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
THE RISING TIDE OF DEMENTIA
THE RISING TIDE OF DEMENTIA

- 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).

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

THE LAW FOUNDATION OF BRITISH COLUMBIA

Alzheimer Society BRITISH COLUMBIA
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.

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

Views of the person with dementia.
HOLDING ONE ANOTHER IN A TIME OF DEMENTIA

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.

Narrative and decision-making.
In D. O’Connor & B. Purves (Eds.).
Decision-making, personhood and dementia: Exploring the interface (pp. 25-36).
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).

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?

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.

Dementia and Decision-Making

Ethical and Legal Framework

Gather Information

Establish a Good Communication Plan

Who do you trust to make decisions on your behalf, in your best interest, of benefit to you? This person must have the knowledge, experience, and available time to do the job properly.

Planning Ahead

Consider values and wishes that speak to your autonomy, dignity and worth.

Putting Your Affairs in Order

Consider which legal documents are right for you, your needs and your situation, such as:
- Enduring power of attorney
- Representation agreement
- Advance directive
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.
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


- References: