

## Care of the dying - palliative care and legal frameworks

This is one in a series of articles on the topic of euthanasia, assisted suicide and end of life care available on the website [johnwyatt.com](http://johnwyatt.com)

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Euthanasia and assisted suicide – current realities internationally

Euthanasia and assisted suicide – UK experience

Euthanasia and assisted suicide – underlying social forces

Euthanasia and assisted suicide – the argument from autonomy

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Risks of legalising assisted suicide

Euthanasia and assisted suicide – Christian responses and perspectives

Medical issues in the care of the dying person

Care of the dying – palliative care and legal frameworks

*“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”* Cicely Saunders

It's a strange paradox that here in the 21<sup>st</sup> century, the expertise of pain specialists and the power of new pharmacological and other approaches to symptom control have never been greater. This is particularly true in the UK which is internationally recognised as a world leader in pain control and palliative care. Yet despite these remarkable advances the pressure to legalise medical killing in the UK and elsewhere has never been so urgent. This strongly suggests that the drive to change the law is not so much based on enlightenment and compassion for those who suffer (whatever the public rhetoric), as much as on the drive for autonomy, individualism and “lifestyle choice”.

This article looks at the practice of palliative care as an alternative to assisted suicide, and then looks at the current legal framework concerning medical and care decisions at the end of life.

### ***Curative treatment and palliative medicine***

Building on the pioneering work of Cicely Saunders and others, palliative medicine has developed a philosophy which separates it from most forms of conventional medicine. The goals of conventional curative medical treatments can be summarised under three headings: the reversal of disease processes in order to ensure the preservation, protection and prolongation of life, the preservation and restoration of normal human functioning, and the relief of pain and other distressing and unwanted symptoms. In terms of priorities, in

most medical treatment the protection and preservation of life comes first and all other goals are sub-ordinate.

Conventional medical treatment may also be subdivided into “curative treatment” – where the goal is to destroy completely disease processes within the body and restore the patient to health, and “active medical treatment” where the goal is to alter the course of the disease, without bringing a permanent cure. For instance, in many forms of advanced cancer intensive chemotherapy can significantly prolong life but cannot cure the disease completely.

Hospital doctors often refer to limitations of treatment or “ceilings of care”. The decision to give any treatment has to be made after weighing up potential benefits against potential burdens and risks. As a person’s disease progresses, the likelihood of benefitting from invasive treatment decreases and the likelihood of side-effects and complications increases. Clinicians may then determine (with the knowledge and agreement of the patient) that there should be a ceiling of care beyond which they will not go, in order to reduce the harms to a patient caused by overtreatment. Ceilings of care may include the decision not to commence cardiopulmonary resuscitation in the event of a cardiac arrest, if it is agreed that resuscitation would be unlikely to succeed and deprive the individual of a peaceful death. A person with advanced disease may decide against being admitted to hospital, or against being transferred to an intensive care unit, accepting that they would rather receive palliative care and symptom control instead of the additional burdens imposed by invasive, uncomfortable and medically futile treatment.

### ***The goals of palliative care***

Palliative medical treatment is appropriate once it is clear that curative treatment is unlikely to bring any benefit. It has different goals and priorities compared with conventional medical treatment. Since death is now inevitable, the primary goal of all palliative treatment is the relief of pain and distressing symptoms. The aim of palliative care is neither to prolong life, to try to ensure that death is held back for as long as humanly possible, nor is it to deliberately shorten life, to hasten death and bring the end of life as rapidly as possible. Instead the aim is to concentrate elsewhere - on the person’s well-being and experience of life in the precious last days, weeks and months that may remain. To help people “live before they die”.

More than sixty years after Cicely Saunders started her revolution, palliative medicine is developing and rapidly advancing. Innovations and improvements in pain relief and symptom control continue to take place. From a medical perspective, symptom control in terminal cancer is usually very effective. But many more people are now dying from neurological conditions such as multiple sclerosis, or chronic respiratory or cardiac failure,

bringing new challenges to creative and skilled caring. Research into improved care for those with chronic neurological and cardiorespiratory conditions is now a major focus, and incremental advances in palliative techniques and interventions continue to take place.

### ***End of life or terminal care***

It is often helpful to distinguish palliative care, which may continue for many weeks, months and even years, from end of life or terminal care, which is an important sub-section of palliative care. This is the care given to a person in the final hours of their life, a period usually covering a few hours up to 2-3 days. During this phase the person may be described as “actively dying”. The individual person may be fully conscious or may move in and out of consciousness. Control of unpleasant symptoms is even more critical than previously, and the family may need a great deal of intensive support at a very difficult time. This kind of care is often delivered in a hospice or a person’s own home where possible, with detailed attention to the needs of the whole person – their physical and mental symptoms, their need for relationships and family support, and their spiritual needs. However in some cases, particularly where there are complex symptoms or a patient is not fit enough to be transferred and death is imminent, end of life care is best given in hospital.

Using a slow infusion of pain-killers, anti-vomiting medication and mild but non-lethal sedatives, people can remain comfortable without hastening death. With skilled care many people remain conscious and able to communicate without being in marked discomfort or distress. It is generally recognised that it is helpful to identify the terminal phase in which the patient is “actively dying” so that unnecessary interventions can be stopped and appropriate care can be provided.

However diagnosing when death is imminent is a far more imprecise science than many lay people realise and accurate prediction of death in non-cancer patients is particularly difficult. The truth is that there are no very precise ways of telling accurately when a patient is in the last days of life.

It is not unusual for an individual who appears to have entered the final last hours of life to reverse their course and show some temporary improvement, sometimes for days, weeks or even longer. It is also undoubtedly true that the reaction of the individual to the approach of death may make a substantial difference. Some people approach death with acceptance and equanimity, whereas others may fight to stave off death for as long as possible, perhaps because they wish to see a family anniversary, or other significant event.

It is important that relatives and carers understand that it is frequently impossible even for highly experienced health staff to predict the timing of death with any accuracy. As discussed in other articles death and dying have profound symbolic importance for us as

moderns, because they challenge the comforting illusion that we are in control of our own lives or of the lives of those who are close to us. Walking with a dying person to the end reminds us forcefully that we are fragile, limited and dependent beings.

### ***Attitudes of palliative care specialists to euthanasia and assisted suicide***

The great majority of specialists in palliative medicine have remained strongly opposed to the legalisation of euthanasia and assisted suicide. In a 2015 survey of specialists from the UK Association of Palliative Medicine 82% opposed a change in the law on assisted suicide. Another recent survey by the Royal College of Physicians found that 92% of palliative care physicians opposed medically assisted suicide. It is striking that those with the greatest practical experience of caring for dying people are also those who are most strongly opposed.

One prominent example is Baroness Illora Finlay, Professor of Palliative Medicine at Cardiff University, who is an active campaigner against the legalisation of assisted suicide. She stresses the remarkable advances that have been made in pain and symptom control since she started work in the 1970's. Experienced practitioners, like Baroness Finlay, observe that terminally ill patients frequently experience feelings of hopelessness, despair and depression, and at that moment death may seem the obvious way out. The patient may ask in desperation why the doctor doesn't just kill them to end it all. But carers learn to identify and address "the question behind the question" – "Why me?", "Why now?", "Why does no one seem to care?" The request to be killed may in fact be an expression of fear, hopelessness or despair and to the experienced and compassionate carer it offers an opportunity for deeper understanding, engagement and support.

### ***Communicating honestly with the healthcare team and with loved-ones***

As the terminal phase of life approaches there are important topics that may need to be discussed with the medical team, family and care-givers:

*Are there important things I want to accomplish before I die? Are there people, relationships to restore, affairs to set in order?* Dying offers an opportunity for priorities to be changed, and some people find an intensity of purpose despite physical frailty and fatigue.

*What symptoms am I likely to suffer, and how can these be reduced?*

Talking to professionals in advance can provide reassurance about the range of treatments that are available to ensure unpleasant symptoms are well controlled. Being honest about our fears and anxieties can help the healthcare team to ensure that our particular concerns are addressed.

*Where would I like to die?* Although in reality many people die in hospital, most people when asked would prefer to die at home, or in a hospice. Community palliative care teams exist to provide excellent end of life care in a variety of settings.

*Who will support me spiritually?* Good palliative care aims to support the whole person, and to address all forms of distress – physical, psychological and spiritual. Maintaining good pastoral care from friends at church or from a trusted pastor or elder may be of vital importance in sustaining Christian faith as death approaches. We are not alone in the Christian family and we are called to bear one another's burdens, to be there for one another and to say to each one, "it's good that you are alive".

### ***Making palliative care widely available***

Only about 10% of all deaths in the UK occur in specialist hospices. The majority of people die in a NHS hospital. Outside the UK, hospice care is even more uncommon. Many specialists have tried to take the very best care practices and techniques developed in the hospices and make them widely available in general hospitals and in the care of people dying at home.

But this has proved problematic and challenging. High quality palliative care is not technologically sophisticated but it does not come easily or cheaply. It requires a skilled, experienced and motivated multidisciplinary team available around the clock. The Liverpool Care Pathway (LCP) was a UK initiative to translate the best practices of palliative care developed in hospices into a form suitable for staff without specialist palliative care experience working in a NHS general hospital. The LCP was originally developed by the Royal Liverpool University Hospital and the Marie Curie Hospice in Liverpool for the care of terminally ill cancer patients. Sadly, this well-meaning initiative led to many highly publicised instances of poor care, failures of communication between staff and relatives and accusations that staff were using the LCP protocol inappropriately to hasten death.

In 2013 an official review panel was set up into the working of the LCP and a report was published entitled "More Care Less Pathway". The panel concluded that the LCP was not being applied properly in many cases and that generic protocols were the wrong approach. It was recommended that use of the LCP should be replaced by an end of life care plan for each patient, together with good practice guidance for the patient's specific condition.

The controversies around the provision of palliative care highlight that people often have specific and widely differing concerns about the care they will receive when they are close to death. A commonly expressed concern is that the individual may be neglected and abandoned as death approaches, and that hospital staff may covertly attempt to ensure that they die rapidly, by withdrawing fluids and giving excessive doses of sedation. These

understandable concerns have led people to insist that they receive active medical treatment up to the end of life together with clinically assisted nutrition and hydration (that is food and fluids that is given by a tube – usually directly into the stomach).

However the opposite concern is also frequently expressed, namely that the doctors will attempt to keep the individual alive far too long, using painful and distressing invasive treatments, instead of allowing death to occur from natural causes. These understandable concerns have led people to insist that they do not receive life-sustaining or active medical treatment if it can bring no benefit and that clinically assisted nutrition or hydration should not be given in the terminal phase.

In summary every individual is different and good palliative and end of life care must be highly sensitive and responsive to the wishes of the individual and their family.

### ***Can we afford to provide palliative care for everyone who needs it?***

As stated above good quality palliative care is not cheap. An authoritative independent review in 2011 found that over 450,000 people in the UK needed good palliative care services every year and over 90,000 per year were not receiving proper care. However the same review found that providing appropriate palliative care in the community across the UK, enabling those who wanted to die at home, would be overall cost-neutral for the state. This is because the cost of dying in hospital is considerably greater than dying at home with appropriate professional support and care.

It was estimated that the NHS spent 460 million pounds on palliative care in 2011. This is a large sum but it represents considerably less than 1% of the NHS total budget per year. As a country we put vastly more resources into research into finding new treatments for cancer and other means of extending life than we do into providing good palliative care for everyone who needs it. So there is no doubt that we, and all those in developed countries, can afford this kind of care. The issue is about our priorities for allocating healthcare resources. Sadly, providing good palliative care in poor countries who can allocate only a few dollars per person per year for healthcare is a major challenge, but there has been remarkable recent progress in the provision of palliative care in low resource countries through charities and NGO's.

### ***Current legal framework for end of life decisions***

This section focuses on the current legal framework in England and Wales although similar legislation is now in force in many jurisdictions. The bedrock of current medical law is that all decisions about medical treatments must be taken in the patient's best interests and that if the patient has legal capacity to decide on their own treatment, then the patient must

give their free and informed consent to all treatment. If a patient with capacity refuses treatment, then the doctors must respect that refusal, even if it leads to the shortening of life. If the patient has capacity then the next of kin and other relatives have no legally binding right to be involved in treatment decisions, although of course the patient may wish them to be involved.

In England and Wales the Mental Capacity Act governs the care which is provided to adults who lack capacity to make decisions on their own behalf. The fundamental principle is that all care must be provided in the individual's "best interests" and in a way that causes the least restriction on their rights and freedom of action.

According to the Act every adult is presumed to have capacity to make decisions on any matter unless it has been determined that they lack capacity. The law also recognises that each person may have capacity to make some decisions but not others. In other words you may have the legal capacity to make a relatively minor decision, but not one with serious and irreversible consequences. All reasonable steps must be taken to enable you to make your own decisions, including ensuring that the information is presented in a way that you can easily understand. With regard to the care of the dying patient, if the medical team conclude that the patient lacks capacity then it is their duty to make treatment decisions based on the best interests of the patient.

The Mental Capacity Act sets out the steps that should be taken to determine a person's best interests. This will include consideration of:

- a) their past and present wishes and feelings (and in particular any relevant written statement made when they had capacity)
- b) the beliefs and values that would be likely to influence their decision if they had capacity
- c) any other factors that you would be likely to consider

In addition the Act states that the doctors should take account of the views of relatives, any person that was previously named for that purpose, anyone engaged in caring for the person, and any named individual with a Lasting Power of Attorney (see next paragraph).

Many relatives mistakenly believe that they have the legal right or duty to make medical decisions on behalf of the individual who is dying. However this is not correct. If the dying person still has legal capacity then it is entirely up to that individual to what extent relatives and carers should be involved. If the person loses capacity then, under the Mental Capacity Act, the legal responsibility for treatment decisions rest with the treating doctors (and particularly with the doctor who carries overall responsibility for their care – in hospital practice this is a named consultant). However the medical team do have a duty to consult

the next of kin, and other relatives and carers, as part of the process laid down by the Act in determining the best interests of the patient.

Under the Mental Capacity Act there are two main ways for a person to make preparations in advance to help with decision-making at the end of life, when they may have lost capacity.

### ***Lasting Power of Attorney***

The first option is to create a Health and Welfare Lasting Power of Attorney (LPA). This involves signing a formal document that appoints one or more named individuals to make decisions on your behalf, if and when you lose capacity. The LPA may be given to a spouse, a close adult relative, a close friend or to a solicitor. If you appoint more than one attorney they can be appointed either so that they must act together or so that they can act separately. You can also appoint replacements if the primary attorney(s) become unable to act. The LPA only comes into force once you have lost capacity and the LPA has been registered with the Office of the Public Guardian (OPG).

Health and welfare LPAs cover decisions including accommodation, care, and all aspects of day to day living as well as decisions on medical matters. If you wish, you can give your Attorneys authority to give or refuse consent to life-sustaining treatment on your behalf. The medical team will be legally bound to follow your Attorneys' decisions. The Attorneys have a legal responsibility to act in the person's best interests. Not surprisingly under current English and Scottish law an LPA does not give legal right to an Attorney to authorise euthanasia or assisted suicide of the individual concerned – such acts are illegal. Registration of an LPA with the Office of the Public Guardian takes about three months and so advance planning is necessary. An LPA can be made, revoked or updated at any time so long as you still have mental capacity to do so.

### ***An Advance Decision***

The alternative mechanism laid down in the Mental Capacity Act is a legally binding document called an Advance Decision. This is sometimes referred to as a "living will". It is an expression of the person's wishes about future treatment or about some other aspect of their general health and welfare that may arise in the future.

The main value of an Advance Decision is to *refuse consent* to a particular treatment. It is not possible legally to demand any particular treatment but it is possible to refuse consent in advance, including refusal of life-supporting treatment. If the Advance Decision relates to life-supporting treatment it must be in writing and signed by the person in the presence of a

witness who must also sign the document. There is no form of prescribed wording but clearly the more precise the better.

At some future time, if the person is admitted to hospital with a life-threatening illness, the medical team will need to decide whether the Advance Decision is valid. In particular they will need to determine that the Advance Decision relates to the particular circumstances and treatment(s) which are being considered. They will also need to check that the person has not subsequently withdrawn the decision and that they have not behaved subsequently in a way which is clearly inconsistent with it.

### ***What are the advantages and disadvantages of the Lasting Power of Attorney and the Advance Decision?***

The Advance Decision is much more straightforward to set up and there are fewer formalities involved. However in reality it may be much less useful than initially appears. It is very hard to predict in advance the precise clinical circumstances that may occur months or years later, when you may be admitted to hospital in an incapacitated form. As a result the Advance Decision may turn out to be invalid in practice, because it does not deal with the precise treatments or conditions which are being considered by doctors.

Alternatively, it might be argued by doctors or relatives that the person had changed their mind following the writing of the document. There is also the possibility that an advance decision may have unforeseen consequences. For instance an elderly person with a life-limiting condition might write an advance decision giving a blanket refusal to any form of life-support treatment. However this might mean that doctors would fail to give intensive treatment for an incidental treatable condition such as pneumonia, even though treatment might have given a good chance of prolonging reasonably healthy survival by many months.

The LPA by comparison is legally more robust and covers a very wide range of possibilities. Your Attorneys are given legal power to act on your behalf, including in circumstances that you had not imagined in advance, provided always that they act in what they believe are your best interests.

This means they must take account of your past and present feelings and beliefs. As a result it is very valuable to write a separate document which sets out your wishes, beliefs and values regarding medical treatment and care at the end of your life. This document which states your wishes can be updated as you see fit. (See below for more detailed discussion about this form of statement).

The gives very wide legal powers to the Attorney. This may create a level of responsibility which some may see as burdensome. For instance you may wish to nominate a spouse or grown up son or daughter as your Attorney. Months or years later it is possible that you

are admitted to hospital in an unconscious state and an acute life-threatening illness is diagnosed. If it is covered under the wording of the LPA, then your loved-one carries strong legally-binding powers to give consent or to refuse life-sustaining treatment on your behalf. The doctors will almost certainly be bound to follow your Attorney's decisions. This means that your loved-one must carry responsibility for life and death decisions on your behalf, and they must live with the consequences of those decisions for the rest of their lives.

### ***A written statement of wishes and values***

The Mental Capacity Act specifically makes provision for a person to write a statement of their wishes, feelings and values while they still have capacity. This written statement must be taken into account by the medical teams, by Attorneys and by any others who have to determine the individual's best interests once they have lost capacity. Although this document is not legally binding, it can be extremely helpful for everyone involved. It can be particularly helpful to express your own individual values, concerns and desires about the end of your life.

There is no specific format that the statement should take. It would obviously be helpful to include family members in discussions about the content of the statement, to minimise the possibility of uncertainty or disagreement about implementing your wishes. It is also important to keep any statement up to date and make sure that copies are given to family members, people holding a LPA, the GP and other doctors and carers who may be involved. It is obviously essential that important people in your life are aware of the document. Another practical tip might be to carry a card in your wallet or handbag so that people can be directed to where they can find the relevant document(s) in the event of an unforeseen accident or health issue.

In creating a statement of wishes and values, it is not possible to demand that specific treatments will be given. Medical teams are not obliged to start or to continue medical treatments if they consider them to be against a patient's best interests, and this includes artificial hydration and nutrition.

However, if you are concerned that treatments may be withdrawn inappropriately, for instance in the case of a person with chronic disabilities who worries that doctors might consider that their life was no longer worth living, then it is possible to record these concerns as part of a statement of wishes. For example, it would be possible to state that you wish to be provided with clinically-assisted nutrition and/or hydration where these have a reasonable chance of sustaining your life or easing your symptoms.

A sample Statement of Wishes and Values written for a Christian believer who is facing a life-limiting illness is available on the website [johnwyatt.com](http://johnwyatt.com)

## ***Conclusion***

Good palliative care allows people to die at peace, and with dignity, and (just as important) it enables them to live before they die. But, as so often, the right way is not necessarily an easy way. We have seen that there may be complex technical, legal and personal issues that must be addressed if the very best level of medical, nursing and personal care is to be provided in the last weeks, days and hours of life. Perhaps of greatest importance is the need to start a conversation with our closest relatives and friends, in advance of the crisis.

This material is adapted from *Right to Die? Euthanasia, assisted suicide and end of life care*, by John Wyatt, published by IVP.

For further articles on the topics of euthanasia, assisted suicide and end of life care visit the website [johnwyatt.com](http://johnwyatt.com)