THE IRISH COUNCIL FOR BIOETHICS

COMHAIRLE BITHEITICE NA hÉIREANN

Law Reform Commission
Bioethics: Advance Care Directives
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Is It Time For Advance Healthcare Directives?

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Definition of Advance Directives

- *An Advance Directive is a statement made by a competent adult relating to the type and extent of medical treatments s/he would or would not want to undergo in the future should s/he be unable to express consent or dissent at that time.*

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Why the “need” for ADs

- The indisputable advances of medicine and technology and fantasies about immortality have frequently led **to depriving the dying of their death.**

Why the “need” for ADs

- End-of-life treatment involves ethical dilemmas, and under identical clinical circumstances health care professionals with different religious, cultural and ethical backgrounds may adopt different approaches.
- End-of-life decisions in European vary greatly depending on regional cultural differences.

Why the "need" for ADs

- Significant differences based on the doctor's religious/cultural affiliation are seen in the choice of end-of- life practices such as:
  - time of therapy limitation,
  - time from limitation to death,
  - the availability of patient's wishes,
  - the discussion of end-of-life decisions with the patient's family and other health care workers, and
  - the reasons given for the lack of discussions with families.

Why the "need" for ADs

- Decisions that run contrary to patients' strongly held religious or personal beliefs which are made without the patient's or families' knowledge or discussion represent a serious ethical problem in end-of-life care.

Origins of Advance Directives

- 1950s-1960s – medical/social advances:
  - Artificial ventilation/Cardiopulmonary resuscitation
  - Awareness of patient autonomy
- Late 1960s- the concept of Advance Directive (AD) originated in the US
- 1976 –California Natural Death Act - competent adult could decide to withhold or withdraw life-sustaining treatment in the event of terminal illness.
  - **Karen Ann Quinlan** 1976– PVS, her father decided to remove her respirator based on belief that she would not have wanted to be kept alive artificially. (Quinlan survived until 1985 sustained by a feeding tube).
  - **Nancy Cruzan** 1983– PVS, witnesses gave evidence of previous statements relating to her healthcare preferences – her feeding tube was removed.

Expansion of AD's Internationally

- By 1992 all 50 American States had a legislative framework relating to AD's (living wills and/or power of attorney)
- Specific legislation relating to AD's has been in place for some time in various European countries
- Finland (1992)
- The Netherlands (1994)
- Denmark (1998)
- Belgium, Spain (2002)
- UK (2005)
- Austria (2006)
- Luxembourg/Switzerland/Germany legislation in preparation

Expansion of AD's Internationally

- European Convention on Human Rights and Biomedicine (1997)
- Article 9 "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account"

Ethical Framework for ADs
AUTONOMY

- Autonomy: an individual's right to think and act as s/he wishes, free from external influences and provided those wishes do not inflict harm on others.
- ADs are recognised as an expression of autonomy and as a useful tool enabling control over medical treatment into the future, when individuals may lack the capacity to express autonomous preferences.

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Ethical Framework for ADs
BENEFICENCE –v- AUTONOMY

- The traditional Hippocratic moral obligation of medicine is to provide net medical benefit to patients with minimal harm, that is, beneficence with non-maleficence.
- To do this the patient's autonomy for what constitutes benefit for one patient may be harm for another should be respected
- Although there are some general norms of human needs, benefits and harms, people vary in their individual perceptions and evaluations of their own needs, benefits, and harms.
- Jehovah's Witness attitudes to blood are a vivid illustrations of this variability.

Ethical Framework for Ads
BENEFICENCE -v- AUTONOMY

- Thus even to attempt to benefit people with as little harm as possible requires, where possible, discovery of what the proposed beneficiary regards as a benefit, regards as a harm, and regards as the most beneficial and least harmful of the available options.
- Ads can address this desire
- Individuals can also express their right to autonomy by deciding what treatment they want or don't want as well as a decision not to make an advance directive.
- An individual should not be obliged to prepare an advance directive, to avail of medical treatment or to gain admission to a nursing home, as such an obligation could be seen as a breach of autonomy.

Ethical Framework: Limitations to Autonomy

- An individual's right to autonomy is not absolute – one individual cannot compel another to act against his/her conscience
  - Cannot put undue pressure on health care professionals to meet unrealistic or illegal treatment demands.
  - Competent individuals should expect a doctor to respect the decision they make even if the doctor believes it to be incorrect or irrational.

Ethical Framework: Limitations to Autonomy

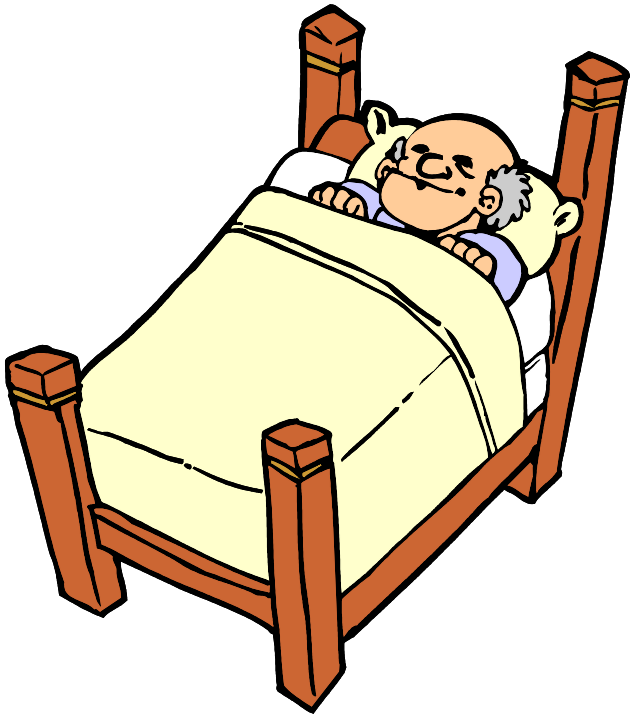
- Healthcare professionals have a duty of care and where a patient's request is contrary to their conscience/ethos, they should continue to provide care until another healthcare professional is found who is willing to uphold the patient's treatment decisions. (*This is a particularly controversial issue*)

Ethical Framework: "Future Self"

- An individual's views/values regarding
- treatment could change with
  - Age
  - Onset/progression of illness
  - Prospect of future medical advances
- *Do these changes reflect a change in a person's identity? Should the "previous self" be able to dictate to the "future self"?*

Case Study
DEMENTIA AND PERSONAL IDENTITY

- Twenty years ago, Sir Harvey Head retired from his chair at the London Neurological Hospital, where he had specialized in dementia. His colleagues remember him as a skilled diagnostician and as a wide-ranging conversationalist, sometimes very forthright in his disagreements with them. He himself said he did not suffer fools gladly. His only weakness as a doctor was a certain lack of sympathy for his demented patients.
- To those close to him, he privately expressed his horror of the condition: "I would rather be dead than be in this God-awful state." And he left an advance directive instructing medical staff not to take any steps to save his life were he ever to become too demented to be competent to refuse treatment himself.



Case Study
DEMENTIA AND PERSONAL IDENTITY

- During his retirement he developed dementia. He was unable to remember anything about his professional life and his speech became very incoherent. His previous forcefulness disappeared and he seemed to be a sweet and gentle person. He was admitted to hospital having has contracted pneumonia, which could probably be treated with antibiotics
- The decision had to be made as to whether he should be treated for this. He was asked about it but did not understand the question. His family gave them his advance directive. Some of them said it should be acted on. Others said that he was a different person then, and that, as he seems contented with his life now, he should be treated for the infection.

Case Study
DEMENTIA AND PERSONAL IDENTITY

- **Questions**
- Should his AD be honoured and antibiotics withheld?
- Is he the same person who made the advance directive?
- Does his present contentment make his continued life worthwhile and override his past misgivings about living with dementia?
- Is the issue of personal identity relevant to what should be done?

Scope

- ADs can cover a multitude of issues regarding medical treatment
  - life-prolonging treatment
  - end-of-life care
  - Organ/body donation
- BMA (UK) Guidelines: ADs not restricted to hospital care but can include decisions on:
  - Hospice Care
  - Home Care
  - Nursing Home Care

Treatment Refusals

- Given the right to self-determination, treatment decisions, particularly refusals of treatment, outlined in an AD should be followed provided they are legal
- Yet there can be some debate about what constitutes treatment, especially in relation to artificial nutrition and hydration (ANH):
  - ANH – natural means of preserving life, moral obligation to provide it unless overly burdensome on the patient (Medical Council/An Bord Altranais)
  - or
  - ANH – medical treatment which can be refused like any other

- Ireland: from a legal perspective ANH considered medical treatment. Mental Capacity Act 2005 UK requires a specific written signed and witnessed refusal of ANH.

Treatment Requests

- An AD could be used to compel a doctor or healthcare professional to provide specific treatment/procedure.
- This raises the questions of what constitutes medical futility
- People may have unrealistic expectations of the efficacy of treatments e.g. CPR
- Potential tension between clinical judgment and a patient's wishes

Informed Consent

- In order to decide whether to accept/refuse treatment, individuals should be fully informed of treatment options
- Can a person be truly informed about all future medical eventualities or aware of the potential developments in medical science?
  - Competent individuals may forgo receiving information yet still consent to or refuse treatment in contemporary situations
  - Individuals can update their ADs to account for progress
  - Individuals can avail of counselling from healthcare professionals, solicitors or religious advisers

Specificity

- The degree of interpretation required for an individual's advance directive depends on the level of detail involved.
- General Preferences: e.g. "heroic measures", "decent quality of life", "dignified death"
  - can be difficult to interpret, resulting in them being given less ethical weight/legal status.
  - some individuals perceive an advance directive as a tool to enable them to maintain involvement in their medical treatment by providing personalised guidance for future treatment decisions, without expecting such wishes to be legally binding

Specificity

- Detailed ADs: e.g. refusal of treatments – antibiotics, artificial ventilation, CPR, ANH – can generally be adhered to.
- The need for clarity and specificity regarding treatment refusals is particularly important for AD's that are intended to be legally binding
- The AD should outline, in clear and unambiguous terms, not only the treatment the individual wishes to refuse/request but also the specific medical situations in which they intend that refusal/request to apply

Differing Circumstances

- Can a pregnant woman make an AD if it will have a detrimental effect on the child she is carrying?
- Should parents be able to make ADS for the treatment of their children?

Revoking ADs

- An individual can revoke his/her AD at any time (provided s/he is competent)
- Questions have been raised about allowing incompetent individuals to revoke their own advance directive
  - permitting incompetent individuals to revoke their advance directives defeats the purpose of preparing the directive in the first place
  - the views of incompetent individuals, with regards to their contemporaneous treatment situation, should be taken into account and weighed against the treatment preferences outlined in their advance directive
- Can be withdrawn orally: to avoid confusion revocation should be recorded in the individual's medical records

The Practice

- Legally valid in USA for many years:
  - Poor uptake- only 20% hospital population
  - Higher uptake:
    - Terminally ill, higher income, college education, female, white
- Reasons given for poor uptake
  - Perceive as being for sick and elderly
  - Don't know enough about them
  - Difficult to execute –
    - Often vague statements leading to wide interpretations
  - Don't make a difference to care received
  - Happy for family to make substituted judgment
  - Cultural reasons