Ad-hoc Committee - End of Life Assistance Bill - Consultation

Response from the *Scottish Council on Human Bioethics* - 12 May 2010

The **Scottish Council on Human Bioethics (SCHB)** is an independent, non-partisan, non-religious registered Scottish charity composed of doctors, lawyers, biomedical scientists, ethicists and other professionals from disciplines associated with medical ethics.
The principles to which the SCHB subscribe are set out in the ***United Nations Universal Declaration of Human Rights (1948).***

***Question 1:* Do you agree a person should be able to request end of life assistance from a registered medical practitioner?**

The SCHB considers that both euthanasia and assisted suicide are dangerous and unnecessary. This is because:

1. Euthanasia and assisted suicide would undermine the protection due to the most vulnerable persons in society

Legalising euthanasia and assisted suicide is dangerous because vulnerable people may begin to consider death as a possible option for releasing family members, carers and the broader society from the responsibility of providing support. These vulnerable people, such as the elderly, may then believe that their death is a greater good and that they have a duty to pursue euthanasia or assisted suicide.

Vulnerable people need to know that they are valued and unconditionally accepted by the community. 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. Indeed, the manner in which the weakest and most vulnerable members of society are treated reflects the true identity of a society because it reveals its core values.

2. Euthanasia and assisted suicide would undermine the relationships of health care professionals with their patients

While all admit the inevitability of death, intentionally and actively pursuing the death of a patient, fundamentally changes the role of the physician, changes the doctor-patient relationship and changes the role of medicine in society. Moreover, physicians alone are not qualified to make quality of life decisions.

Some physicians may also become hardened to death and to causing death, particularly when patients are old, terminally ill, or disabled. Legalising euthanasia would give persons, such as physicians, power that could be too easily abused, and a responsibility that they should not be permitted to have. In very rare cases, physicians such as Harold Shipman[1], may actually feel

[1] Harold Shipman: The killer doctor, BBC News, 13 January 2004, http://news.bbc.co.uk/1/hi/uk/3391897.stm

empowered in being able to provoke death and escape prosecution because of the evidential problems which would arise in this Bill.
In the light of these cases, many vulnerable groups of people and their families may begin to mistrust the real intentions of their doctors.

Historical precedent in the Netherlands demonstrates that progression to involuntary euthanasia requires only four accelerating factors: favourable public opinion, a handful of willing physicians, economic pressure and no convictions for those involved. If legislation allowing euthanasia comes into effect, and political and economic interests are brought to bear, the generated momentum could prove overwhelming.

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

Physical suffering can be adequately alleviated in all but the rarest of cases with up to 95% of patients having their pain and/or symptoms effectively relieved when treated by healthcare professionals with the relevant expertise[2,3].

In addition, the administration of short episodes of sedative drugs can be considered as an appropriate alternative to manage distress and restlessness of persons facing imminent death. This can happen when patients are often barely conscious as a result of their disease (not because of the drugs) and are no longer capable of consciously working through their issues. In this case, palliative care helps patients (and sometimes also their families) by calming their terminal agitation.
Usually, the treatment is a matter of gradually increasing the level of drugs according to effect. However, there are occasions when a patient is very agitated and rapid use of large doses of drugs is essential for the safety and comfort of the patient and others.

Nonetheless, there will always be rare occasions where a patient's symptoms cannot be completely controlled. Often these are patients who cannot resolve an issue or cannot cope with a symptom, such as with severe breathlessness. Some may also have significant psychological and/or spiritual distress which they find difficult to resolve. Indeed, almost all patients with symptoms which cannot be completely controlled have elements of this distress which is not recognised as physical.
These individuals, who are already drowsy and dying of their illness, may then request some form of sedation to relieve the burden of such suffering, in which case it may be possible to manage their distress and agitation without side effects. In other words, drugs are administered and monitored to induce a state

[2] Organisations such as the Hospice Movement reveal that suffering can be adequately alleviated in all but the rarest cases. See also Pain Control - BBC - http://www.bbc.co.uk/religion/ethics/euthanasia/euth_pain_control.shtml; Using Opioids to Control Pain, http://www.painlaw.org/opioids.html

[3] When correctly used to relieve pain in a patient who is terminally ill, morphine should never cause death. By contrast it usually lengthens life and improves its quality. This is because the therapeutic dose of morphine, which relieves pain, is virtually always well below the toxic dose which ends life and because the relief from pain which it brings removes stress factors in the patient's condition.

of decreased or absent awareness (unconsciousness) in order to increase comfort in the dying process rather than, in any way, shortening life[4].

It is very unusual for palliative care to have to use continuous sedation to keep a lucid patient asleep in order to address intolerable physical and/or mental distress. Indeed, sedating people deliberately to deal with their suffering is a very rare occurrence in the UK.

Of course, it is important that patients with difficult symptoms are not promised complete relief since this is beyond the realm of medicine. In this regard, it should be noted that palliative care does not only seek to work in the area of medicine since it also endeavours to provide non-clinical support and the right environment for patients to express and work through their distress.
Thus, few patients request euthanasia or assisted suicide when their physical, emotional and spiritual needs have been adequately addressed.

4. Euthanasia and assisted suicide should not be considered as a medical procedure

Euthanasia and assisted suicide undermine the traditional goal of medicine, namely to cure and care but not to harm or kill patients.
Moreover, research demonstrates that most sustained demands for euthanasia are actually considered by persons suffering from existential problems or because they have an extreme concept of control and independence[5]. In other words, the argument in favour of euthanasia is more about control than medicine.

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

Advocates of euthanasia or assisted suicide suggest that individuals should be able to determine their own dignity and quality of life, unrestricted by the moral, cultural, religious, or personal beliefs of others. 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 incorrect and disturbing to suggest that any person can ever lose his or her human dignity. Though human dignity is not a scientific concept, it is something that everyone should always accept is found in every person to an equal extent. This is in accordance with the ***United Nations' Universal Declaration of Human Rights*** which affirms in its preamble "*the inherent*

[4] Nathan I Cherny, Sedation for the care of patients with advanced cancer, Nature Reviews Clinical Oncology 3, 492-500 (September 2006).

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

dignity and…the equal and inalienable rights of all members of the human family" as *"the foundation of freedom, justice and peace in the world".*

At present, we live in a society where human dignity is universal, equal and inherent. However, legalising euthanasia would mean that society would accept that some individuals can actually lose their inherent human dignity and have lives which no longer have any worth, meaning or value.
It would also mean denying the human dignity which is due to an individual, in order for him or her to be legally killed. In other words, it would give the message that human dignity is only based on subjective choices and decisions and whether a life meets certain quality standards.

In this regard, it should be noted that a society that no longer believes in the inherent dignity of human life cannot offer any valid argument against the taking of life of others, who may be considered unworthy of human dignity. It becomes a society that has lost its trust in the intrinsic value and meaning of life and cannot comprehend why it should be endured.
This is in complete opposition to a responsible benevolent and compassionate society which continues to affirm and defend the lives of all its members and the notion that every human life is full of value, meaning and richness even though persons may be aged, dependent on others or may have lost their autonomy. Therefore, in order to function consistently, society must reject the option of euthanasia if it does not want to undermine basic societal and fundamental values.

6. Full and complete autonomy undermines the concept of human dignity

Advocates of euthanasia suggest that a person's fear of disability and dependency should enable him or her to die while he or she is still autonomous and that euthanasia would enable self-determination to exist. In other words, individuals have the right to take decisions concerning their own life and death situations in accordance with their own values and beliefs. These should not be imposed by a court, a physician or a family member. Thus, advocates of euthanasia suggest that nobody has the right to impose on the terminally-ill and the dying an obligation to live out their lives when they themselves have persistently expressed the wish to die.

In response to this, the SCHB notes that:

The recognition of every individual's full, complete and total autonomy is antithetical to the concept of human dignity and to the proper functioning of an interactive society. Accepting such an extreme form of autonomy would mean the atomisation of each human being whereby every person would live as a completely free and independent individual. Society, as such, would then cease to exist.

Indeed, the very concept of human dignity is dependent on persons having relationships with one another in an interactive society. It is not based on an individual's own limited personal subjective views of himself or herself. In this

respect, it should be noted that it is only because society believes in the human dignity of persons, that it respects their autonomy.

Moreover, being dependent on others should never be associated with a loss of dignity. All are born dependent on others, and many will die dependent on others. Being dependent on others at different times in a person's life is a basic characteristic of human existence.

In addition, the legalisation of euthanasia and assisted suicide may undermine the autonomy and impose a level of coercion on medical and other health care practitioners or individuals. They may, indeed, feel obliged to carry out an act of euthanasia against their wishes or personal beliefs.

7. Human dignity is grounded on an interdependent society

Some supporters of euthanasia argue that persons should be able to decide, for themselves, whether or not they have lost their dignity and that this decision does not have any consequence for other members of society.

In response to this, the SCHB notes that:

In an interactive society, making a choice about the value of a life (even one's own) means making a decision about the value of other lives.
In other words, persons who consider that their lives are no longer worth living or that they have lost their dignity imply that the lives of persons in similar (or worse) medical situations are also not worth living and should be ended. A right to die may then become a duty to die (see comment 1.).

Similarly, persons who believe that their lives are no longer worth living or that they have lost their dignity must also reject the worth, value and meaning that others, such as their family, friends and even society, are giving to their lives. But to consciously deny and reject the value, meaning and worth given by others to our lives, without attenuating circumstances such as a psychological disorder, means putting oneself at the centre of all that matters. Moreover, to reject the intrinsic dignity that another person is seeking to give to our lives represents a denial of this other person's capacity to confer dignity which is tantamount to rejecting him or her as a person.
Thus, personal opinions about worth, meaning and value of human life matter to the whole of society.

8. Neither suicide nor euthanasia should be seen as acceptable alternatives

The attempted suicide of an individual, such as a young person, is never seen as something to be encouraged in society. Instead, great concern is raised regarding the individual's state of mind and the fact that he or she may need psychological assistance or counselling. In other words, it would be completely unethical to help someone commit suicide in these circumstances.

In the light of this, it is difficult to consider how any form of assisted suicide can be considered.

Conversely, if assisted suicide were decriminalised, a risk would then arise that the suicide of individuals, such as healthy young persons, would also be considered as acceptable to society at the very moment when the Scottish government is trying to reduce the very high suicide rates in some parts of the country with programmes such as ***Chooselife*** (www.chooselife.net).

Moreover, with euthanasia or assisted suicide, as opposed to suicide, another person must believe that it would be preferable for the person wishing to die not to continue living. In other words, euthanasia and assisted suicide, reflect the unacceptable belief by one person that another person has lost, or can lose, his or her dignity to such an extent that his or her life is not worth living and should be ended.

When society acknowledges the acceptability of one person being willingly involved in the death of another person, dangerous consequences as to the manner in which the whole of society considers the value, meaning and worth of human life are to be expected.

9. The request to die may not reflect the patient's real wishes

Generally, experience shows that once people receive palliative care and are comfortable, with their fears concerning suffering being addressed, they often change their minds about wanting to end their lives[6].

There is also good evidence that a desire for death in terminally ill patients can vary with time and is closely associated with clinical depression which can often be treated[7]. States of delirium and/or confusion are common in palliative care patients and are sometimes so subtle that they are difficult even for clinicians to recognise. It is impossible to be absolutely confident that a request for a life to be ended does not arise from a disordered state of mind.

In other words, whilst many people are competent to make decisions about their wish for euthanasia and assisted suicide, many are not. This opens the possibility that a decision to end a person's life could be made by a second person such as a nominated proxy. The complexities arising from such conditions could lead to a serious abuse of power.

<u>Question 2:</u> Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill? No.

[6] 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.

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

Question 3: ***Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?*** No.

Question 4: ***The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?*** No.

Question 5: ***Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?*** No.

Question 6: ***Do you have any other considerations on the Bill not included in answers to the above questions?***
Further concerns and discussions relating to euthanasia and assisted suicide can be found at: www.schb.org.uk (publications).

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