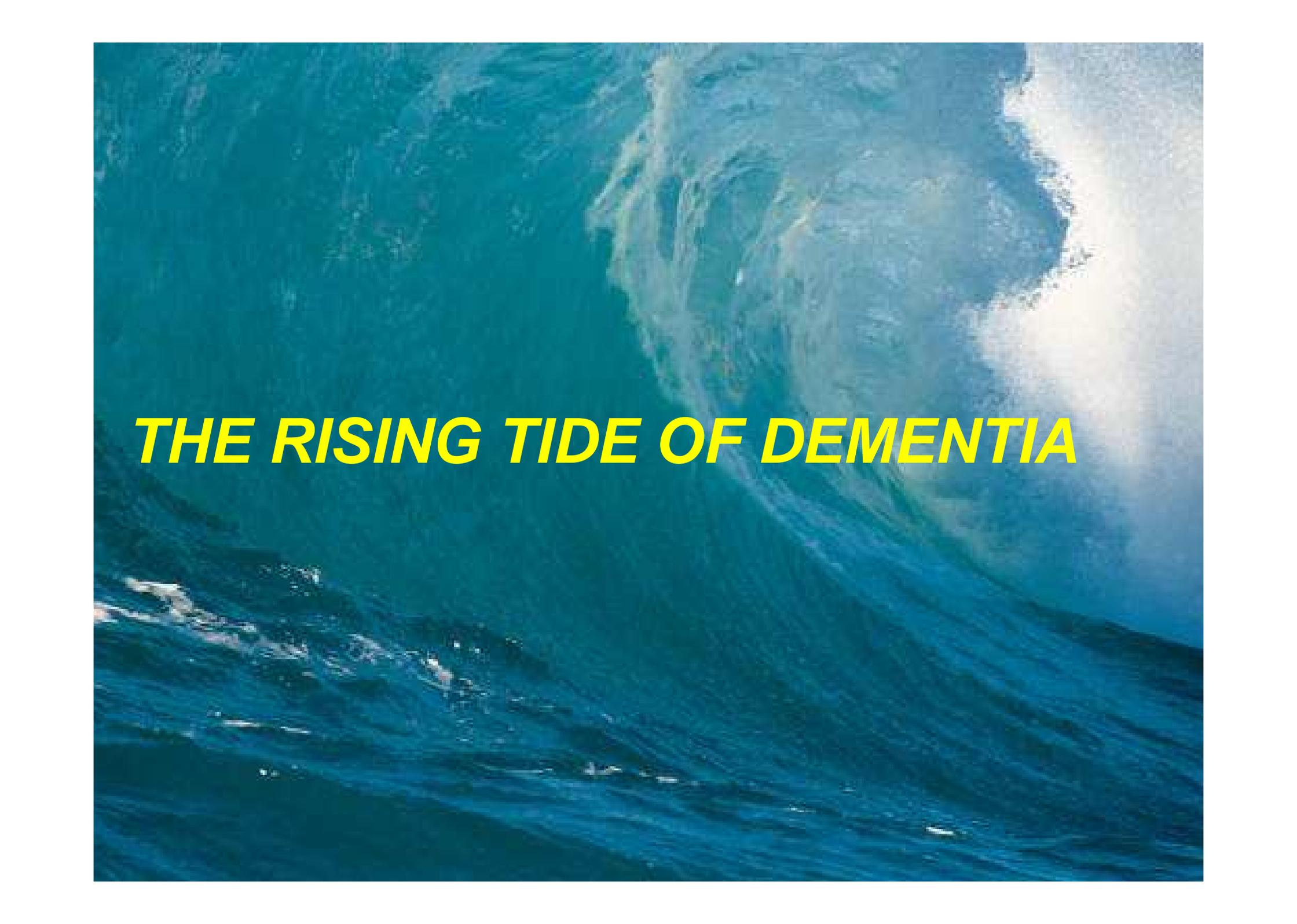
Old Age Contemplating Youth: A Painting by Ruth Rintel



AGEISM

Reflection: A Painting by Ruth Rintel



A dramatic photograph of a massive blue wave crashing, with white foam at the crest. The water is a deep, vibrant blue, and the sky is a lighter, hazy blue. The wave is the central focus, moving from the right side of the frame towards the left.

THE RISING TIDE OF DEMENTIA

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- ❖ 1 in 11 Canadians over the age of 65 has Alzheimer's disease or a related dementia.
- ❖ Of the 500,000 Canadians affected by dementia, more than 71,000 of them are under the age of 65, and approximately 50,000 of them are under the age of 60.
- ❖ As it stands today, the number of Canadians living with Alzheimer's disease or a related dementia will more than double within a generation (25 years).

—Alzheimer Society of Canada (2009).

Retrieved September 2, 2010 from:

<http://www.alzheimer.ca/english/media/putyourmind09-release.htm>.

OVERVIEW

- ❖ The Project
- ❖ Ethical and Legal Perspectives
- ❖ Background Paper
- ❖ Resources Developed
- ❖ Group Discussion



PROJECT

*Guiding Ethical and Legal Planning for
Persons with Dementia and Their Families*





We live in a culture that is, at least in large segments, dominated by heightened expectations of rationalism and economic productivity, so clarity of mind and productivity inevitably influence our sense of the worth of a human life.

—Post, S. G. (2000, p. 5).
*The moral challenge of Alzheimer disease:
Ethical issues from diagnosis to dying (2nd ed.).*
Baltimore and London: The Johns Hopkins University Press.

PERSPECTIVES ON PERSONHOOD

“The conceptual view we have of the person will affect the care we are prone to give” to those with severe dementia.

—Hughes, J. C. (2001, p. 86).
Views of the person with dementia.
Journal of Medical Ethics, 27(2): 86-91.





HOLDING ONE ANOTHER IN A TIME OF DEMENTIA

—Lindemann, H. (2009).
Holding one another (well, wrongly, clumsily) in a time of dementia.
Journal Compilation. Metaphilosophy , 40(3-4):0026-1068.
I.I.C. and Blackwell Publishing Company.
Malden, MA: Blackwell Publishing Ltd.

DECISION-MAKING

...When we make decisions with or for people living with dementia, how we do this reflects and constitutes the sort of people we are, and are becoming. Decision-making is thus not a neutral act but one entwined with ethics and thus with character.

—Baldwin, C. (2009, p. 34).
Narrative and decision-making.
In D. O'Connor & B. Purves (Eds.).
Decision-making, personhood and dementia: Exploring the interface (pp. 25-36).
London, UK: Jessica Kingsley Publishers.

I FEEL DISCREDITED AND DEVALUED

It hurts when I am second-guessed or when people ignore me and talk to my family partner in care before talking to me. I do not like being treated like a child or treated as though I am not there. I sometimes do not feel validated, or I feel that I am no longer considered 'an expert' capable of making valid decisions.

—Murray Alzheimer Research and Education Program, University of Waterloo. (2007, p. 5).

Enhancing Communication: An Inspirational Guide for People Like Us with Early-stage Memory Loss: A "By Us For Us" Guide.

Retrieved January 19, 2012 from

http://marep.uwaterloo.ca/products/BUFU/88483_enhancing.communication.pdf.

DECISION-MAKING AND DEMENTIA

...How can the relationship between personhood, dementia and decision-making ability be conceptualized and understood? Where do notions of capacity fit, particularly when premised upon cognitive functioning?

— O'Connor, D. & Purves, B. (2009, p. 15).
Decision-making, personhood and dementia: Mapping the terrain.
In D. O'Connor & B. Purves. (Eds.). (pp. 11-21).
Decision-making, Personhood and Dementia: Exploring the Interface.
London, UK: Jessica Kingsley Publishers.

THE SIGNPOSTS



SIGNPOSTS

- ❖ Looking for help.
- ❖ Getting a diagnosis.
- ❖ Respecting the person with dementia.
- ❖ Planning ahead for resources you will need to put your affairs in order.
- ❖ Living each day to the fullest.
- ❖ Moving into a care facility.
- ❖ Coming to the end of the journey.

People with dementia should be supported to help them take part in decisions as much as possible. If they can't make decisions entirely on their own, then they may still be able to make decisions jointly with trusted family or friends.

— Nuffield Council on Bioethics.

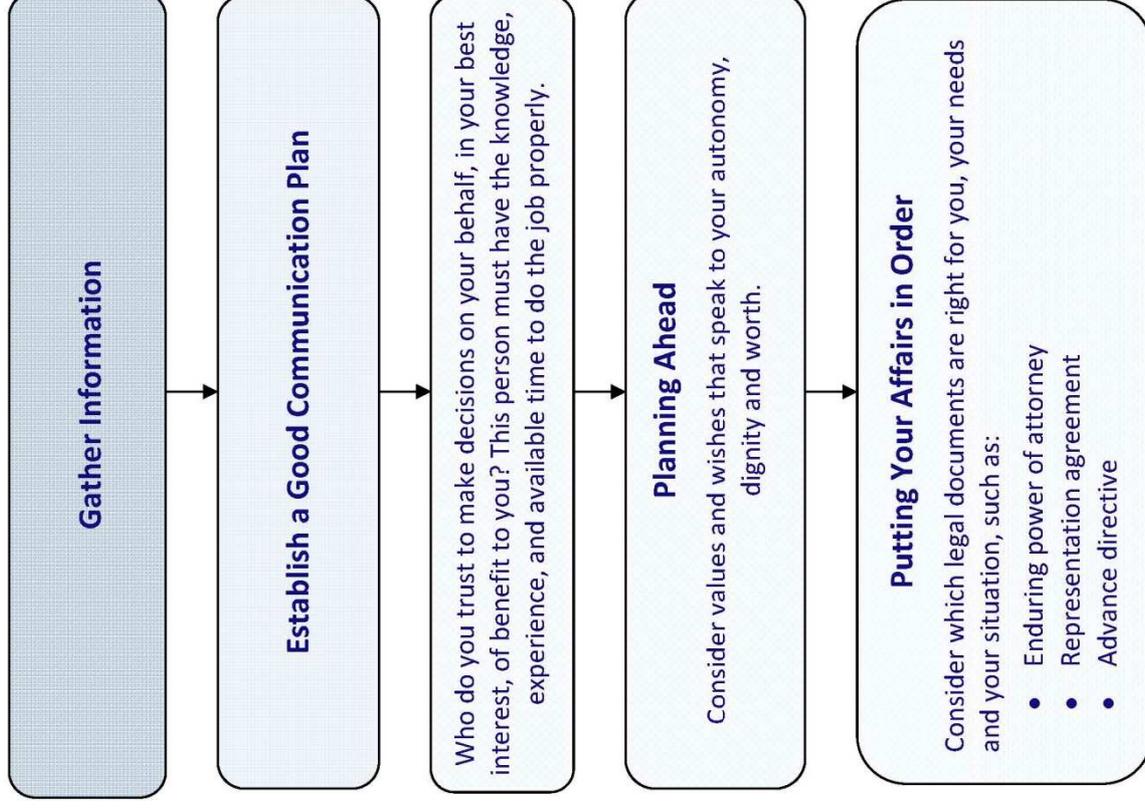
Previous projects/Dementia/Ethical Framework.

Retrieved August 25, 2012 from

<http://www.nuffieldbioethics.org/sites/default/files/Nuffield%20Dementia%20report%20Oct%202009.pdf>.

Dementia and Decision-Making

Ethical and Legal Framework



PURPOSE OF CHECKLIST

The checklist provides an overview of ethical and legal points to help guide:

- ❖ A person in the early stages of dementia.
- ❖ A family member or caregiver who is assisting a person with dementia (e.g., who accompanies the person to the doctor's or lawyer's office).
- ❖ The individual who actually has to use the legal documents (e.g., the family member with power of attorney).
- ❖ The health team member who needs to know about legal tools.

DISCUSSION

1. Think of an example from your own practice or experience where this framework might be useful.
2. What strengths do you think the framework would provide?
3. What challenges do you anticipate in implementing a framework such as this?
4. What relevant strategies would be important?
5. How might this kind of tool be generally available to other aging contexts?
6. Other comments...

Thank you to all persons with dementia and family members who provided guidance.



RESOURCES

- ❖ Alzheimer Society of B.C.: www.alzheimerbc.org .
- ❖ References:
 - Nuffield Council on Bioethics. *Dementia: Ethical Issues*. Retrieved March 30, 2013 from <http://www.nuffieldbioethics.org/sites/default/files/Nuffield%20Dementia%20report%20Oct%202009.pdf>
 - Rodney, P., Harrigan, M. L., Jiwani, B., Burgess, M. & Phillips, C. (2013). A further landscape: Ethics in health care organizations and health/health care policy. In J. Storch, R. Starzomski & P. Rodney (Eds.). (pp. 358-383). *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice*. (2nd Ed.). Don Mills, ON: Pearson Canada Inc.