Legal and ethical issues around end of life care in dementia - lecture

June 14th 2017
Morning session
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Agenda

• Definition of end of life
• Legal method
• Introduction to ethical dilemmas
• Four ethical principles
• Duty of care
• Mental capacity
• Best interests and advocates
• Advance decisions
• Abuse and neglect
• Advance care planning
• Deprivation of liberty safeguards
• UN Convention on Rights for Persons with Disabilities
• Artificial nutrition and hydration
• Do not attempt resuscitation
• Assisted suicide and euthanasia
Introduction to ethical dilemmas

• Τα ετηικα, referring to philosophical inquiry into good and evil

• Ethical dilemmas arise when more than one, sometimes opposite, actions arise because those involved in the situation have different perspectives. And because the ethical principles may suggest different courses of action.
Ethical & Legal

Ethics

The Law
Legal method “IRAC”

• Issue(s)
• Rule(s)
• Application
• Conclusion
End of life definition:

“Patients are ‘approaching the end of life’ **when they are likely to die within the next 12 months.** This includes those patients whose death is expected within hours or days; those who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events.” (GMC)
Four ethical principles

- **Autonomy**: Respect the uniqueness and dignity of each person, self, and others.
- **Non-maleficence**: Prevent harm and removal of harmful conditions.
- **Beneficence**: Act to remove harm or promote benefit.
- **Justice**: Treat individuals equally.
Duty of care

• You have a duty of care to all those receiving care and support in your workplace. This means promoting wellbeing and making sure that people are kept safe from harm, abuse and injury.

• Wellbeing could be defined as the positive way in which a person feels and thinks of themselves.

• Your professional code of conduct tells you how you are expected to behave.

• Your duty of care is also to other workers, for example, in a hospital, to doctors, nurses and healthcare support workers but also to caterers, cleaners and maintenance workers. If you are a home care worker you will probably work alone in a variety of homes, but there may well be other people in the premises, as well as whoever you are there to support.
Dilemmas that may arise between the duty of care and an individual’s rights and carers wishes

• When professionals suspect that a person with dementia is suffering harm from a carer or other family member or friend, they have both a legal and an ethical duty to act to protect the person with dementia as a ‘vulnerable adult’.

• The autonomy and well-being interests of the person with dementia may be highly complex, and any benefits associated from a long-standing relationship must be weighed in the balance along with the nature and extent of the harm.
Example of a difficult area - “therapeutic lying”

Cunningham (2005) has shown that professionals often use euphemisms for lying such as ‘bending the truth’ to ease their conscience and rationalise their actions.

A survey revealed that 24 out of 34 residential, nursing, and inpatient units caring for people with dementia said that medicines were sometimes given covertly (J R Soc Med 2000; 93: 408–11).

However, the Nursing and Midwifery Council (NMC) standards and code state that all nurses must be "open and honest, act with integrity". The code of conduct from the General Medical Council (GMC) has a similar approach.
The Mental Capacity Act [2005] (MCA) is based on five key principles.

• Every adult has the right to make decisions for themselves. It must be assumed that they are able to make their own decisions, unless it has been shown otherwise.

• Every adult has the right to be supported to make their own decisions. All reasonable help and support should be given to assist a person to make their own decisions and communicate those decisions, before it can be assumed that they have lost capacity.

• Every adult has the right to make decisions that may appear to be unwise or strange to others.

• If a person lacks capacity, any decisions taken on their behalf must be in their best interests.

• If a person lacks capacity, any decisions taken on their behalf must be the option least restrictive to their rights and freedoms.
Assessing mental capacity

• The Act sets out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time.

• It is a 'decision-specific' test. No one can be labelled 'incapable' as a result of a particular medical condition or diagnosis.

• A lack of capacity cannot be established merely by reference to a person's age, appearance, or any condition or aspect of a person's behaviour which might lead others to make unjustified assumptions about capacity.
To test if the person has capacity:
• Does the person have an impairment of the mind or brain, or a disturbance of mental function?
• If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

To have capacity to make a decision, someone must be able to:
• Understand the information relevant to the decision.
• Retain the information.
• Use that information as part of the process of making the decision.
• Communicate his/her decision either by talking, signing, or any other means.
Informed choice and effective communication

• Choices can only be made if people have information. If they know the options, the risks and possible implications they can make the choice that is right for them.

• This is ‘informed’ choice.
The kinds of support people with dementia may need include:

- making sure their hearing aid is working, or they have their glasses on.
- explaining things in a way that is easy to understand.
- using pictures, for example when choosing what meal to have.
- having someone who can speak the person's own language to explain the decision to them choosing the best time of the day to talk about the decision.
- Some decisions are very difficult and people may need time to make them. People might also change their mind several times. This doesn't mean they can't make the decision themselves.
The importance of consent

• Obtaining the patient’s consent is usually a prerequisite of any clinical intervention.

• However, some cognitively impaired patients may not be able to give valid consent. Following years of consultation and legislative review, the Mental Capacity Act [2005] (MCA) provides a statutory framework of ‘best interests’ decision-making on behalf of incapacitated individuals.
This principle is upheld in law and means that medical interventions will generally be unlawful in the absence of the patient’s consent, regardless of how unwise or unjustified the patient’s decision may appear.
Independent Mental Capacity Advocates

• The **Mental Capacity Act [2005]** provides that an **Independent Mental Capacity Advocate** must be instructed to represent a person who lacks the requisite capacity, when it is proposed that the person should receive “**serious medical treatment**” or be provided with long-term accommodation in a hospital or care home by the NHS or residential care by local authority.

• The duty to instruct an Independent Mental Capacity Advocate applies if there is no person (other than a professional or paid carer who can be consulted in determining the person’s best interests.
• Independent Mental Capacity Advocates have prescribed statutory functions, including gathering evidence and preparing a report on the person’s best interests.
There are some broad approaches to decision making.

1. Valid choice

(a) Contemporaneous valid choice: A choice (e.g. refusal of treatment) made about a current situation is valid if the person has capacity, is properly informed and can make the choice voluntarily and without coercion.

(b) Prior (advance) valid and applicable choice: The person now lacks the capacity to make the choice but had previously, when he or she had capacity, made a choice that was valid and that is applicable to the current circumstances.

2. Hypothetical choice (*substituted judgement*)

(a) External sense: The choice that the person would have made at a time shortly before losing capacity had he or she considered the current situation.

(b) Internal sense: What the person would now choose were he or she (magically) to regain capacity for long enough to make a valid choice.

3. Best interests

The decision that would maximise the person’s wellbeing. Wellbeing is not necessarily the same as what a person validly chooses: people may make valid choices that do not maximise their own wellbeing, for example a choice may be foolish, or it may be made to benefit another.
“Best interests”

The best interests principle of the Mental Capacity Act [2005] promotes a holistic view of a person’s life, and lays out a process to help a ‘lead’ decision-maker to make a decision, taking into account what the individual lacking capacity would have wanted, if they had been able to make their own decision.
Surrogate decision making

• As dementia progresses, many people will reach a stage where they are no longer able to make decisions for themselves.

• At this point, decisions about lifestyle, healthcare, medical treatments and end-of-life care become the responsibility of someone else—referred to as a substitute, proxy or surrogate decision-maker (SDM).

• There are many ethical issues for family members and others, not least of which is how to negotiate the complexities of decision-making in a way that supports the person’s right to make autonomous choices and promotes their quality of life.
Lasting power of attorney

• Adults can give someone else the power to make decisions about their money and property. This is called making a Lasting Power of Attorney (property and affairs).

• Lasting powers of attorney (LPAs) let you choose a person (or people) you trust to act for you. This person is referred to as your ‘attorney’, and you can choose what decisions they are allowed to make for you.
Solicitors who advise clients on drawing up a lasting power of attorney (LPA), and solicitors who are acting as an attorney under an LPA. Any solicitor intending to give advice about an LPA or act as an attorney under an LPA must be aware of the provisions in the Mental Capacity Act 2005 (MCA 2005) and the Mental Capacity Act 2005 Code of Practice (Code of Practice). Solicitors should also be familiar with the relevant guidance produced by the Office of the Public Guardian (OPG).
Advance decisions

• An **advance decision** (sometimes known as an *advance decision to refuse treatment*, an ADRT, or a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future.

• An advance decision is **only** legally binding as long as it complies with the **Mental Capacity Act** [2005], and meets a number of specific conditions.

• It lets your family, carers and health professionals know whether you want to refuse specific treatments in the future. This means they will know your wishes if you are unable to make or communicate those decisions yourself.
Abuse and neglect

*Physical elder abuse*

Physical elder abuse is non-accidental use of force against an elderly person that results in physical pain, injury, or impairment. Such abuse includes not only physical assaults such as hitting or shoving but the inappropriate use of drugs, restraints, or confinement.
Elder neglect—failure to fulfill a caretaking obligation—constitutes more than half of all reported cases of elder abuse. It can be intentional or unintentional, based on factors such as ignorance or denial that an elderly charge needs as much care as he or she does.
Deprivation of liberty safeguards (DoLS)

A deprivation of liberty occurs when:

‘The person is under continuous supervision and control and is not free to leave, and the person lacks capacity to consent to these arrangements.’
The key elements of these safeguards are:

• to provide the person with a representative – a person who is given certain rights and who should look out for and monitor the person receiving care

• to give the person (or their representative) the right to challenge a deprivation of liberty through the Court of Protection

• to provide a mechanism for a deprivation of liberty to be reviewed and monitored regularly
• The Deprivation of Liberty Safeguards can only be used if the person will be deprived of their liberty in a care home or hospital. In other settings the Court of Protection can authorise a deprivation of liberty.
UN Convention on the rights of persons with disabilities

- The **UN Convention on the Rights of Persons with Disabilities** was ratified by the United Kingdom in 2009.

- The Convention’s purpose is to protect the rights of people who have long-term physical, mental, intellectual, or sensory impairments. Whilst not directly incorporated into our domestic law, it is applied both by the Strasbourg and domestic courts as an aid to interpretation of the ECtHR.

- The Convention has been celebrated as a new paradigm and as a revolution in human rights law for persons with disabilities.

- The Convention has a wide field of application and encompasses civil and political rights as well as economic, social and cultural ones.
These rights are extensive and cover matters such as the right to life, access to justice, independent living, education, work and cultural life.

Two articles of the Convention are particularly relevant for the purposes of mental capacity law and the DoLS.

• **Article 12** sets out the right of persons with disabilities to enjoy to legal capacity on an equal basis with others.

• **Article 14** stipulates that the “existence of a disability shall in no case justify a deprivation of liberty”.
Advance care planning (ACP)

**Advance care planning** is the process whereby patients, in consultation with healthcare professionals, family members, and other loved ones, make individual decisions about their future healthcare, to prepare for future medical treatment decisions.
Difference between ACP and care planning

- The difference between ACP and planning more generally is that the process of ACP is to make clear a person’s wishes and will usually take place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.
With the individual’s agreement, discussions should be:

• documented
• regularly reviewed
• communicated to key persons involved in their care.
• If the individual wishes, their family and friends may be included.
Examples of what an ACP discussion might include are:

- the individual’s concerns
- their important values or personal goals for care
- their understanding about their illness and prognosis, as well as particular preferences for types of care or treatment that may be beneficial in the future and the availability of these.
• The outcome of ACP may be the completion of a statement of wishes and preferences or if referring to refusal of specific treatment may lead onto an advance decision to refuse treatment (Chapter 9 MCA 2005 Code of Practice). This is not mandatory or automatic and will depend on the person’s wishes.

• A statement of wishes and preferences is not legally binding. However, it does have legal standing and must be taken into account when making a judgement in a person’s best interests.
• Careful account needs to be taken of the relevance of statements of wishes and preferences when making best interest decisions (Chapter 5 MCA 2005 Code of Practice).

• If an advance decision to refuse treatment has been made it is a legally binding document if that advance decision can be shown to be valid and applicable to the current circumstances. If it relates to life sustaining treatment it must be a written document which is signed and witnessed.
When should ACP take place?

• The “right” timing for physicians to take the initiative in planning care for patients with dementia in the last stage of life is unclear.

• Access to specific health care services or admission to a health care facility for long-term care, such as an NH, may trigger the initiating or reviewing of ACP discussions.

• The timing of ACP is influenced by barriers such as prognostic uncertainty, fear of damaging positive coping strategies, potential workload of having earlier ACP with patients or simply because of unawareness of the needs of patients.
Artificial nutrition and hydration

**Bland** (Airedale NHS Trust v Bland [1993] 1 All ER 821)

Anthony Bland was 21 years old when overcrowding at the Hillsborough football stadium lead to him being badly crushed.

He was left permanently unconscious, in persistent vegetative state.

Three years later the hospital Trust applied to the court for a ruling whether it would be lawful to discontinue artificial hydration and nutrition, resulting inevitably in his death.
The House of Lords considered that:

• Artificial nutrition and hydration is regarded as a form of medical treatment.
• There is no distinction between an omission to treat a patient (withholding) and discontinuance of treatment once commenced (withdrawing).
Since the Bland case the Mental Capacity Act 2005 and the Human Rights Act 1998 have been introduced and must be considered in all such cases.
Lambert and Others v. France (application no. 46043/14)

In an important step away from Pretty v UK, the Grand Chamber of the Strasbourg Court has upheld the right of to die with dignity by ruling that there would be no violation of Article 2 (right to life) of the European Convention on Human Rights if artificial nutrition and hydration were to be withdrawn from a patient in a persistent vegetative state.
• Medically-assisted nutrition and hydration should be considered medical interventions rather than a basic provision of comfort.

• Promoting early discussions with the patient and family about the goals of care and treatment choices, including the expected benefits and burdens of artificial nutrition and hydration based upon the best available evidence, is ethically appropriate, respects family and patient autonomy, and facilitates informed decision making.
Do not attempt resuscitation

There are three main circumstances in which the English law allows DNAR decisions to be made:

1. Where a patient, with capacity, asks not to be resuscitated. This must be respected and a DNR order implemented to alert all healthcare professionals not to attempt resuscitation. A patient can request a DNR order at any time.
2. Where a doctor considers that resuscitation is likely to be “futile”, i.e. in their medical opinion, CPR will not work.

3. Where a doctor considers, having had full consultation with the patient, that the burden of CPR outweighs the benefit to the patient, i.e. that CPR may restart the heart and breathing, but the patient is likely to be left with a poor quality of life (a benefit v burden test).
129. If cardiac or respiratory arrest is an expected part of the dying process and CPR will not be successful, making and recording an advance decision not to attempt CPR will help to ensure that the patient dies in a dignified and peaceful manner. It may also help to ensure that the patient’s last hours or days are spent in their preferred place of care by, for example, avoiding emergency admission from a community setting to hospital. These management plans are called Do Not Attempt CPR (DNACPR) orders, or Do Not Attempt Resuscitation or Allow Natural Death decisions.

130. In cases in which CPR might be successful, it might still not be seen as clinically appropriate because of the likely clinical outcomes. When considering whether to attempt CPR, you should consider the benefits, burdens and risks of treatment that the patient may need if CPR is successful. In cases where you assess that such treatment is unlikely to be clinically appropriate, you may conclude that CPR should not be attempted. Some patients with capacity to make their own decisions may wish to refuse CPR; or in the case of patients who lack capacity it may be judged that attempting CPR would not be of overall benefit to them. However, it can be difficult to establish the patient’s wishes or to get relevant information about their underlying condition to make a considered judgement at the time they suffer a cardiac or respiratory arrest and an urgent decision has to be made. So, if a patient has an existing condition that makes cardiac or respiratory arrest likely, establishing a management plan in advance will help to ensure that the patient’s wishes and preferences about treatment can be taken into account and that, if appropriate, a DNACPR decision is made and recorded.
Assisted suicide and euthanasia

• Euthanasia is the act of deliberately ending a person's life to relieve suffering.

• For example, a doctor who gives a patient with terminal cancer an overdose of muscle relaxants to end their life would be considered to have carried out euthanasia.

• Assisted suicide is the act of deliberately assisting or encouraging another person to kill themselves.

• If a relative of a person with a terminal illness were to obtain powerful sedatives, knowing that the person intended to take an overdose of sedatives to kill themselves, they may be considered to be assisting suicide.
• Both active euthanasia and assisted suicide are illegal under English law.

• Depending on the circumstances, euthanasia is regarded as either manslaughter or murder and is punishable by law, with a maximum penalty of up to life imprisonment.

• Assisted suicide is illegal under the terms of the Suicide Act (1961) and is punishable by up to 14 years' imprisonment. Attempting to kill yourself is not a criminal act in itself.
Pretty v. United Kingdom (2346/02) was a case decided by European Court of Human Rights in 2002. Diane Pretty was suffering from motor neurone disease and was paralysed from the neck down, had little decipherable speech and was fed by a tube. It is not a crime to commit suicide under English law, but the applicant was prevented by her disease from taking such a step without assistance. It is however a crime to assist another to commit suicide (section 2(1) of the Suicide Act 1961). Pretty wanted her husband to provide her with assistance in suicide. Because giving this assistance would expose the husband to liability, the Director of Public Prosecutions was asked to agree not to prosecute her husband. This request was refused, as was Pretty’s appeal before the Law Lords.

In a unanimous judgment, the Court, composed of seven judges, has found Pretty’s application under articles 2, 3, 8, 9 and 14 of the European Convention on Human Rights admissible, but found no violation of the Convention.

Significant conclusions include that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from Article 2 of the Convention.

As concerns Pretty’s right to respect for private life under Article 8, the Court considered that the interference in this case might be justified as “necessary in a democratic society” for the protection of the rights of others.
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THANK YOU!