Death with dignity: the debate in England

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The concept articulated in the title of this conference, ‘death with dignity’ can have many interpretations, which is of course why there is so much debate on a subject that at first sight would appear to be uncontroversial. All participants in the debate will agree that death with dignity is a good to be aspired to for everyone but what is not universally agreed is how death with dignity can be achieved in different situations, and perhaps more fundamentally what it is we actually mean by death with dignity. In this lecture I will attempt to identify and explain some of the arguments and dilemmas that have informed discussion about death with dignity in England over the past twenty years and to set this in the context of developing legal and professional regulation governing end of life decision making.

A dictionary definition of dignity is the quality or state of being worthy of esteem or respect. This is sometimes expanded to include self respect and not just the respect of others. The English Department of Health has recently launched a campaign, ‘Dignity in Care’ to promote the concept of patient dignity within all aspects of health and social care. The concept of dignity in this initiative includes notions of respect, autonomy, privacy, and self worth [http://www.scie.org.uk/publications/guides/guide15/index.asp] . The elaboration of the concept includes criteria that focus on patient independence, choice and self determination. This focus on autonomy and self determination underpins the aims of organisations such as Dignitas in Switzerland and ‘Dignity in Dying’, the main pro voluntary euthanasia organisation in the UK. However not all people facing the end of their life are able to make autonomous choices. Many lack decision making capacity because of their illness, their age, or their level of intellectual ability. It would seem odd if the concept of death with dignity did not include these people so we perhaps need to look further than autonomy in developing our ideas about what it truly means to respect someone’s dignity particularly at the end of their life.

I will therefore start my overview of the legal framework on end of life decision making in England by considering decisions regarding people who lack capacity before moving on to the current law and political debate on end of life decisions made by capacitous individuals.

Early cases in English law on end of life decision making addressed the question of whether life sustaining treatment should be withheld or withdrawn from a patient who was unable to make a decision for him or her self. Several cases involved very young children and the judgements focussed on the futility of the treatment and the degree of suffering that continued existence with the treatment would inflict. Decisions in these cases tended to be guided by the opinion of the medical profession as to whether continued treatment was in the child’s best interests. More recent decisions have taken more account of parental views on the quality of life experienced by the child and hence the assessment of the child’s best interests. Of interest is that there also seems to be a
greater recognition that an assessment of the child’s quality of life should be made in relation to that individual child and not a generic conception of the quality of life expected by a healthy child of similar age. This could be interpreted as a reflection of the increasing importance given to respect for persons as unique individuals whatever their capacity. Treating with dignity in the absence of autonomy. As Justice Hoffman put it when discussing the benefits of the life of a child with myotonic dystrophy who required continuous ventilation and was only able to move the muscles in his eyebrow.

‘It is impossible to put a mathematical or any other value on the benefits. But they are precious and real and they are the benefits, and only benefits, that M was destined to gain from his life.’


The key legal case in England which set the law on withholding or withdrawing life sustaining treatment in adults who lack capacity was that of Tony Bland. This was a young man who suffered severe hypoxia during a major disaster that occurred at a football stadium in 1989 which led to him being in a permanent vegetative state. In 1992 his physicians sought a declaration from the court that it would not be unlawful to withdraw artificial nutrition and hydration, thus allowing him to die. His family were in agreement with the physicians’ views. The case went to the highest court in England at the time, the House of Lords, and several key points of law were decided in the judgement.

1. That artificial nutrition and hydration was a medical treatment.
2. That the sanctity of life principle was not absolute in English law.
3. That withdrawal or withholding of life sustaining medical treatment was lawful if continuation of the treatment was not in the patient’s best interests.

The principle of best interests in English law was and remains the fundamental principle governing treatment of people who lack capacity to make decisions about their own treatment. This was so before the Bland case but in Bland their Lordships applied that principle to a case where discontinuing treatment would result in death. As such they were recognising that there are situations and conditions where the burden of treatment is so great and the quality of life maintained by the treatment is so low that this outweighs the benefit of continued life. In considering whether the treatment was in Tony Bland’s best interests Sir Thomas Bingham referred to wider and less tangible considerations than pain and suffering.

‘An objective assessment of Mr Bland’s best interests viewed through his eyes would in my opinion give weight to the constant invasions and humiliations to which his inert body is subject; to the desire he would naturally have to be remembered as a cheerful, carefree, gregarious teenager and not an object of pity…’

This statement seems highly relevant to the development of a concept of dignity for patients who are in the dying process or who are being sustained by treatment without which their underlying condition would lead to death.  
Airedale NHS Trust v Bland [1993] AC 789
The Mental Capacity Act 2005

The principle of best interests as the legal requirement for treating people who lack capacity has now been set in statute with the enactment of the Mental Capacity Act by the UK Parliament. The Act sets out the following principles

A person must be assumed to have capacity unless it is established that he lacks capacity.

A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action. 

Mental Capacity Act section 1

The Act considers decisions at the end of life and in particular the withdrawing or withholding of life sustaining treatment. In the section on best interests it makes clear that a decision regarding life sustaining treatment cannot be motivated by a desire to bring about death but acknowledges that it can be made if it is in the patient’s best interests.

Where the determination relates to life-sustaining treatment he (the person making the decision) must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

MCA section 4(5)

This reference to motivation on the part of the clinician is a reminder that in English law killing is unlawful and that the law draws a distinction between intending to bring about death and acting in a way that death is a foreseeable but not intended consequence. It is however an interesting question as to whether a clinician who makes a decision to withdraw feeding and hydration from a patient in permanent vegetative state because it is not in the patient’s best interests to continue with the treatment can be said not to intend that the patient dies when death will be a direct consequence of this decision.

The Mental Capacity Act also considers decisions regarding life sustaining treatment in its section on advance refusals of treatment which I shall come to presently.

Thus for patients, either adults or children, who lack capacity English Law is fairly clear about end of life decisions.

• The decision must be in their best interests
• Best interests is wider than just pain and suffering
• The decision must not be motivated by a desire to bring about death
• Withdrawing and withholding treatment are classified as omissions of treatment rather than actions (an important distinction as we will see later)
• Artificial nutrition and hydration is medical treatment
Professional guidance for physicians from the General Medical Council and the British Medical Association have reiterated these legal points and provided a professional framework for a decision making process at the end of life.

*General Medical Council. Guidance on withholding and withdrawing life sustaining treatment (currently being revised)*

Patients who have capacity

I will now turn to the legal and ethical debate in England regarding end of life decisions by people who have capacity or who make an advance statement about their wishes before they lose capacity. When a decision involves refusal of a treatment by a competent/capacitous adult the law is very clear, and was re stated in a well publicised case in 2002. In this case a lady who had suffered a spinal artery haemorrhage which had left her paralysed from the neck down and requiring mechanical ventilation to breathe requested that her treating medical team disconnect her ventilator, provide her with appropriate medication so that she did not suffer as she became unable to breathe and so to let her die. Her clinicians refused to follow her instructions because they felt that to do so would in effect be killing the patient, an act contrary to their duty as clinicians to preserve life and thus against their ethical principles and code of practice. The patient’s mental state was assessed by several psychiatric experts and she was found to be competent to make this decision. The case was unusual in that it was the first time in England that a court had convened in a hospital but the case was heard with full court attendance in a side room of the intensive care unit where the patient was being cared for. The judge in this case, Justice Butler Schloss, re stated the legal principle of informed consent, that any adult who had capacity (and adults in English law are assumed to have capacity unless it has been demonstrated that they lack capacity) can refuse any treatment, even life sustaining treatment, and that to treat someone who has not given consent to such treatment would be a battery and liable to civil damages.

It would appear that respect for autonomy, a component of dignity, is enshrined in law and overrides any public interest in maintaining life, provided the person making the decision has capacity. As Lord Donaldson stated in the earlier case of Bland

‘This situation gives rise to a conflict between two interests, that of the patient and that of the society in which he lives. The patient’s interest consists of his right to self-determination – his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society’s interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount.’ Airedale NHS Trust v Bland [1993] AC 789 p112

The Mental Capacity Act has also made clear that this principle of respecting the right of the individual to make decisions for him/herself holds true for decisions made in advance which are to apply in the event of a person losing capacity, even when those decisions go against medical opinion or the interests of society. Advance directives (or specifically in the Mental Capacity Act, Advance Refusals of Treatment) are as binding, if they are valid and applicable to the situation, as if the person was making a contemporaneous decision about his or her healthcare. The requirements for an advance refusal of life sustaining treatment are:

- The person making it must be over eighteen
- The statement must be written, signed and witnessed
- The statement must specify that it relates to life sustaining treatment

If the criteria are fulfilled then a clinician providing treatment contrary to the directive would be open to prosecution in battery.
English law seems to be making a clear statement that the principles governing treatment at the end of life are:

1. Capacitous choice must be respected.
2. A valid advance refusal is the same as a capacitous choice and must be respected.
3. If the person lacks capacity the decision must be in the person’s best interests.
4. Best interests must take account of the persons past and present wishes, beliefs and values (MCA section 4(6))

Acts and omission
Having noted the emphasis on patient autonomy and patient views informing decisions about best interests it is interesting to note the different approach of English law when patients request active measures to end their life or assistance from their physicians in bringing their life to an end. The year before Ms B (the lady with spinal artery haemorrhage) requested that her doctors remove her ventilator support another patient also sought help from the courts to allow her to end her life when her disease had reached a stage that she no longer wished to continue living. Diane Pretty was a lady with motor neurone disease whose condition was deteriorating to such an extent that it was not possible for her to take her own life even if she wished to. She therefore sought a declaration from the court that if her husband assisted her in taking her own life he would not be prosecuted under the Suicide Act 1961 which prohibits aiding and abetting suicide. Mrs Pretty argued that refusal to provide this reassurance was a breach of her rights under articles 1, 2 and 8 of the European Convention on Human Rights, a right to life, prohibition of torture, and a right to a private and family life. Her case was rejected by the House of Lords in England and she appealed to the European Court who also rejected her claim that her rights had been denied under the convention. The court ruled that

"It did not appear to be arbitrary for the law to reflect the importance of the right to life, by prohibiting assisted suicide while providing for a system of enforcement and adjudication which allowed due regard to be given in each particular case to the public interest in bringing a prosecution, as well as to the fair and proper requirements of retribution and deterrence."

Mrs Pretty’s autonomous wish was to have control over her death and to die at a time of her choosing. Her husband’s autonomous wish was to assist her in this by administering the medication that would bring about her death. The courts judged that her right to self determination in this respect was constrained by the public interest in the importance of the right to, or sanctity of, life. This seems to be at odds with the statement by Lord Donaldson in Bland that society’s interest in preserving life gives way to the individual’s right to self determination.

The key difference on which English law appears to turn with regard to end of life decisions and respecting patient autonomy is the distinction between an act and an omission. Deliberately performing an act, for example giving an injection, which results in the person’s death is unlawful and would be regarded as murder. However omitting to provide a treatment, for example withholding or withdrawing artificial nutrition, which results in a person’s death may be lawful if it is thought to be in the patient’s best interests. If a patient requests that life sustaining treatment be omitted then her wishes must be respected and it would be unlawful (a battery) to continue to treat her. If a patient requests that her physician performs an act that brings about death her wishes cannot be respected and compliance with them would be unlawful (murder or assisted suicide depending on the act performed).
Suicide tourism and the English legal response

Diane Pretty died in England without her husband assisting her death. However since 2001, 115 people have travelled from the UK to a Swiss clinic (Dignitas) in order to have an assisted death. To date there have been no prosecutions of relatives who have travelled with them but there have been police investigations. Several cases have made news headlines for example the case of Daniel James, a 23 year old rugby player who was paralysed from the neck down in a sporting accident. These cases have focussed the debate on the legal position of those who travel to Switzerland to support their loved ones in the act of suicide. The fact that no prosecutions have taken place does not mean that they will not do so. This year another lady, Debbie Purdy sought clarification of the law on this issue. Ms Purdy has multiple sclerosis and although not near death or contemplating assisted suicide at present sought clarification on whether her partner would be prosecuted if he assisted her to commit suicide when her condition had deteriorated and she decided to end her life. She lost her case in the High Court and Court of Appeal but in July 2009 five Law Lords rules that the Director of Public Prosecutions must specify when he would prosecute in such cases. They cited Article 8 of the European Convention on Human Rights as supporting her right for respect for a private life which included deciding how she wished to spend her dying days. This decision was hailed as a victory by supporters of assisted dying in the UK while opponents said they would seek legal advice in an attempt to overturn it.

In September 2009, in response to the Law Lord’s ruling in the Purdy case, the Director of Public Prosecutions set out new guidance in this area. The guidance sets out 16 factors that would be in favour of a prosecution for assisted suicide. These cover issues such as whether the person committing suicide had capacity, whether there was any coercion, or whether the person assisting had assisted other suicides. There are a further 13 factors listed as mitigating against prosecution, including whether the person committing suicide had a terminal illness or severe disability with no likelihood of recovery, whether the person assisted was wholly motivated by compassion and whether the person committing suicide had expressed clear and settled views on the matter. The focus is very much on ensuring that the decision to commit suicide is a fully informed autonomous decision and that the act of assistance is a unique act motivated by compassion and undertaken by someone with a close relationship with the person committing suicide. This would rule out physician assisted suicide as an example where prosecution might not be considered in the public interest. The guidance also makes explicit that active euthanasia is illegal.

The views of parliament

In 2006 Lord Joffe presented a Bill to parliament that would have legalised physician assisted suicide. The Assisted Dying Bill set out criteria under which it would be legal to prescribe a lethal injection for a patient to take in order to end their life. These included a requirement that the person had capacity, was not depressed, had less than six months to live and was suffering unbearably, that a second physician had examined the patient, and that the patient had been offered appropriate palliative care measures. The Bill sparked heated debate both within and outside parliament which was essentially polarised between an argument for individual freedom of choice on the one side and an argument for protection of the vulnerable on the other side. Opponents of the Bill used the ‘slippery slope’ argument to claim that any movement in the law to allow physician assisted suicide would put pressure on vulnerable patients, the elderly and those with disabilities, to take their own life. The public interest in protecting the vulnerable was thought to outweigh the individual interest of self determination. Both sides would consider that they are in favour of death with dignity. Public opinion, as judged by polls, was divided and the British Medical Association voted against physician assisted suicide. The Bill was blocked in the House of Lords by 48 votes.
In 2009, following the case of Debbie Purdy, an amendment was tabled to the Coroners and Justice Bill that was going through parliament. This amendment would have removed the threat of prosecution from those who go abroad to support someone who commits suicide. The amendment was defeated by 194 votes to 141.

The debate on assisted suicide continues in the UK. It is likely that a new Bill will be put before parliament in the not too distant future. In the meantime patients continue to travel to Switzerland to seek death. Patients who have capacity, whether they are vulnerable or not, can continue to request withdrawal of life sustaining treatment or to refuse its initiation.

Postscript

A recent case has sparked further debate on end of life decision making. A 26 year old woman with mental health problems took poison 3 days after writing an advance refusal of treatment stating that in the event of her taking the poison she did not want doctors to treat her except to relieve any pain. Doctors at the admitting hospital complied with her wishes and she died. This case has prompted calls for a review of the law on advance directives and the extent to which a person has a right to make decisions that result in her death.

The story continues......