Scottish Council on Human Bioethics

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Date: 15 April 2005 – Mr. Jeremy Purvis MSP

Dying with Dignity

Consultation response on behalf of the Scottish Council on Human Bioethics:

The **Scottish Council on Human Bioethics** (SCHB) is very grateful to **Mr. Jeremy Purvis MSP** for this opportunity to respond to his consultation on assisted suicide entitled **Dying with Dignity**. It welcomes Mr. Purvis' intent to promote public understanding and discussion on this topic.

In addressing the consultation, the SCHB has formulated the following responses:

Questions:

It would be very helpful in the development of the Bill to receive views on the proposals outlined in this consultation, and responses to the following questions would be particularly appreciated:

<u>Question 1.</u> Please specify any concerns that you have with the proposal and how these could be addressed.

Scottish Council on Human Bioethics Response

1. Support for health care professionals in palliative care.

The SCHB would like to share Mr. Purvis' commitment for investments in healthcare and the resources that are being directed towards palliative care. With him, it would also like to show its support to all health care professionals who offer assistance and provide compassion and understanding to patients who are terminally ill or dying.

2. The proposed Bill would breach Article 9.c. of the Council of Europe Parliamentary Assembly Recommendation 1418 (1999) on the protection of the human rights and dignity of the terminally ill and the dying which states that:

The Assembly therefore recommends that the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while:

i. recognising that the right to life, especially with regards to a terminally ill or dying person, is guaranteed by member states, in accordance with Article 2 of the European Convention on Human Rights which states that "no one shall be deprived of his life intentionally":

ii. recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person;

iii. recognising that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death.

3. The near unanimity of European countries do not accept assisted suicide:

The Consultation entitled **Dying with Dignity** is misguided when it suggests, in page 11, that assisted suicide is possible in countries such as Germany and France. In these countries, assisted suicide may not be an offence as such but is still impossible without criminal charges being brought. In Germany, for example, the person assisting in the suicide has a legal duty to initiate lifesaving emergency measures as soon as the person willing to die loses consciousness. If the assisting person omits this action, he or she may be liable for prosecution¹.

Moreover, in a document on assisted suicide, prepared by the Council of Europe and published on the 20th of January 2003, which contains the replies to a questionnaire from 34 countries of the Council of Europe and the USA, only three European countries (The Netherlands, Estonia and Switzerland) specifically indicated that their legislation would not regard such an undertaking as an offence provided certain conditions were met².

Thus, when the <u>primary intention</u> of a physician is to end the life of a patient through an intervention (including the withdrawal of life-sustaining treatment), then this intervention would be prohibited in most Council of Europe member states.

If, on the other hand, a physician follows good medical practice and addresses the best interests and well-being of the patient and this practice has, as a side effect, the shortening of the patient's life, then no objections would be normally brought against the physician in all the countries concerned. The doctor's intention is the critical distinction between physician assisted suicide and good palliative care.

4. It is wrong to suggest that any person can ever lose his or her human dignity:

It has been suggested that individuals should be able to determine their own dignity and quality of life. For example, it has been proposed that persons who fear that they will lose their dignity during the final stages of a terminal illness should be able to 'die with dignity' before these stages occur.

In response to this the SCHB notes that it is wrong to suggest that any person can ever lose his or her human dignity. Indeed, even though human dignity is a belief, it is a belief that everyone should always believe is found in everyone to an equal extent.

With assisted suicide, as opposed to suicide, another person must also accept that it would be preferable for a person wishing to die not to continue living. In other words, in assisted suicide, an individual must accept that the human dignity of another person can be lost and that his or her life is not worth living.

Therefore, the very title of the consultation *Dying with Dignity* cannot mean anything in the context of assisted suicide. Indeed, dying with dignity means caring for, and protecting the dignity of, the terminally ill and dying person, not helping them kill themselves (for a discussion of the concept of human dignity see response to question 6).

¹ Replies to the questionnaire for member States relating to euthanasia, Council of Europe, 2003, http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/Activities/Euthanasia/Answers%20Euthanasia%20Questionnaire%20E%2015Jan03.asp#TopOfP age

² Replies to the questionnaire for member States relating to euthanasia, Council of Europe, 2003, http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/Activities/Euthanasia/Answers%20Euthanasia%20Questionnaire%20E%2015Jan03.asp#TopOfP age

5. Palliative care can address the suffering of a terminally ill person:

It has been suggested that assisted suicide would enable persons who become terminally ill and find themselves in an unbearable situation, to not have to suffer a slow, drawn-out death.

In response to this the SCHB notes that suffering can be adequately alleviated in all but the most extreme cases with up to 90% of patients having their pain effectively relieved³.

Experience shows that once people are comfortable and their fears concerning suffering have been addressed, they often change their minds about wanting to end their lives. Similarly, patients with an illness such as motor neurone disease (a serious progressive neurological disorder) are often afraid of choking to death. But studies from the most experienced hospice units have demonstrated that, with appropriate palliative care, this virtually never happens. Thus, few patients request assisted suicide when their physical, emotional and spiritual needs are properly catered for.

This is also reflected in recent research concerning the *Oregon Death with Dignity Act* which indicated that 46% of patients who received interventions, such as control of pain, referral to a hospice program or a trial of antidepressant medication, changed their minds about assisted suicide. This compares to the 15% of those for whom no interventions were made⁴.

This research confirms evidence coming from the Netherlands which shows that two thirds of requests for assistance with suicide or euthanasia are rescinded when procedures such as palliative interventions are initiated ⁵.

And even in the extremely rare cases where suffering does not respond to treatment, the possibility of using artificial transient sedation exists to keep the patient asleep in order to address the intolerable physical and/or mental distress. Thus, there is absolutely no reason for anyone to die in pain.

6. Assisted suicide would undermined the protection due to the most vulnerable persons of society:

It has been suggested that, at present, assisted suicide appears to be extensively practised in secret and that it is this reality that carries the greatest potential for abuse. The pressures that can influence end-of-life decisions will be more pernicious if exercised in the dark. The gap between law and practice must be reconciled if respect for the rule of law is to be maintained. Abuse will not disappear with legislation, but will surely be reduced.

In response to this the SCHB notes that having the option of assisted suicide is dangerous since it may be considered by many elderly and other vulnerable people who feel that they are a burden to family, carers and society or that their care may be eating up some of the inheritance which they wanted to pass on.

In a recent survey of physicians' experience with the *Oregon Death with Dignity Act*, doctors indicated that 11% of patients requesting a prescription for a lethal medication had done so because they perceived themselves as a financial burden to others with another 6% indicating that their decision was influenced by insufficient social support being received⁶.

³ Organisations such as the Hospice Movement reveal that suffering can be adequately alleviated in all but the most extreme cases. See also Pain Control - BBC - http://www.bbc.co.uk/religion/ethics/euthanasia/euth_pain_control.shtml

⁴ Linda Ganzini, et. al., Physicians' Experiences with the Oregon Death with Dignity Act, The New England Journal of Medicine, Vol 342, February 2000.

⁵ Van Der Maas PJ, Van Delden JJM, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life, Lancet, Vol. 338, 1991.

⁶ Linda Ganzini, et. al., Physicians' Experiences with the Oregon Death with Dignity Act, The New England Journal of Medicine, Vol 342, February 2000.

In addition, concern has been raised that the legalisation of assisted suicide may encourage women, the poor and those who are members of ethnic minority groups to seek such assistance because of inadequate social support or lack of access to health care^{7,8}.

Vulnerable people need to hear that they are valued and loved. They need to know that society is committed first and foremost to their well-being, even if this does involve expenditure of time and money.

The House of Lords Select Committee in 1994 also recognised the undesirability of anything which could appear to encourage suicide (Paper 21-I, 31 January 1994 - p 49, para 239) when it stated that "We are also concerned that vulnerable people - the elderly, lonely, sick or distressed - would feel pressure, whether real or imagined, to request early death. We accept that, for the most part, requests resulting from such pressure or from remediable depressive illness would be identified as such by doctors and managed appropriately. Nevertheless we believe that the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life." ⁹

7. Assisted suicide would undermine the role of health care professionals:

It has been suggested that curing disease and bringing about death are not mutually exclusive roles, the intention in both cases being the relief of suffering. It is further argued that the primary role of the physician is to care for his or her patient, which must therefore entail respecting their autonomous wish to die.

In response to this the SCHB notes that crossing the boundary between acknowledging that death is inevitable and taking active steps to bring about death changes fundamentally the role of the physician, changes the doctor-patient relationship and changes the role of medicine in society. The physician's role has always been to cure and care for his or her patients, not help to kill them. Physician Assisted Suicide would indeed contravene the Hippocratic Oath which includes the statement that "I will administer no poison, even if asked".

In addition, it has been shown that doctors are unprepared to end the lives of their patients. This is reflected by evidence from the USA which shows that 15% of physician assisted suicide attempts did not result in the death of the person¹⁰. For example, in January 2005, an Oregon man's attempt with doctor-assisted suicide took a bizarre turn when he woke from a coma nearly three days after the attempt and lived for two more weeks before dying of natural causes (he had lung cancer)¹¹.

⁷ Linda Ganzini, et. al., Physicians' Experiences with the Oregon Death with Dignity Act, The New England Journal of Medicine, Vol. 342, February 2000.

⁸ Foley KM. Competent care for the dying instead of physician-assisted suicide. New England Journal of Medicine, Vol. 336, 1997.

⁹ Judgments - The Queen on the Application of Mrs Dianne Pretty (Appellant) v Director of Public Prosecutions (Respondent) and Secretary of State for the Home Department (Interested Party) - House of Lords: http://www.parliament.the-stationery-office.co.uk/pa/ld200102/ldjudgmt/jd011129/pretty-2.htm

¹⁰ Emanuel EJ, Daniels, ER, Fairclough DL, Clarridge BR, The practice of euthanasia and physician-assisted suicide in the United States: adherence to propose safeguards and effects on physicians, JAMA Vol. 280, 1998.

¹¹ Don Colburn, Failed assisted suicide raises questions in Oregon, The Times-Picayune, 7 March 2005, http://www.nola.com/national/t-p/index.ssf?/base/news-0/111017850021920.xml

This gives cause for concern since it demonstrates that the procedure may actually add to the suffering of the person and deny the tranquil death being sought¹². Research in the Netherlands also shows that complications occurred in 7% of cases of assisted suicide, and problems with completion (a longer-than-expected time to death, failure to induce coma, or induction of coma followed by awakening of the patient) occurred in 16% of cases. Moreover, the results show that in 18% of cases of assisted suicide the physician decided to administer a lethal drug to the patient, which thus became cases of euthanasia, usually because things were not going as envisaged¹³.

In the Netherlands, where assisted suicide and voluntary euthanasia is permitted, Dr Johann Legemaate, of the KNMG (Royal Dutch Medical Association), indicated to the House of Lords in their 2005 report that "many doctors prefer euthanasia for practical and clinical reasons, because when it is assisted suicide you hand over the medication to the patient and he has to take it himself. It may have side effects which will lead to the doctor acting anyway. For that reason most doctors prefer euthanasia"14.

8. The legalisation of assisted suicide would lead to unworkable laws:

It has been suggested that legalising assisted suicide could give physicians some protection against the law.

In response to this, the SCHB notes that the legalisation of assisted suicide may impose upon medical professionals obligations which may be unworkable with the possibility of penalties (or prosecutions) applying if these are not respected.

Furthermore, if the criminal law sought to proscribe the conduct of those who assisted the suicide of the vulnerable, but exonerated those who assisted the suicide of the non-vulnerable, it could not be administered fairly and in a way which would command respect.

9. Assisted suicide will eventually lead to euthanasia:

If assisted suicide is legalised but euthanasia is not, some competent patients may not be able to end their own lives for purely physical reasons. This would happened, for example, in the case of patients with neurological illnesses who have problems with swallowing or using their hands and patients who are physically too weak to take all the oral medications themselves¹⁵. Thus, the legalising of assisted suicide would inevitably be a first step to legalising euthanasia as well.

Question 2. What are your views on using the definitions of 'Adult' and 'Incapable' as set out in the Adults with Incapacity (Scotland Act) 2000.

In light of SCHB's stance that assisted suicide is unethical, this question carries insufficient weight for consideration.

¹² Nuland, S.B., Physician-Assisted Suicide and Euthanasia in Practice, The New England Journal of Medicine, Vol. 342, 2000.

¹³ Johanna H. Groenewoud *et .al.*, Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands, The New England Journal of Medicine, Vol. 342, 2000.

¹⁴ Select Committee on Assisted Dying for the Terminally III Bill Report, 2005, paragraph 168, http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8608.htm#a37.

¹⁵ Johanna H. Groenewoud *et .al.*, Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands, The New England Journal of Medicine, Vol. 342, 2000.

Question 3. By whom should reporting mechanisms be administered?

In light of SCHB's stance that assisted suicide is unethical, this question carries insufficient weight for consideration.

<u>Question 4.</u> What period, within which death is diagnosed should a patient be entitled to request assistance to die?

In light of SCHB's stance that assisted suicide is unethical, this question carries insufficient weight for consideration.

<u>Question 5.</u> What would the financial burdens on the NHS, public sector, and medical organisations or private organisations arising from this Bill be?

In light of SCHB's stance that assisted suicide is unethical, this question carries insufficient weight for consideration.

Question 6. Do you have any further comments to make?

Scottish Council on Human Bioethics Response

1. What is Human Dignity?

The SCHB notes with interest that the title of the consultation makes reference to the concept of 'dignity'. In this regard, the Council concurs that it would be helpful to try to define what 'human dignity' actually means before addressing the issues related to assisted suicide.

Like many other terms in ethics and philosophy, 'dignity' has often been used as an empty slogan, or a cover for intellectual undress¹⁶. Indeed, it cannot be fully accounted for by other concepts such as respect and autonomy, beneficence, non-maleficence or justice. But this does not invalidate the basic idea.

In the Oxford English Reference Dictionary, 'dignity' is defined as the 'state of being worthy of honour and respect' 17. In other words, it incorporates aspects of 'honour' and 'respect' but also of 'value' and 'worth' which can be bestowed or recognised by:

- (1) oneself but only if one can 'see' oneself from another person's perspective and/or
- (2) other persons.

This means that if a solitary human being found himself or herself on a desert island and if this individual did not believe in any celestial being nor on the existence of anyone else on earth, then the human dignity which would come from another person would not exist.

If, in addition, the individual did not consider himself or herself worthy of any honour and respect then he or she could not be considered as having any human dignity whatsoever.

It should also be noted that the concept of human dignity is not a scientific one. No individual will ever be able to prove whether or not a person is endowed with human dignity.

From a scientific perspective, a human being is made up of a 'large pile of cells' containing about 70% water and a few other chemical compounds who is eventually destined to become, with time, a handful of dust.

Thus one of the problems about bestowing human dignity to others or to oneself is the circular nature of this process. Scientifically, the assignment of human dignity from a 'pile of cells' to another or the same 'pile of cells' does not have any meaning!

Because of this, it should be remembered that secular human dignity is only a *belief*, a belief which is somewhere 'out there'.

And in our modern societies, this important belief in human dignity has also become a belief that everyone agrees should always be believed is found in everyone to an equal extent.

This universal nature of human dignity has arisen in order to address the unacceptable abuses which took place in the past history of humanity. For example, before the slave trade was abolished or during the Second World War, many persons believed that specific categories of peoples did not have the same human dignity as themselves and were, therefore, considered as second class citizens.

¹⁶ Commenting on the appearance of this vague usage in connection with end of life treatment, a US presidential commission observed: "Phrases like... `death with dignity'... have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred.": President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to forgo life-sustaining treatment*. Washington, DC: US Government Printing Office, 1983: 24.

¹⁷ The Oxford English Reference Dictionary, Second Edition, Edited by Judy Pearsall and Bill Trumble, Oxford University Press, 1996.

Therefore, in order to support the concept that human dignity can never be taken away, national and international declarations have been prepared which seek to confer human dignity to all persons of society. In so doing, they define, in a way, what all human persons should believe (but cannot prove scientifically). This was done for example with the:

United Nations' Universal Declaration of Human Rights¹⁸ which states in Article 1 that:

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Council of Europe's Convention on Human Rights and Biomedicine¹⁹ which states in *Article 1 (Purpose and object)* that:

Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

In this respect, the official Explanatory Report of the **European Convention on Human Rights and Biomedicine**²⁰ indicates that *Article 1* should be interpreted in the following manner:

- 17. The aim of the Convention is to guarantee everyone's rights and fundamental freedoms and, in particular, their integrity and to secure the dignity and identity of human beings in this sphere.
- 18. The Convention does not define the term "everyone" (in French "toute personne"). These two terms are equivalent and found in the English and French versions of the European Convention on Human Rights, which however does not define them. In the absence of a unanimous agreement on the definition of these terms among member States of the Council of Europe, it was decided to allow domestic law to define them for the purposes of the application of the present Convention.
- 19. The Convention also uses the expression "human being" to state the necessity to protect the dignity and identity of all human beings. It was acknowledged that it was a generally accepted principle that human dignity and the identity of the human being had to be respected as soon as life began.

At the national level, the German Constitution is the most impressive example of the need to base the whole social and political order on the principle of human dignity which was prepared only a few years after the Second World War. This was done in order to avoid a return to the inhuman ideologies and practices which had recently taken place in Germany. Thus the German Constitution's first article states that²¹:

Human dignity is inviolable. To respect and protect it is the duty of all state authority.

¹⁸ Adopted and proclaimed by United Nations General Assembly resolution 217 A (III) of 10 December 1948, http://www.un.org/Overview/rights.html

¹⁹ Council of Europe Convention on Huma Rights and Biomedicine (ETS No.: 164), http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc

²⁰ Explanatory Report of the European Convention on Human Rights and Biomedicine, http://conventions.coe.int/Treaty/en/Reports/Html/164.htm

²¹ See a detailed commentary on this article by Ernst Benda: «Die Würde des Menschen ist unantastbar», in Beiträge zur Rechtsanthropologie, ed. Ernst-Joachim Lampe, Stuttgart, Steiner Verlag, 1985, p. 23. In Roberto Andorno, The paradoxical notion of human dignity, http://www.revistapersona.com.ar/9Andorno.htm

Many other national constitutions also affirm this principle as the basis of legal systems²².

These texts emphasise the universal and absolute nature of the concept of human dignity. In other words, they support the notion that *no person* (including oneself) can lose his or her human dignity at any time in his or her life. Indeed, to reject such a notion would not only seriously challenge the whole concept of human dignity but would be an extremely serious precedent in a world that has fought so hard to endow *all* persons with the same dignity. In addition, the concept of a person being able to lose human dignity would dangerously undermine the most fundamental ideas embodied in these texts which often form the foundations of our modern societies.

2. The bestowing of human dignity

As we have previously seen, it is possible to bestow human dignity both to others and/or to oneself. But though these two concepts are related to one another, it may be useful to look at them separately.

2.1. Human dignity given by and to oneself

The ability to confer human dignity or self-respect to oneself by 'seeing' oneself from another person's perspective is not a simple concept. In a way, it demands, that a person can 'see' himself or herself outside of his or her physical body and confer human dignity to himself or herself. Curiously this aspect of self-awareness is also something that only human beings can do in contrast to animals.

The kind of human dignity which is assigned by and to oneself is also somewhat more subjective than that which is given by other persons. Indeed, it depends on the manner in which an individual considers himself or herself. For example, some persons may have a very healthy respect for themselves while others do not.

But it remains an important concept. There have been occasions in the history of humanity, when the only dignity conferred to an individual was that which was assigned by the person to himself or herself. For example, many persons, in the past, who were often treated worse than animals and bereft of any respect for their human dignity only survived because they constantly reminded themselves of their own human dignity.

Consequences for the discussion on suicide and assisted suicide

In the very unfortunate and tragic situation where a person seeks to commit suicide, the individual may perceive that he or she will or has lost all value and dignity in his or her own eyes.

Though this may contravene the above human rights instruments since they also apply to the manner in which a person should see himself or herself in addition to others, it is often accepted that this has happened as a consequence of grave psychological distress in the individual.

This is one of the reasons why the Suicide Act 1961 was enacted in England and Wales in order to abrogate the rule of law which had previously made it a crime to commit (or to attempt to commit) suicide. In the past, the main effect of the criminalisation of suicide was to penalise those who attempted to take their own lives as a result of grave psychological distress. And this was considered as completely inappropriate. It also cast an unwarranted stigma on innocent members of the suicide's family and led to

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²² See Constitution of Belgium, art. 23; Constitution of Switzerland, art. 119 (concerning biotechnological interventions on human beings and nature); Constitution of Ireland, Preamble; Czech Republic Constitution, Preamble; Constitution of Spain, art. 10; Constitution of Sweden, art. 2; Constitution of Finland, art. 1; Constitution of Greece, art. 7.2; Constitution of Poland, Preamble, art. 30; Constitution of Lithuania, art. 21; Constitution of Slovenia, art. 34; Constitution of Russia, art. 21; Constitution of South Africa, Section 7.1 and Section 10; Constitution of Mexico, art. 3.1, 25; Constitution of Israel, art. 1; Constitution of Brazil, art. 1; etc. See a selection of legal texts which mention dignity explicitly, in Dignity, Ethics and Law, ed. J. Knox and M. Broberg, Copenhagen, Centre for Ethics and Law, 1999. In Roberto Andorno, The paradoxical notion of human dignity, http://www.revistapersona.com.ar/9Andorno.htm

the distasteful result that patients recovering in hospital from a failed suicide attempt were prosecuted, in effect, for their lack of success²³.

At present, when a person's suicidal tendencies are discovered by health care professionals or members of society, it is then expected that this person will be encouraged not to commit suicide while psychological assistance is provided. In a way, the person is also reminded that whatever he or she may think of himself or herself at the given time, he or she continues to be valued and given dignity by other members of society. In other words, the dignity assigned by others to the distressed person helps to compensate the perceived lack of dignity which he or she assigns to himself or herself.

But the fact remains that a person who chooses to commit suicide without suffering from any psychological distress would still be undermining the very concept of human dignity. It also means that persons who believe that they will or have lost their 'dignity' or consider that their lives are no longer worth living are discriminating against themselves.

Sadly, this kind of self-discrimination also means that the individuals are, indirectly, implying that the dignity of persons in the same or in worse situations than themselves has also been lost. The persons seeking death may deny that this is happening but because of the relational nature of the belief in human dignity, this conclusion may be inevitable.

Thus, it is wrong to suggest that any person can ever lose his or her human dignity. Even though human dignity is a belief, it is a belief that everyone should always believe is found in everyone to an equal extent.

2.2. Human dignity which is bestowed by other persons

The human dignity which is bestowed by other persons to an individual is based on a 'relational' concept of interactions between different persons. It is something that exists because persons live in a society which enables them to give and take aspects such as love, honour and respect.

As we have seen, the assignment of this kind of human dignity would not exist if a person found himself or herself on a desert island. But this situation of complete and utter solitude would also be similar to the situation of a person who believed that he or she was due full and complete autonomy. Indeed, this kind of complete autonomy is contrary to the very essence of 'relational' human dignity which comes from others. In other words it would not enable human dignity to even exist.

This is in contrast to the special kind of autonomy which actually comes with, and is dependent upon, relationships, which enables human dignity to exist and which is crucial in the field of medical ethics. This means that the essential dignity of every human being is altogether different from what is implied, for example, in the Oregonian political slogan, "death with dignity."

Thus, if assisted suicide is attempted because a person considers that they will or already have lost their dignity then they must also deny the dignity that comes from other people.

Consequences for the discussion on assisted suicide

If a person insists on the kind of complete and total autonomy which is required for assisted suicide, then though he or she may not realised it, the individual is denying and refusing the very concept of human dignity that is conferred by others. But assisted suicide also means, in contrast to suicide, that the person wishing to die demands that another person should believe, accept and agree that he or she has lost or can lose his or her human dignity and is no longer worthy of honour and respect. In other words, that it would be preferable for a person wishing to die not to continue living.

²³ Judgements - The Queen on the Application of Mrs Dianne Pretty (Appellant) v Director of Public Prosecutions (Respondent) and Secretary of State for the Home Department (Interested Party) - House of Lords: http://www.parliament.the-stationery-office.co.uk/pa/ld200102/ldjudgmt/jd011129/pretty-2.htm

With assisted suicide we have, therefore, a person wishing to die and who believes that he or she has lost or can lose his or her dignity being helped by another person to die and who also accepts that the person has lost or can lose his or her dignity.

But, as indicated above, the concept of being able to lose human dignity is a very dangerous concept to support. Indeed, if ever there were a right for a person to demand assistance in suicide, it would mean that society completely accepts and consents to the undermining of the founding principles of:

- The United Nations' Universal Declaration of Human Rights,
- The Council of Europe's Convention for the Protection of Human Rights and Fundamental Freedoms (which is based in the Universal Declaration of Human Rights), and
- The Council of Europe's Convention on Human Rights and Biomedicine.

But another dangerous consequence of assisted suicide would be the manner in which it would undermine the way in which any suicidal tendencies of an individual, even a young healthy person, would be considered. If the concept that one can actually lose one's human dignity is accepted then it may mean that it would be acceptable to help any person commit suicide. This would happen instead of showing concern as to the individual's state of mind and the fact that he or she may require psychological and psychiatric assistance and support.

3. Respect for human dignity

As we have seen, human dignity is a notion which is universal and does not have exceptions. But it is possible for persons to treat other persons in a way that does not reflect the respect due to their human dignity. For example, this may arise when a person is physically maltreated or even raped by others. Because of this, society needs to remain vigilant and continue to monitor its legislation and put forward proposals which seek to protect and support the human dignity of all its members. By so doing it attempts to reconcile the manner in which different persons treat each other with the dignity which they are due. This is also why society will seek to discourage and even prosecute those individuals who do not conform to the behaviour which is expected of them.

For society to do the reverse, i.e. give up and negate the human dignity of a person in order for the individual to be legally treated in an undignified manner would be an extremely dangerous precedent. This would happen in societies which would consider changing the law instead of increasing its physical, psychosocial and spiritual support to the terminally ill and the dying. Thus the best way to respond to a patient's physical and psychological pain in the final stages of illness is not to decriminalise assisted suicide but to step up the development of palliative care facilities²⁴.

However, it is also possible for persons to treat themselves in a way that does not reflect the respect due to their dignity or to believe that circumstances such as a lack of autonomy and a dependence on others is undermining the respect due to their dignity.

Thus, it has been proposed that persons who fear that they will lose the respect due to their dignity during the final stages of a terminal illness should be able to 'die with dignity' before these stages occur. This is reflected in a survey of physicians' experiences with the *Oregon Death with Dignity Act* which indicated that the most common conditions and values that played an important part in the patient's decision to request a prescription for a lethal medication were:

- loss of independence (57% of patients),
- poor quality of life (55% of patients),
- readiness to die (57% of patients), and
- a desire to control the circumstances of death (53% of patients)²⁵.

²⁴ Jean-Paul Harpes, The contemporary advocacy of euthanasia, in Euthanasia Volume 1 – Ethical and human aspects, Ethical Eye series, Council of Europe Publishing, p. 35.

²⁵ Linda Ganzini, et. al., Physicians' Experiences with the Oregon Death with Dignity Act, The New England Journal of Medicine, Vol 342, February 2000.

But again, it would be very unfortunate for these persons to believe that they can lose part or all their dignity because they will no longer be in total control of their lives. Questions should indeed be asked concerning the way in which such people understand the concept of human dignity when they seem to believe that dignity is dependent on the manner in which they control their lives.

As infants are completely dependent on their parents without any perceived lack of human dignity, governments around the world should encourage societies comprising an ageing population to accept that elderly people may also become dependent on others without losing any of their dignity. Thus, it may be preferable to seek to encourage these persons to consider themselves as having preserved their dignity even though they may be losing some control over their lives.

In summary, persons are capable of committing suicide or having assistance to suicide before they consider that they will lose their dignity because they will no longer have complete control or autonomy over their lives. However, by so doing they will also undermine the inalienable, immutable and universal belief of human dignity that they should have for themselves and which the persons assisting them in the suicide should also have for themselves.

4. Inviolability of Life

The belief in the inviolability of life is based on the belief of human dignity and is, therefore, not a scientific notion. However, it is also a belief that forms a basis of all human societies.

The argument underpinning the belief in the inviolability of life is that all human life has worth and therefore it is wrong to take steps to end a person's life, directly or indirectly, no matter what the quality of that life. This is in keeping with both traditional codes of medical ethics and a general perception of what doctors and other health professionals should do, that is save and preserve life.

For example, the reason why suicide was unlawful until 1961 was that it was considered to desecrate the dignity of life enshrined in the United Nations' Universal Declaration of Human Rights (1948) and the Council of Europe's Convention on Human Rights (1950). Thus, if a person chooses to kill himself or herself without any attenuating circumstances, then this action can only be considered as undermining the universal nature of human dignity which is found in all human persons.

What a person is indeed doing when killing themselves or someone else without attenuating circumstances is taking the <u>responsibility</u> of the decision to end a life by indicating that this life is better terminated than continuing to live. In other words, at the specific moment when the killing takes place the person being killed is no longer endowed of any value, worth or respect by the person doing the killing. But as we have seen this undermined the whole concept of the universal and inviolable nature of human dignity. This is reflected in the fact that as Articles 1 and 3 of the United Nations' Universal Declaration of Human Rights indicates human dignity and the right to life are un-separable.

One challenge to this principle in the context of health care is to ask should life be preserved at all costs.

There is indeed a difference between letting a person's life come to a natural end and taking responsibility of killing that person without attenuating circumstances. In the first case, one is not undermining human dingity, in the second, one is undermining the worth of an individual.

5. Quality of Life

In the context of a medical condition, the term 'quality of life' usually refers to the overall effects of a combination of factors, including health and the presence of symptoms, and reflects a person's ability to function physically, psychologically and socially. The term can include subjective feelings of well-being, fulfilment or satisfaction resulting from factors beyond the specific impairment. Somebody with a disability but who is otherwise healthy might be expected to report a good quality of life, whereas someone with a troublesome and painful chronic disease that restricts what they are able to do in which they have a

perceived a paucity of hope, meaning and self worth would likely report that their quality of life is poor.

One of the modern trends in biomedical ethics is to replace the notion of human dignity with that of quality of life which reflects a more 'physical' and/or sensual perspective of life. However, one of the problems with considering quality of life is the question of how this is defined and by whom. A consideration of someone's quality of life may be very different to that of the person who is living the life. Moreover, if a person's quality of life becomes the measure in which a life is 'worth' living then human life could be graded in relation to the amount of 'pleasure' it could be considered to produce with different qualities having different and very unequal values.

In addition, issues relating to the quality of life do not remove the challenges relating to the belief in the inviolability of life.

The quality of life of an individual cannot be linked with whether he or she should live. In other words, no person in society can say that a life is not worth living based on any 'quality of life' arguments. To do so would undermine the very structure of civilised society. This is because the inviolability of life which is itself based on the belief in human dignity supports the founding principles of:

- The United Nations' Universal Declaration of Human Rights,
- The Council of Europe's Convention for the Protection of Human Rights and Fundamental Freedoms (which is based in the Universal Declaration of Human Rights), and
- The Council of Europe's Convention on Human Rights and Biomedicine.

Quality of life may be partial or very much reduced but this does that mean that a life has no worth or should not be lived!

6. Acts /omissions distinction

This distinction argues that there is a difference between actively killing someone and refraining from an action that may save or preserve that person's life. Thus it is morally wrong to push someone into a river to their death but we may not have a moral duty to leap into the river to save someone who is drowning. The difference is one of responsibility and intent. In a medical context this distinction would mean that a doctor could not give a patient a lethal injection to end his or her life, whatever the circumstances, but could, withhold treatment that may sustain it. Thus, in the first case the physician would be responsible for killing the person and the act could be assimilated to murder whereas, in the second, the physician will be letting nature 'take its course' and respecting the reality that life has a natural end. Moreover, withholding treatment would only be permissible if the patient's burden of treatment was so great, that it would not to be in the patient's best interests to continue treatment. For example, it may be permissible not to ventilate a patient if he or she was in chronic respiratory failure.

49. These arguments were however contested by others. We were told that, while it might be argued that there was little difference from the patient's standpoint between on the one hand allowing a refusal of futile or burdensome treatment and on the other refusing assistance with suicide or voluntary euthanasia, from the standpoint of the physician the two situations were quite different—in that he is acceding in the one case to a patient's request to let his or her illness take its natural course, while in the other he would be required to bring the patient's life to an end prematurely²⁶.

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http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm

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²⁶ House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p.22

Autonomy

41. Autonomy was defined for us by Professor John Harris, Bio-ethicist and Philosopher at the University of Manchester, as "the ability to choose and the freedom to choose between competing conceptions of how to live". "It is only by the exercise of autonomy," Professor Harris continued, "that our lives become in any real sense our own. The ending of our lives determines life's final shape and meaning, both for ourselves and in the eyes of others. When we are denied control at the end of our lives, we are denied autonomy"²⁷.

42. To a large extent, of course, autonomy over the time and mode of one's own death already exists—as suicide is not an offence in law. The debate in this case is over assisted suicide or, in the case of persons who are not physically able to take their own lives, voluntary euthanasia. It was suggested to us by Professor Jonathan Glover of the Centre of Medical Law and Ethics at King's College London that there could be a denial of autonomy under the law as it stands at present. It was, he suggested, "discriminatory and objectionable that somebody who is capable of committing suicide is able to do that, but somebody who happens to lack the physical capacity to do that is denied it" (Q 53). The same point was made to us by Baroness Greengross²⁸.

Persons asking for euthanasia/assisted suicide

Dr Rob George, a consultant in palliative care at University College London Medical School, argued on the basis of his own experience that patients requesting assistance to end their lives tended to be "people who wish to be in control... people who are not willing or prepared to engage the issues that may underlie the problems that arise" (Q 356) and that what is needed in such cases is a range of support services to enable the patient to address his or her fears. Dr George described this approach as "respecting the autonomy of the individual as self-government rather than purely self-determination" (Q 367)²⁹.

Professor Leigh, for the ABN, made the same point—that what most terminally ill people want is effective symptom control. "The people who are left over," he added, "who are not satisfied with that approach, are a very small and very often pro-active group of people for whom the simple burden of the disease—not the dying bit—is what really hits them hard and really makes life intolerable. They cannot bear the continued loss of function" (Q 1151). Dr Carole Dacombe had had the same experience and believed that palliative care specialists must be prepared to listen to

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 $^{^{27}}$ House of Lords, Select Committee on Assisted Dying for the Terminally III Bill, Assisted Dying for the terminally III Bill, Volume I, Report, p.20

²⁸ House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p.20

²⁹ House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p.23

such patients (Q 1913). Dr Tom Shakespeare of PEALS believed that: "the people in society who are most keen on this measure are older people, people who are in their seventh or eighth decade, who have had a very vigorous life and who have had control and choice in all areas of their life and really want it at the end of life" (Q 532). It was however also suggested to us by palliative care specialists that others, including patients who have experienced poor symptom control, also make requests for their lives to be ended (Q 387). Professor Foley summed it up as follows: "The question that you need to ask is—are we attempting to cater to a very small population of patients who want control over the end of their life and want physicians to provide that control?" (Q 2116)³⁰.

163. What we were told about the typical character traits of those who avail themselves of the ODDA reflects what we had heard from others in the United Kingdom. Ms Glidewell saw them as "pragmatic, matter-of-fact persons who have always been in control of their lives and ordered their lives and want control. I see it over and over as the reason why people say that they want control of their dying process and want to avert having to be cared for in a way that is offensive to them... It is crystal clear to them that they want to name the day, and when they are finished, when life has served them, and enough is enough, they are done" (Q 643). Dr Goy, referring to studies she had carried out, told us that "most folks said they find being cared for to be intolerable and they have had a lifetime of needing to be responsible and have learned, one way or another, not to depend on others but to be self-sufficient" (Q 753). They tended, she said, to regard religion—though not necessarily spirituality—of little importance and to be "self-confident heading into a great void of nothingness, with no recrimination or retribution for making this choice: they are quite comfortable with it. Typically they do not have a concept of Heaven or the Great Beyond" (Q 774)³¹.

244. There was general agreement among our witnesses that the number of people who might be regarded as serious about ending their lives, who are not psychiatrically ill and who are unlikely to be deflected from their purpose is very small indeed and comprises to a large extent terminally ill people who have strong personalities and a history of being in control of their lives and whose suffering derives more from the fact of their terminal illness and from the loss of control which this involves than from the symptoms of their disease. If therefore it should be accepted by the House that there is a case for such exceptional individuals to be afforded assistance to end their lives, consideration would need to be given to how the parameters of any new law could be set in such a way as to ensure that the take-up rate is limited to such people³².

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³⁰ House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p.51

³¹ House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p. 59-60

³² House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p. 83-84

Relationship between pride and independence on others and Humility and dependence on others.

Legislation

58. It is necessary to consider also judgments given both by the House of Lords (2001) and by the European Court of Human Rights (2002) in response to appeals by Dianne Pretty. Mrs Pretty, who was suffering from motor neurone disease and was paralysed from the neck downwards, though with her intellect and capacity to make decisions unimpaired, appealed against a refusal on the part of the Director of Public Prosecutions (DPP) to give an undertaking that her husband, Brian Pretty, would not be prosecuted under Section 2 of the 1961 Suicide Act if—as Mrs Pretty said she desired—he were to help his wife to commit suicide.

Both appeals were rejected, and Mrs Pretty died shortly afterwards of natural causes³³.

59. In giving its reasons for refusal, the House of Lords ruled that Article 2 of the ECHR, which enunciated the principle of the sanctity of human life and provided that no individual should be deprived of life by means of intentional human intervention, did not imply the right of an individual to choose whether to live or die. Having also ruled that Section 2 of the Suicide Act was not discriminatory (because the Act conferred no right to commit suicide), the House of Lords commented that the DPP could not exercise his discretion not to bring a prosecution under that Act in advance of criminal charges being brought. The ECHR judgement followed similar lines, confirming that no "right to die" could be derived from the Convention. It added that "the law which criminalised assisted suicide was designed to safeguard life by protecting the weak and vulnerable, and especially those not in a condition to take informed decisions, against acts intended to end life or to assist in ending life. The blanket nature of the ban on assisted suicide was not disproportionate, as there was flexibility, in that consent was needed from the DPP to bring a prosecution and a maximum sentence was provided allowing lesser penalties to be imposed as appropriate" [23]³⁴.

The five issues to be looked at are:

- (1) Human Dignity
- (2) Quality of Life
- (3) Autonomy
- (4) Killing
- (5) Suffering

³³ House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p.25

http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm

³⁴ House of Lords, Select Committee on Assisted Dying for the Terminally Ill Bill, Assisted Dying for the terminally Ill Bill, Volume I, Report, p.25

http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm

Glossary:

<u>Human Dignity</u>: Belief that a human person has a state of being worthy of honour and respect. Human Dignity is different from 'Quality of Life' which represents a more 'physical' and sensual perspective of life.

<u>Quality of Life:</u> In the context of a medical condition, it usually refers to the overall effects of a combination of factors, including health and the presence of symptoms, and reflects a person's ability to function physically, psychologically and socially.

The term, however, can include subjective feelings of well-being, fulfilment or satisfaction resulting from factors beyond the specific impairment. Somebody with a disability but who is otherwise healthy might be expected to report a good quality of life, whereas someone with a troublesome and painful chronic disease that restricts what they are able to do in which they have a perceived a paucity of hope, meaning and self worth would likely report that their quality of life is poor.

<u>Euthanasia</u>: Comes from the Greek roots *eu* (well) and *thanatos* (death), literally 'to die well' or 'a good death'. The term is generally understood as an intervention (an intentional act or omission) to end the life of a person by someone else who believes that it would be preferable for the person to die than to continue living³⁵. The key motive is intent. Euthanasia has, as its first objective, to bring about intentionally the death of a person.

Suicide: Active intervention by which a person ends his or her own life.

<u>Passive Suicide</u>: Suicide without an active intervention, whereby a person makes a conscious and contemporaneous decision not to accept or to withdraw from life-sustaining treatment with the aim of hastening his or her own death. Passive suicide recognises the fundamental right of a patient not to accept a medical intervention even if it may save his or her life. This right is recognised in most countries³⁶.

<u>Assisted Suicide</u>: The act whereby a person aids, abets, counsels or procures a suicide or an attempted suicide of another individual.

<u>Physician Assisted Suicide</u>: The act whereby a physician prescribes a lethal medication to a person, but the person administers the dose himself or herself.

Assisted Dying: Term used to cover both Assisted Suicide and Euthanasia.

<u>Intervention in the health field</u>: Any intentional activity, withholding of activity or the withdrawal of activity in the health field. Interventions include:

- <u>Medical treatment</u>: Any positive intentional activity designed to address a specific physical or mental disorder in the best interests of the person. Artificial nutrition and hydration are not generally recognised as treatments (however, since the Bland case (1993) in England and Wales artificial feeding can be considered as a form of treatment).

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An example of an application of this judgement is given in the case where a woman paralysed from the neck down was given the right to die - BBC - 2002: http://news.bbc.co.uk/1/hi/health/1887281.stm

³⁵ http://www.euthanasia.com/definitions.html

³⁶ In the case of Airedale NHS v. Bland, Lord Musttill indicated that "If the patient is capable of making a decision whether to permit treatment and decides not to permit it his choice must be obeyed, even if on any objective view it is contrary to his best interests. A doctor has no right to proceed in the face of objection, even if it is plain to all, including the patient, that adverse consequences and even death will or may ensue...".

- Extraordinary treatment: Any treatment which:
 - holds no reasonable hope of benefit;
 - would place disproportionate burdens on the patient in relation to likely benefit;
 - is too expensive for the healthcare service in relation to its possible benefit.
- <u>Basic care</u>: Any positive healthcare activity which is part of the fundamental needs of a person and does not specifically address a physical or mental disorder.

Advance directives do not generally include basic care, which is considered as always being necessary in order to provide humane assistance.

(The General Medical Council accepts that there is no legal or commonly accepted definition of basic care nor of what is covered by this term. In the medical profession it is most often used to refer to procedures or medications which are solely or primarily aimed at providing comfort to a patient or alleviating that person's pain, symptoms or distress. It includes the offer of oral nutrition and hydration. Indeed, a distinction is generally made between 'artificial' and 'oral' nutrition and hydration where food or drink is given by mouth, the latter being regarded as part of basic care³⁷. Others, however, disagree with this distinction.)

<u>Best interests</u>: The highest level of well-being that is achievable for a specific person. Best interests include medical benefit, respect for the wishes and beliefs of the patient including his or her spiritual and religious beliefs.

<u>Benefit:</u> The clinical advantage or the net gain that a person may receive through a particular intervention. Since the Bland case (1993) in England and Wales, benefit has included non-clinical benefit and may encompass the very existence of a person (being alive).

<u>Persistent vegetative state (PVS):</u> a condition resulting from brain damage, characterised by a lack of consciousness, thought and feeling although reflex activities, such as breathing, continue.

<u>Artificial hydration:</u> The provision of solutions of salts and glucose by artificial means in order to overcome a pathology in the swallowing mechanisms. The solutions are given parenterally as a temporary measure to prevent fluid depletion. As the sole treatment over weeks their use is associated with progressive under-nutrition and eventually death.

<u>Artificial nutrition:</u> The provision of nutritious fluids containing balanced proportions of fat, carbohydrate, protein, vitamins and trace elements by artificial means in order to overcome a pathology in the eating mechanisms. Intravenous feeding requires considerable clinical skill and organisation since it is liable to major complications, particularly blood-borne infection. It is reserved for patients with intestinal failure³⁸.

<u>Artificial ventilation</u>: The provision of mechanical ventilation (generally accompanied by the need for circulatory support) when a patient's spontaneous ventilation is not adequate to sustain life. It is regularly used in critically ill patients to gain control of their ventilation and as prophylaxis for impending collapse of other physiologic functions.

If artificial ventilation is subsequently found to be futile it is usually withdrawn on the basis of a patient's best interests. This is because the clinical benefits no longer exceed the burdens and the patient's imminent death is inevitable.

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³⁷ General Medical Council, Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making, August 2002, http://www.gmc-uk.org/standards/default.htm

³⁸ Caroline Ashby, Nucleus, October 1999, pp4-6