

'The Sanctity of Life'

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Good afternoon and thank you for asking me to speak at your conference.

I think the first and most important thing for me to say is to stress that the amount of paper you see before me is not related to the length of time I intend to speak but the paucity of my eyesight.

The next point is to clarify the standpoint from which I speak. I have been a nurse for more than 40 years and latterly, for 15 years or so, until my retirement in 2009, I worked as a senior nursing lecturer at the centre for clinical excellence at Leeds and examined for the University. My experience therefore comes from a clinical standpoint with academic overtones. Or should that be undertones?

I have had experience in many clinical fields related to today's topics, for example I have cared for women seeking an abortion - nurses are required by their professional code of conduct (MNC 2008) to care for women before an abortion is carried out and also after that procedure, but they are permitted by law to refuse to be part of the procurement process in line with their conscience. However we must be careful when using the word abortion to remember that it is a medical term and that there is a difference between spontaneous abortion (often referred to as miscarriage) and the medical or artificially induced end to a pregnancy.

I have also worked in a fertility clinic, albeit many years ago, and before the development of contemporary concerns such as cloning, embryological research and genetic engineering.

This idea of caring for someone as opposed to being involved in a clinical procedure is also of course relevant when caring for those who may have attempted suicide or who continually poison their bodies by a variety of means - alcohol, nicotine and other drugs, resulting in life shortening illnesses or conditions. There needs to be an understanding that care must be given, and given well, to all, regardless of one's own beliefs and values.

All these issues are of course about the Sanctity of Life, the reason we are here today. A tremendously difficult phrase to define as it depends in which context, law, religion, philosophy etc. we are working. In general terms I take it to be that it is a belief that all life is sacred from the point of conception and therefore has a right to life. Meaning that life is special because we are made in the image of God or because we have a soul as a special gift from God. Because of this special nature human life is sacred and should be valued and respected.

Some would also use this term, The Sanctity of Life, to define a wider ethical approach, not one just concerned with a handful of bioethical issues (euthanasia, abortion, etc.) but the entire range of moral concerns that human beings face from abortion to poverty, from war to the death penalty, from child abuse to concerns with the environment.

I believe that all human beings should be valued, irrespective of age, sex, religion (or none), social status or their potential for achievement. Human life is a basic good as opposed to an instrumental good, a good in itself rather than as a means to an end.

So where to start? As my specific expertise is around acute oncology and, for the last 28 years palliative care, it would therefore seem most sensible to me to concentrate on issues such as Euthanasia, Suffering, Quality of Life, etc. which all relate to palliative care. You may feel that

most of what I have to say is interlinked and it is difficult to separate one issue from another. This is certainly the case as I see it as these are complex ideas and today only allows me to consider a few things very superficially. But hopefully it gives us a place to begin to think about what is important to us.

Euthanasia of course literally means "good death" but is more usually used in everyday discussions to relate to mercy killing or assisted suicide - those being helped to die by others. However the concept of a good death is an interesting one. Most of us if asked could articulate what we would consider a good death to be, possibly pain free, not lingering, family and loved ones around us, etc. but it is of course very subjective. Within healthcare there is a notion that a good death is one devoid of as much suffering as possible but also cannot be achieved without someone sitting with the person who is dying — the concept of "presencing" as defined by the theorist Patricia Benner - someone being alongside as death occurs supporting the person on their journey, yet my experience throughout all my career is that people will invariably wait until they are alone to die. Families may sit for hours, or even days with loved ones, and it is at the moment when someone leaves to find themselves a drink or to visit the bathroom when death occurs. It is as if the person needs to "do" the act of dying on their own. This of course is often very distressing for families and probably not what most of us would expect we would want of a good death.

So back to euthanasia;

Euthanasia is generally divided into several categories:

Passive - the withdrawal of treatment resulting in the death of a person.

Active - an action taken to cause death as the disease process or condition is not sufficient on its own to cause death, or the person would be in unbearable pain or would suffer for a long time. This is of course illegal in this country.

Voluntary - the patient can make their views known and asks to die.

Involuntary - the patient is unable to communicate their wishes or views.

So passive euthanasia is about the withdrawal of treatment, usually when that treatment is considered to be futile or when the treatment burden is perceived as too great for the person; however is there a difference between the withholding of treatment in the first place and the withdrawing of treatment once established? Decisions to withhold or withdraw treatment are among the most difficult for patients, families and healthcare professionals to make.

Prolonging a patient's life usually, but not always, provides a benefit to that patient. The benefit may be around their health in its broadest sense i.e. around the promoting of psychological or spiritual wellbeing or the wish to see a special event; the birth of a child or the return of a loved one from abroad.

It is not an appropriate goal of medicine to prolong life at all costs, with no regard to its quality or the burdens of treatment. But is this at odds with a Christian definition of the Sanctity of Life? Of course it is increasingly possible through the use of technology to sustain life almost indefinitely.

Most people accept that treatment should not be prolonged indefinitely, i.e. when it has ceased to provide benefit for the patient. But all those concerned, including society, need reassurance that each individual decision is carefully thought through, is based on the best quality information available and follows a widely agreed procedure.

Confusion has arisen from the fact that guidance from the courts on withdrawing artificial nutrition and hydration specifically refers to patients in a persistent vegetative state, without making reference to other serious conditions in which a decision to withhold or withdraw artificial nutrition might arise.

You will remember the case of Tony David ("Anthony") Bland (21 September 1970 - 3 March 1993) was a supporter of Liverpool F.C. injured in the Hillsborough disaster. He suffered severe

brain damage that left him in a persistent vegetative state whereby the hospital, with the support of his parents, applied for a court order allowing him to 'die with dignity'. As a result he became the first patient in English legal history to be allowed to die by the courts through the withdrawal of life-prolonging treatment. The judgement hung on the fact that nutrition and hydration in this situation were seen as treatment and not care.

Care can never be withdrawn.

This of course is not the situation in the States where there are recorded cases of people being in a persistent vegetative state for many years. You will, I'm sure, be aware of high profile cases around this issue - the case of Terri Schiavo; a seven year battle between her parents, her husband and the courts.

So can we make the presumption that passive euthanasia is acceptable in some situations? That we do not have to keep people alive in any circumstances - that we are working against God's plan if we prevent someone from dying - as God plans for them to die.

Then there is the concept of Agape, that is, it is the kindest thing to allow them to die. We should not be prolonging someone's suffering by making them live longer. We should allow them to die with dignity, allow nature to take its course.

One other consideration that must be raised here is that of the doctrine of double effect. The principle of double effect is often mentioned in discussions of what is described as palliative care, care for patients with a terminal illness, especially those in need of pain relief; the concern that to give analgesics to relieve pain may shorten life.

The doctrine of double effect, is a set of ethical criteria for evaluating the permissibility of acting when one's otherwise legitimate act (for example, relieving a terminally ill patient's pain) will also cause an effect one would normally be obliged to avoid (for example, the patient's death.) Double—effect originates in Thomas Aquinas's treatment of homicidal self-defence (*Summa Theologiae*, IIa-IIae Q. 64, art. 7).

This set of criteria states that an action having foreseen harmful effects practically inseparable from the good effect is justifiable if upon satisfaction of the following:

- the nature of the act is itself good, or at least morally neutral;
- the agent intends the good effect and not the bad either as a means to the good or as an end itself;
- the good effect outweighs the bad effect in circumstances sufficiently grave to justify causing the bad effect and the agent exercises due diligence to minimize the harm.

It is often thought that the administration of a high dosage of opioids is sometimes allowed for the relief of pain in cases of terminal illness, even when this can cause death as a side effect. This argument played a great part in the 1957 acquittal of suspected serial killer Dr. John Bodkin Adams, a case which established the principle in British law.

Some, including some Catholic ethicists, hold that this concept is morally different from deliberate euthanasia for the relief of pain. In addition, support for the view that palliative care and euthanasia are close companions is based on the assumption of a fine line between pain relief, or relief of severe distress, and causing death. In practice, opioids have a very wide safety margin when used appropriately and in the context of pain relief that is titrated (adjusted) to the individual patient. Similarly, sedatives are not lethal when used only to relieve distress and at the lowest dose to avoid dangerous adverse effects. Today, palliative care experience and research has shown that it is possible to manage pain or distress without hastening death and double effect is not viewed as being a part of palliative care practice.

But even when these assumptions are made, double effect seems to provide at least part of a

justification for administering drugs to relieve pain. But, the primary purpose of this action must be to relieve the burden of suffering for the patient.

But what about suffering?

It is sometimes argued that there is a positive value in suffering. Down the generations it has been seen that in suffering there is concealed a particular power that draws a person close to Christ, a special grace. Indeed my own Grandmother would repeatedly tell me that God never gives us a burden that He knows we cannot carry, but I do have to say that on occasions I have come close to feeling that the Good Lord had mistaken me for someone else, but then I have survived a number of major problems, so perhaps she was right after all.

My experience whilst working in Sarajevo, now a Muslim city since the fall of former Yugoslavia, is that this idea of suffering is also part of Islam. But I have to confess that I found it very difficult to care for people in severe pain at the end of their life who would either categorically refuse analgesia or ask my opinion as to the usefulness of Paracetamol in end of life care. My reading would also suggest that this is a tenet of Hinduism and other faiths as well.

John Paul II wrote "It is suffering, more than anything else, which clears the way for the grace which transforms human souls". However while we must acknowledge that some Christians will want to accept some suffering for this reason, in my experience most Christians, and non—Christians, are not so heroic; so there is nothing wrong in trying to relieve suffering. In fact it seems to be acceptable, a good thing to do so, as long as it does not intentionally cause death. M Scott Peck, in "The Road Less Travelled" has written that in a few weeks at the end of life, with pain properly controlled a person might learn how to negotiate a middle path between control and total passivity, about how to welcome the responsible care of strangers, about how to be dependent again. . . .about how to trust and maybe even, out of existential suffering, at least a little bit about how to pray or talk with God.

Those without a faith may also feel that there is some value in suffering. It is thought that it provides an opportunity to grow in wisdom, character and compassion. Suffering is something which draws upon all the resources of a human being and enables them to reach the highest and noblest points of what they really are. Suffering allows a person to be a good example to others by showing how to behave when things get difficult.

But it isn't easy to define suffering. Most of us can decide when we are suffering but what is suffering for one person may not be suffering for another. Within healthcare there is an assumption that suffering is far greater than just the experience of pain, it also encompasses psychological, spiritual emotional and social distress, and as such needs a multidisciplinary approach to affect relief if relief is possible, so pain relief and its associated issues is only part of the answer.

In the late 1960's there was a debate which grew and grew at the Children's Hospital in Sheffield, between 2 eminent doctors around the nature of suffering and the Sanctity of Life which resulted in much press coverage and eventually a televised debate in the early 1970's concerning how to treat children born with spina bifida. One, a physician and a German Jew, a survivor of the Holocaust, the other a catholic Professor of surgery with a spinal kyphosis; the surgeon felt that all children born with a spinal malformation, regardless of severity, should undergo surgery, be given the chance of survival — even if some sadly later died from problems associated with that surgery, the physician felt that children with severe congenital problems should only receive palliative care, should be made comfortable and fed only when they cried for food; a debate that couldn't be resolved but which illustrates the polarity of beliefs about suffering and the sanctity of life.

I have mentioned when discussing the doctrine of double effect the art and science of palliative care. This is where my real love lies as it allows me to treat each patient as an individual; an individual who identifies their own needs and negotiates with me as to how they can best be met. Not a professional telling a patient which is the best road to take.

I had better define palliative care.

There are many definitions but the one that is universally accepted is that of the World Health Organisation 2002.

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organization, 2002.

You will see that I have underlined some of these points - I would like to come back to them a little later if I may.

Within healthcare the understanding of palliative care has moved on since 2002. Whilst the above definition is still very relevant its use has been broadened in 3 important areas.

1. That palliative care is not just an approach to offer people at the end of life but all the way through an illness and relates more efficiently to care of those with a condition or a disease process that cannot be cured.
2. That it is sometimes important to offer people the opportunity to access a palliative care approach or palliative services much earlier in a disease trajectory, possibly even at the point of diagnosis, not as a last resort.
3. Palliative care whilst having been developed from a cancer perspective is not just for people experiencing cancer, it is an applicable model for all those with palliative needs e.g. cardiac disease, neurological disease, renal disease, etc.

As you will see from this definition Palliative Care is all about quality of life and this is the final issue I would like to look at. And here we are back to the phrase "difficult to define".

Quality of life is a ubiquitous concept that has different philosophical, political and health related definitions. But concentrating only on the health perspective Quality of Life is a descriptive term that refers to an individual's emotional, social, and physical well-being, and their ability to function in the ordinary tasks of living.

Seed and Lloyd presented data in 1977 from a Social Science Research Council Survey which had asked people what quality of life meant to them; 23 per cent said a happy marriage, 19 per cent related it to contentment, 10 per cent referred to social relations. The rest talked in terms of income, standard of living and having consumer goods, but overall humanistic concerns were mentioned more frequently than materialistic ones.

We all have ideas and opinions about what constitutes quality of life, but can it be defined in anything but individual personal terms? And if this is the case, does it matter?

Quality of life is therefore a subjective concept and wholly individual, and whilst there are probably some givens for example freedom from pain and other distressing symptoms, everything else is down to the individual, different for you, different for me.

It can however be measured in part by the use of theoretical models which are increasingly important when evaluating the benefits and burdens of new treatments and methods of care and in moving care forward.

So what is important to you?

Family, independence, art, music, faith?

Picture 1 — this is how I see quality of life myself. (A vibrant young woman)

Picture 2 — but this is probably a more accurate picture (Three more elderly ladies!)

To conclude I see palliative care as being an equally good definition for all care, what is often described as best practice, irrespective of diagnosis or stage of life; but it is also a useful tool in the consideration of the Sanctity of Life. It affirms life and regards death as a normal process; it intends neither to hasten or postpone death; it integrates the psychological and spiritual aspects of care; it offers a support system to help people live as actively as possible until death; it aims to enhance the quality of life.

I am unsure what you had hoped to have gained from my presentation but the one thing that you will have worked out by now is that I have no answers to any questions, only more questions.

Thank you.