Ethical-Legal issues in Care of Persons with Advanced Dementia

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“I am not afraid of death, I am just afraid of what you have to go through to get there”

(Chandler 2008)
Objectives

- Identify the ethical and legal issues in relation to the person with advanced dementia.
- Identify ethical and legal concepts relevant to ethical decision-making in advanced dementia.
- Explore ethical and legal decision-making in dementia care practice.
Background (1)

“Dementia is a syndrome characterised by progressive cognitive impairment and is associated with impairment in functional abilities and, in many cases, behavioural and psychological symptoms. There may be memory loss, usually related to short-term memory, communication difficulties, changes in personality or mood and problems with spatial awareness” (The Irish National Dementia Strategy 2014, p.10).

Dementia is one of the biggest challenges facing contemporary health and social care today. In Ireland, it is estimated that there are 48,000 people living with dementia and this number is set to rise exponentially in the coming decades.

It is a progressive and generally terminal condition.
Dementia care practice is complex, contextual and occurs in the messiness of the real world of health and social care practice.

Hughes (2011) calls for a palliative care approach in dementia from the time of diagnosis until death that incorporates a holistic approach and emphasis on the person’s quality of life.

Contemporary talk: **Supportive Care** in which there is an absence of dichotomies such as care versus cure or high tech versus low tech! The focus is on the **PERSON**.

Competent ethical and legal practice is central to such a perspective!
Advanced dementia

- Completely dependent on others for all aspects of daily living
- Profound communication difficulties.
- Loss of ability to walk, followed by inability to stand, problems sitting and loss of head and neck control
- Muscle wasting, risk of flexion contractures
- Loss of ability to eat
- Increasing difficulty swallowing food and fluids
- Bladder and later bowel incontinence
- Inability to recognise self in the mirror. Inability to recognise others.

(Oldred and Bryant 2008)
End-of-life

- End of life care is similar for any dementia diagnosis.
- Serious physical & cognitive impairments.
- Most frequent cause of death = infection.
- Many complex issues arise.

(Caron et al 2005)
Think point 1!

- Identify the ethical and legal issues you encounter in your dementia care practice.

- Remember to consider the everyday issues as well as the ‘big’ issues you encounter.
You may have noted:

- Challenges in communication with the person or with colleagues and family.
- Assessing competence.
- Behaviours that challenge.
- Environmental suitability.
- Maintenance of privacy and dignity.
- Resistance or refusal of care.
- Medication.
- Ordinary versus extraordinary treatment, e.g. use of antibiotics.
- Telling the truth.
- Recognising the terminal phase (Carron et al 2005)

- Freedom to walk.
- Pain and symptom management – noted to be under-assessed, under-diagnosed and under-treated (Miller, Linton and Mezey 2000).
- Decisions relating to nutrition and hydration.
- Giving diagnosis.
- Advance care planning.
- Resuscitation.
- Not knowing the person’s wishes.
- Informed consent.
- Transfer to acute care???
Having identified the relevant issues, it is important to consider the knowledge and competencies necessary to address these in practice.

Two core contributors to this are ethics and law as we will now examine.
Ethics and Law

- Interlinked but not synonymous!

- **Ethics is** the study of moral thought and action
  - Bioethics – pertaining to humans & healthcare.

- **Law is** the set of rules of a particular country which regulate the actions of people and which may be enforced by the courts.
We are involved in ethical & legal dilemmas posed by

Players:
Person, Drs, nurses, family, MDT, significant others

Legal - what must be done
Practical - what can be done
Ethical – what ought to be done

Play
The particular situation

Stage
Context of care
LTC, home, hospital
Ethical and Legal decision-making

- Decision making in the context of dementia care involves competent interdisciplinary collaboration, a focus on the person with dementia, their values and preferences, and consultation/inclusion of relevant stakeholders where ethically and legally appropriate.
- Ethical approaches
  - Theories, principles, frameworks/models etc.
- Legal approaches
  - Human rights (e.g. self-determination, privacy (right to consent and refuse consent, confidentiality etc. life, bodily integrity, right to die with dignity).
  - Capacity.
Ethical approaches

- Ethical theories traditional, e.g.
  - Deontology, teleology and virtue ethics.

- Ethical theories contemporary, e.g.
  - Postmodern approaches, feminist, caring and narrative approaches.

- Ethical principles
  - “Principles are rule-based criteria for conduct that naturally flow from the identification of obligations and duties” (Butts and Rich 2013, p.22).
    - Autonomy, Beneficence, Non-maleficence, Justice (Relation to legal concepts)

NB Ethical pluralism (Park 2012)
Legal approaches

O The issue of cognitive impairment is one of the only areas where the interpretation of the law is very closely aligned with ethics.

O The ethical principles previously outlined have relevance here.

O “The ethical principle that each person has a right to self determination finds its expression in law through the concept of consent” (Kennedy & Grubb 2010).
Ethical and legal concepts

- There are a number of concepts that can assist with dementia related decision making particularly in advanced dementia and at end of life:
  - Ordinary and extraordinary means (to include medical futility).
  - Principle of proportionality.
  - Best interests standard.
  - Informed consent and capacity.
  - Doctrine of double effect.
  - Advanced care planning.
The **Process** of Ethical Decision Making in Dementia!

- Benefits from a structured approach informed by different understandings of dementia, ethical and legal concepts, theories, principles and clinician experience. Specific example:

  **Nuffield Council on Bioethics Model (2009)**
  1. A belief about the nature of dementia
  2. A belief about the quality of life with dementia
  3. Recognising personhood, identity and value
  4. Promoting the interests of everyone involved
  5. People with dementia are fellow citizens
  6. A ‘case by case’ approach to decision-making
The Person with Dementia and Decision Making

- In the National Consent Policy (HSE 2013), consent is the giving of permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention.

- **All** persons are presumed to have capacity to make decisions in law, unless the presumption is rebutted.

- Therefore, the process of decision making in dementia starts from here!!
Assessment of Capacity

- Assessment of capacity is based on a **functional approach**.
  - Set out in case law, the National Consent Policy and the Assisted Decision Making Capacity Bill (2013).
- Assessment involves assessing whether:
  - The individual understands and believes the reasons for and nature of the decision to be made
  - The individual has sufficient understanding of the principal benefits and risks of an intervention and alternative options after these have been explained in a manner and in a language appropriate to the individual.
  - The individual understands the relevance of the decision, appreciates the advantages and disadvantages and is able to retain this knowledge long enough to make a voluntary choice.
Where capacity is compromised

- Best interests.
- Role of the family.
- Wardship.
- Enduring Power of Attorney.
- Advanced Care Directive.
Advanced Care Planning

- Advance care planning involves discussion between a person, care provider and frequently those close to the person about the individual’s values and preferences for ongoing healthcare (McCarthy et al. 2011).
- Aim: to arrive at a decision that is clinically appropriate and congruent with the person’s values (Lally and Tullo 2012).
- “The process of advance care planning informs and empowers patients to have a say about their current and future treatment” (Detering et al. 2010, p. 1345).
Five key elements

1. Clarification of the decision to be made.
2. Clarification of the options available.
3. Communication of the risks and benefits of the treatment options.
4. Exploring what is important to the patient/person – values.
5. Determining which decision closely matches with what is important to the patient.

(Lally and Tullo 2012)
Key benefits

- Understanding of available options.
- The person will have the opportunity to discuss such options in terms of their values and preferences.
- Shared decision making.
- A choice that is appropriate for the person.

(Lally and Tullo 2012)
Final thoughts!

- “... in particular the focus on caring for the ‘whole person’, the importance of advance care planning, the provision of adequate pain relief, the avoidance of inappropriate treatment, and support for family should be made available in an appropriate way to people who are [living and] dying with dementia.” (Nuffield Council on Bioethics 2009, p. 55).

- Specific moral and legal dilemmas and issues arise that necessitate clarification, exploration and resolution.

- The materials addressed today are a basis on which to achieve this!
Examples of Professional Guidance

- Professional Guidance for Nurses Working with Older People (ABA 2009).
- Code of Professional Conduct and Ethics For Registered Nurses and Registered Midwives (Nursing and Midwifery Board of Ireland 2014).
- Scope of Practice (Nursing and Midwifery Board of Ireland 2015).
- National Consent Policy (HSE 2013).
- National Quality Standards for Residential Care Settings for Older People in Ireland (HIQA 2009) – in revision.
- Guidance on Dementia Care for Designated Centres for Older People (HIQA 2015).
Resources
(not exhaustive)

- *Dementia Ethical Issues* report on the Nuffield Bioethics Website.
  - [http://www.nuffieldbioethics.org/dementia](http://www.nuffieldbioethics.org/dementia)
- The Irish Hospice Foundation resource on Ethics and End of Life
- Think ahead
  - [http://www.thinkahead.ie/](http://www.thinkahead.ie/)
- Irish Hospice Foundation’s Palliative Care for People with dementia Project
- Health Service Executive & Irish Hospice Foundation (2008) *Palliative care for all; integrating palliative care into disease management frameworks.* HSE/IHF; Dublin.
- Assisted Decision Making (Capacity) Bill 2013