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Date: 9 March 2009 – Margo MacDonald MSP

End of Life Choices (Scotland) Bill

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

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 Scottish Council on Human Bioethics subscribe are set out in the **United Nations Universal Declaration of Human Rights** which was adopted and proclaimed by the UN General Assembly resolution 217A (III) on the 10th of December 1948.

The SCHB is very grateful to Margo MacDonald MSP for this opportunity to respond to the consultation on the **End of Life Choices (Scotland) Bill**. It welcomes Ms. MacDonald's intention to promote public consultation, understanding and discussion on this topic.

Not all questions will be responded to.

Scottish Council on Human Bioethics Response:

The Scottish Council on Human Bioethics is opposed to the legalisation of euthanasia and assisted suicide in Scotland. This is because:

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

Advocates of assisted dying have suggested that it 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:

Physical suffering can be adequately alleviated in all but the most rare cases with up to 95% of patients having their pain and/or symptoms effectively relieved when treated by healthcare professionals with the relevant expertise^{1,2}. 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 lives³. Similarly, patients with an illness,

¹ 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; Using Opioids to Control Pain <http://www.painlaw.org/opioids.html>

² 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. In addition, toxic doses risk causing increased agitation in some patients.

³ 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.

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 dying when their physical, emotional and spiritual needs are properly catered for.

Even in the extremely rare cases where physical suffering does not fully respond to treatment there is the possibility of using artificial transient or (very occasionally) total permanent sedation in patients to keep them asleep in order to address physical and/or mental distress.

In this regard, there will always be rare cases of patients whose symptoms cannot be completely controlled. Often these are patients who have significant psychological and/or spiritual distress which they find difficult to resolve. Indeed, almost all patients with uncontrolled pain have elements of this pain which cannot be recognised as physical.

It is, of course, vital that patients with difficult symptoms are not promised complete relief since this is beyond the realm of medicine. But palliative care does not only seek to work in the area of medical treatments since it also endeavours to provide support and the right environment for patients to express and work through their distress.

Finally, for some, the notion that unbearable suffering should be met with a speedy elimination through assisted dying is superficial because it does not take into account (a) the holistic nature of suffering and (b) the self-realisation that suffering may sometimes bring.

Unbearable suffering has to be qualified and it is difficult to see precisely which cases would be classified as bearable and unbearable. In fact, there are patients who would overcome suffering to reach a healthier state, physically and mentally. Overcoming suffering is part of the human condition; this aspect has to be appreciated to fully understand how to deal with it.

In addition, some suffering may bring about self-realisation by the human person able to understand his or her worth and gain meaning in life (a common feeling many experience in their daily difficulties). This is also dignified and optimistic. It may, therefore, be possible to question whether the potential of this realisation should be ignored by merely defining human dignity through elimination and pessimism.

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

Advocates of assisted dying have suggested 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 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 everyone to an equal extent. This is in accordance with the **United Nations' Universal Declaration of Human Rights** which affirms in its preamble "*the inherent 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*".

In other words, because sick people can become incontinent or cannot feed themselves and become dependant on the care of others, this does not mean that they lose their human dignity.

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

Thus if assisted dying was legalised in Scotland, it would mean that society would accept that some individuals can actually lose their 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.

But no government should ever go back to the abuses of humanity in the past in which human dignity was not believed to be present in certain persons because of certain physical characteristics and that they could therefore be exploited or killed.

In this regard, it should be noted that a society that does not believe in the inherent dignity of human life cannot offer any valid argument against murder. 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. A society where the values of life have been completely undermined and where the killing of a persons is acceptable.

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.

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

Advocates of assisted dying have suggested 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 assisted dying would enable self-determination to exist. In other words, that 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. It is a question of freedom and equality in the face of death.

Thus, advocates of assisted dying have suggested that nobody has the right to impose on the terminally-ill and the dying the obligation to live out their lives where they themselves have persistently expressed the wish to die.

In response to this, the SCHB notes that:

The recognition of every person's full, complete and total autonomy does not enable the concept of human dignity nor, for that matter, an interactive society to exist. Instead, it would mean the atomisation of each human being whereby everybody would live as completely free and independent individuals.

But the very concept of human dignity is dependent on persons having relationships with one another in an interactive society and is not based on an individual's own personal subjective views.

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 is a characteristic of who a person is.

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 assisted dying comes into effect, and political and economic interests are brought to bear, the generated momentum could prove overwhelming.

4. The concept of human dignity cannot exist independently of others

Some supporters of assisted dying have indicated that they should be able to choose whether or not they have lost their dignity and that this does not have any consequences on others.

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.

Indeed, persons who consider that their lives are no longer worth living or believe that they have lost their dignity are, in a way, indirectly indicating that the lives of persons in similar or in worse medical situations than themselves are also not worth living and should be ended.

In the same way, persons who consider that their lives are no longer worth living or believe that they have lost their dignity have to reject the worth, value and meaning that others, such as their family, friends and even society, are giving to their lives. To consciously deny and reject (without attenuating circumstances such as

mental disorders) the value, meaning and worth given by others to our lives can be considered as an extremely nihilistic, self-centred and insensitive behaviour. Thus, personal opinions about worth, meaning and value of human life matter to the whole of society.

5. Assisted Dying should not be considered as a medical procedure

It is often suggested that assisted dying should be considered as a medical procedure undertaken by health care professionals.

In response to this, the SCHB notes that:

Assisted dying actually undermines the meaning of medicine which has always been to cure and care but not to harm or kill patients.

Moreover, research demonstrates that most sustained demands for assisted dying are actually considered by persons suffering from existential problems or because they have such an extreme concept of control and independence that they are prepared to deny their own inherent human dignity to get what they want⁴.

In other words, the argument in favour of assisted dying is more about control than medicine. This is reflected in the fact that most physicians are opposed to this practice⁵ and that in some of the places where assisted suicide is taking place, such as in Switzerland and the US state of Oregon, a physician does not need to be actively involved in the final administration of the lethal poison.

6. Assisted dying would undermine the relationships of health care professionals with their patients

Advocates of assisted dying have 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.

Some physicians may become hardened to death and to causing death and start considering their patients as disposable, particularly when they are old, terminally ill, or disabled. Legalising voluntary assisted dying would give persons, such as physicians, power that could be too easily abused, and a responsibility that they should not be entitled to have. In very rare cases, physicians such as Harold Shipman⁶, may actually feel empowered in being able to provoke death.

Because of these very rare cases, however, many vulnerable groups of people may start to doubt the real intentions of their doctors.

7. Assisted dying should not be legalised just because it is taking place in secret

Advocates of assisted dying have suggested that, at present, it appears to be extensively practised in secret and that it is this reality that carries the greatest potential for abuse. They indicate that the pressures that can influence end-of-life decisions will be more pernicious if exercised in the dark and that the gap between law and practice must be reconciled if respect for the rule of law is to be maintained.

In response to this, the SCHB notes that:

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 Doctors change euthanasia stance, BBC News, 29 June 2006, <http://news.bbc.co.uk/1/hi/health/5123974.stm>

⁶ Harold Shipman: The killer doctor, BBC News, 13 January 2004, <http://news.bbc.co.uk/1/hi/uk/3391897.stm>

It is not because something, which is illegal and unethical, such as murder, is practised in secret that the law should be changed. If this happened it would completely undermine the rule of law in a country.

8. It is wrong to believe that opposition to assisted dying is only based on non-secular belief systems

It has been suggested that only those with religious or other non-secular beliefs are opposed to assisted dying and that they should not be able to oppose those who believe, instead, in the autonomy of the individual to choose when to die.

In response to this, the SCHB notes that:

The belief in the inherent dignity and inviolability of human life is, in fact, based on international globally accepted secular principles such as:

- The **United Nations' Universal Declaration of Human Rights** which affirms in its preamble "*the inherent 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 the national level in Europe, the **German Constitution** has presented the strongest 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 barbarous ideologies and practices which had recently taken place in Germany. Thus the German Constitution's first article states that⁷:

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

Many other national constitutions⁸ also affirm this principle as the basis of legal systems with international legal instruments such as 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**⁹, which is the latest text on the issue, indicating in Article 9.c. 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.

⁷ 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>

⁸ 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>

⁹ Council of Europe Parliamentary Assembly Recommendation 1418 (1999), Protection of the human rights and dignity of the terminally ill and the dying, <http://assembly.coe.int/documents/adoptedtext/ta99/erec1418.htm>

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 principles embodied in these texts which form the foundations of our modern societies.

9. Assisted dying would undermine the protection due to the most vulnerable persons of society

Having the option of assisted dying 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. A risk then exists that these vulnerable people may believe that a right to die is actually a duty to die.

This is reflected in a letter to *The Herald (12 February 2009)* by Dr. Alison Morton-Cooper who, as disabled person herself, indicated that: “*Seen as a financial burden to society, friends and family, it is sometimes assumed that it is better, therefore, for us to shuffle out of sight - and mind - before it gets too uncomfortable for the rest of you.*”¹⁰

Vulnerable people need to hear 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. The manner in which the weakest and most vulnerable members of society are treated reflects the kind of society we are.

10. The request to die may not reflect the patient’s real wishes

There is 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 addressed¹¹. The 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 assisted dying, many will not be. This could mean 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.

Finally, it has been noted that persons receiving palliative care often change their minds about their desire for assisted dying¹².

11. Neither suicide nor assisted suicide 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, a lot of concern is raised as to 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 was ever decriminalised, a risk would then exist that the suicide of individuals, such as healthy young persons, would also be considered as acceptable to society at the very moment when the

¹⁰ Assisted suicide does nothing to bring about dignity in life which disabled people need, *The Herald*, 12 February 2009, http://www.theherald.co.uk/features/letters/display.var.2465080.0.assisted_suicide_does_nothing_to_bring_about_dignity_in_life_which_disabled_people_need.php

¹¹ Linda Ganzini, et. al., Physicians' Experiences with the Oregon Death with Dignity Act, *The New England Journal of Medicine*, Vol 342, February 2000.

¹² 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.

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).

Finally, as soon as a second person is consciously involved in the suicide of a person, and this is accepted by society, 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.

12. Distinction between acts and omission

The distinction between acts and omission argues that there is a difference between actively killing someone and refraining from an action that may save or preserve that person's life. For example, it is considered morally wrong to push someone into a river to his or her death but that a moral duty to leap into the river to save someone who is drowning may not exist.

However, in a medical context there is a moral duty for the physician to undertake what is reasonable to save and preserve life.

In other words, if a certain lifesaving intervention was consciously not initiated by a physician in order to kill a patient, then this could be considered as murder. If, on the other hand, a physician follows good medical practice and addresses the best interests and well-being of the patient and does not initiate futile and burdensome interventions and this, as a side effect, shortens the patient's life, then no objections would normally be brought against the physician.

In other words, the critical distinction between murder and good palliative care is related to the physician's intention which is an extremely important concept in law.

13. Prohibiting assisted dying acts as a deterrent to bypassing post-mortem review committees

Some countries which have legalised assisted dying have changed their legislation in order to only examine the legality of an act of assisted dying after the event has taken place by a post-mortem review committee.

In response to this, the SCHB notes that:

Once an illegal act of assisted dying has taken place it is too late to redress the offence since the patient has died. Thus, it is preferable and more responsible that a prohibition on assisted dying should be in place to deter any abuse or transgressions in this area.

In this respect, it should be noted that a study showed in 2008¹³ that, in the Netherlands, the use of continuous deep sedation increased from 5.6% of deaths in 2001 to 7.1% in 2005 (1,800 people), mostly in patients treated by general practitioners and in those with cancer (in 2005, 47% of sedated patients had cancer v 33% in 2001). At the same time, the use of euthanasia fell from 2.6% of all deaths to 1.7%, representing a decrease of 1,200 cases. Such sedation was provided in conjunction with decisions that potentially hastened death (such as decisions to withhold potentially life prolonging treatment).

For only 47% of all patients who received continuous deep sedation, the sedation was started in the last 24 hours before death.

The authors note that: "*For patients with a longer life expectancy, there is a risk that labelling the decision as continuous deep sedation instead of ending of life might serve as a way to evade the procedural requirements for euthanasia.*"

Finally, by prohibiting assisted dying, it is also possible to consider hard cases in which there is a measure of ambiguity, on a case by case basis, in an appropriate court of law and judged accordingly with a measure fairness and compassion where relevant.

¹³ J. Rietjens, J. van Delden, B. Onwuteaka-Philipsen, H. Buiting, P. van der Maas, A. van der Heide, Continuous deep sedation for patients nearing death in the Netherlands: descriptive study, *BMJ* 2008;336:810-813 (12 April), <http://www.bmj.com/cgi/content/full/336/7648/810>