

# Online Ethics Course

## ***Topic 6: Advance directives and the right to refuse care***



# Intended learning outcomes

*After completing the topic, learners should be able to:*

- 1. Understand the role of advance directives, including how they are used*
- 2. Explain the basis of the right to refuse care*



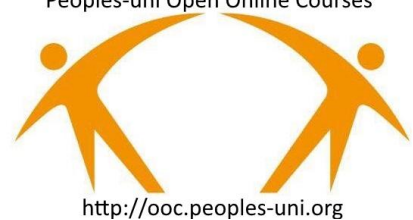
# What is an advance directive?

- An advance directive is a form of decision-making that enables an individual to influence the course of his/her care at some point in the future
- It becomes effective when an individual loses capacity and when the anticipated situation actually occurs
- It is a form of 'living will', outlining treatments that a person does or does not wish to receive



## Cont.

- To be effective, it has to have a formal legal basis; it is therefore not universal and is dependent on jurisdiction
  - E.g., in the UK, the right to *refuse* care is recognised in law, but not the positive right to direct the kind of care that a patient wants to receive



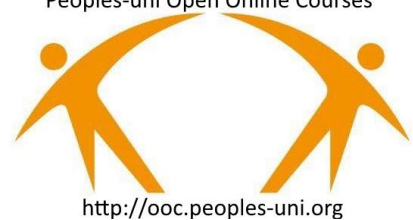
## Cont.

- If it applies in law, any adult can put an advance directive in place, as long as s/he has sufficient legal capacity at the time
- Advance decisions made under duress, including pressure from a relative, are not valid
- Advance decisions cannot be made by a third party; they have to be made by a competent adult, and legally verified



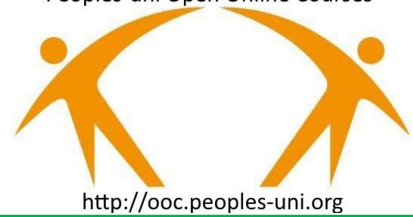
# Law in the UK

- The applicable legislation in the UK is the Mental Capacity Act (2005) <http://www.legislation.gov.uk/ukpga/2005/9/contents>
- It makes provision for someone to appoint an adult (in advance) to be their advocate in respect of decisions relating to health
- The donor (future patient) can appoint a donee (patient advocate) to have a say on matters of health and welfare
- This does not confer the power to give or withhold consent, but it does confer the right for the donee to be consulted



# Law in India

- There is no specific (federal) law on advance directives in India; however, in serious cases, clinicians should initiate discussion with the family on topics such as Do-Not-Attempt-Resuscitation, withholding and withdrawing treatment, and/or when to initiate palliative care [see topic 7]



## Cont.

- In India, constitutional implications arise in connection with the right to life (and the right to die with dignity)
- Euthanasia and assisted suicide are separate topics; however, in public discourse, the issues may overlap
- <http://www.legalserviceindia.com/article/I374-Article-21-and-Constitutional-validity-of-Right-to-Die.html>





# Who needs an advance directive?

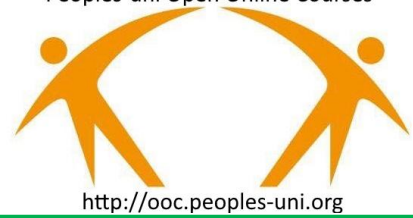
- This legal device is most useful in the case of adults who have a diagnosis (such as motor neurone disease), whereby at some point in the future, the patient is likely to lose autonomy
- The intention is to try and enable the individual to control what happens for as long as possible, by anticipating situations that may arise in the future



## Cont.

The right to refuse specific treatment or *all* treatment could be included, such as

- *Cardiopulmonary resuscitation*
- *Blood transfusion (normal for Jehovah's witnesses)*
- *Escalation to intensive care*
- *Treatment for an otherwise reversible condition, such as giving antibiotics for an infection; artificial ventilation, and/or clinically assisted feeding and hydration*



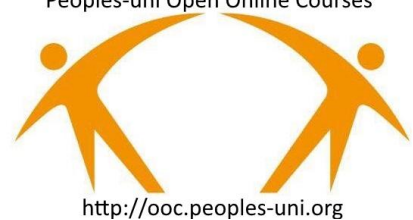
## Cont.

- An individual can refuse all lifesaving treatment, or some lifesaving treatments but not others, or some lifesaving treatment in some situations but not others
- Individuals can express their autonomous wishes when making an advance directive, but they may want to consider the impact that this could have on their care (such as restricting the ability of clinicians to exercise clinical judgment at the time)



## Cont.

- If competent patients have a right to refuse treatment, it does not follow that they have a right to *demand* particular treatments
- To be respected, advance decisions must apply to the circumstances as they are set out in a legal document
- In practice, situations do not always work out as expected; directives are a useful (though imperfect) tool for respecting patient autonomy



# Assisted dying

- Patients do not have a right to ask clinicians to act in a way that could deliberately hasten death – that could compromise professional autonomy and/or put clinicians in breach of the law and codes of ethics
- The law varies between (and sometimes within) countries
- The right to refuse treatment does not automatically confer the right to die



# Are advance directives legally binding?

- The answer varies according to jurisdiction
- In general, if there is a law in place, clinicians have an obligation to check for the existence of advance directives
- If a valid directive is in place, clinicians should do their best to respect previously expressed wishes of the patient and consult with anyone appointed as proxy, and/or having legal power of attorney



## Cont.

- Where an advance directive is utilised to refuse life-saving treatment, clinicians still have responsibility to keep the patient comfortable and as free of pain as possible
- The most common type of directive is a DNAR (do not attempt resuscitation); however, this decision is often made *on behalf of* rather than *by* the patient



# Communication

- A certified copy of an advance directive should be held by the patient's regular health care provider
- Patients should carry something on their person to communicate the existence of the advance directive, including where it can be found
- Family members and next of kin should also be made aware, so that information can then be accessed quickly, especially in case of emergency





## Reading suggestions

- General Medical Council (UK) guidance on end of life
- [http://www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_advance\\_treatment\\_refusal.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_advance_treatment_refusal.asp)
- NHS Choices on end of life care
- [www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx](http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx)
- Advance directives, USA
- <http://www.cancer.org/acs/groups/cid/documents/webcontent/002016-pdf.pdf>
- <http://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303>

*[See also reading list for topic 7]*



# Acknowledgement

Dr Roger Worthington gratefully acknowledges  
generous support in the preparation of these slides from  
Mr CR Chandrasekar and Dr S Visahan