End of Life Assistance (Scotland) Bill

Dr John M Reid

I would like to provide evidence to the End of life assistance bill that is at committee stage currently. I am a Consultant Neurologist at Aberdeen Royal Infirmary. My work involves treating patients with diverse Neurological conditions which can be degenerative and disabling. This includes conditions such as Parkinson's disease, Motor Neuron disease, Multiple sclerosis, Epilepsy, Stroke, Neuropathy and Dementia. My evidence is in the form suggested i.e. 6 questions.

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

I disagree for several reasons. Firstly the bill uses terms which do not explicitly state the actions proposed. It aims to legalise physician-assisted suicide (PAS), that is, a doctor providing the means by which someone can end their own life, and it aims to legalise voluntary euthanasia, that is a doctor administering the means to end another person’s life.

The Bill goes against the ethos of physicians by proposing to cause death, contrary to the Hippocratic oath. No doctor is in favour of suicide. For patients who are in a terminal illness or have overwhelming suffering what they need is palliative and supportive care. The approval of this bill would alter the relationship between patients and doctors. It gives out the message that people with terminal illnesses or neurodegenerative conditions are expendable and a burden to society and will increase pressure on already suffering patients that they no longer valuable to society. It partly comes from a belief by some in our society that everything in life can be controlled – e.g. birth, fertility, health, timing and place of death. We start life in a dependent and fragile condition and many return to a frail and dependent state at the end of our life, which is the natural state of affairs.

What is needed is better and more palliative care. Patients considering ending their life need assessment to see how their lives can be improved. Palliative care is improving and being extended (Cf. Living and dying well bill). The End of life assistance bill is being put forward by Margo MacDonald and previous bills and proponents of PAS have come from high profile individuals who are perhaps not representative of patient groups as a whole. We run the risk of establishing law based on the minority. It is often stated that PAS has overwhelming public support. However in most polls capital punishment for criminals also has the support of the majority. Does this mean it should be legalised?

The majority of doctors will be against this bill as highlighted (Reference 1). The doctors who spend the most time looking after dying patients (Palliative care specialists) are consistently against PAS (Cf. Letter to the Times April 2010-references 1 and 2). It seems incredible that as there has been extensive review and proposed change in monitoring doctors to avoid
tragedies such as occurred with Dr Harold Shipman, that a system is now being proposed whereby, with consent doctors can assist in causing the death of a patient.

Given this is my response to question 1, evidently I disagree with questions 2-5, although I will make some comment on them also.

**Question 2:** Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?

16 years of age is far too young. Taking the example of a person with a spinal injury causing tetraplegia or paraplegia, 16 years of age is a stage in life when someone is very physically active but their personality is not necessarily fully formed. Patients with spinal injuries can take many years of adjustment before they can find meaning and purpose in their life. This Bill offers a quick fix that undervalues the contribution of adults with disabilities to our society.

Regarding the pre-condition of connection with Scotland and being registered with a GP for 18 months, as with other types of legislation there will be slippage in application of the law. Could the scenario exist where a private GP agrees to register patients from other parts of the UK with known degenerative conditions in anticipation of a possible future request for PAS? In this way could Scotland become like Switzerland?

**Question 3:** Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

The category of patients who have disability and find life intolerable sends a message to people with disabilities that they are undervalued. Patients with a terminal illness can be well cared for in a Palliative setting. If this is not occurring, then the onus on our society is to expand Palliative care, not look for 'simple' solutions such as PAS. In terms of predicting that patients with a terminal illness are those whose life will not last longer than 6 months, such predictions made by doctors can be inaccurate (Cf. Mr Al-Megrahi repatriated to Libya). For example my aunt who died from metastatic breast cancer last year was told she would have approximately 12 months left to live, yet survived with the support of a hospice for over two years.

**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?

The safeguards in the bill fail to acknowledge uncertainties in clinical practice. For example, patients often change their minds about wanting to end their lives once they receive palliative care and their fears concerning suffering are addressed.

Can intolerability of life be measured? Tolerability may fluctuate and patients can adjust to situations and care and assistance can be sought. The Bill
overlooks the potential for people to change and for new possibilities in their life.

It appears that only a minimum of two doctors (e.g.) a medical practitioner and a psychiatrist are necessary in this Bill. Where are the safeguards that would require the doctors concerned to know all about the patients condition and background medical history? In addition, there are difficulties in assessing the mental capacity of some patients and not all doctors are aware of the possibilities of palliative care.

**Question 5:** Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

Is there any onus on medical practitioners and psychiatrists to register their assessments with patients requesting PAS/voluntary euthanasia so that the process can be monitored to see that practise is within the law. In fact there appears to be no involvement with the legal profession in this bill. How would abuses be recognised? The system that occurs in the Netherlands where PAS is not necessarily recorded is open to a slippery slope of abuses extending to euthanasia. Safeguards can gradually fall away placing vulnerable people at risk. For example two well known cases regarding Dignitas in Switzerland, one of a 33 year old with ME ('myalgic encephalomyelitis' also known as chronic fatigue syndrome, with no recognised disease of the body, but with a recognised psychological component) and the case of an elderly couple where the wife was dying from a terminal illness and the husband who was frail and could not face life without his wife and so both ended their life simultaneously. Elderly and disabled people will increasingly feel they are a burden and feel pressure to opt for assisted suicide. As a society we should be making them feel valued.

**Question 6:** Do you have any other considerations on the Bill not included in answers to the above questions?

The Bill is silent on what the means to end life are. If this Bill is made legal this will have implications for medical education in that the ways of assessing patients and administering the 'means to end life' (e.g. fatal doses of medication) would need to be incorporated into medical school and post-graduate education. Some doctors may feel unable to provide 'end of life assistance' as they find it morally repugnant and against their own beliefs and against the foundations of medical practise. If they opt out from providing 'end of life assistance' would they be obliged to refer the patient on to another practitioner? This would make the first doctor complicit in the process. What safeguards are there so that a doctor's autonomy is respected and they would not be penalised for not referring a patient on for PAS? The Bill is a threat to our prevailing values in society where we care for people through their suffering, rather than abandoning them to thoughts of suicide. As a Neurologist I treat lots of patients in very difficult life situations with severe disability. For stroke patients, a condition with an in-hospital mortality approaching 20%, I believe quality palliative care is provided. For people with neurodegenerative diseases, I have never personally had a patient intimate a
desire to end their life due to their condition. For this reason I maintain that those proposing the end of life assistance bill are not representative of the patient groups and people with the same conditions. Care and support for categories of neurodegenerative diseases is ever improving with specialist nurses and for those with most severe terminal degenerative conditions (e.g. motor neuron disease) palliative care is being utilised.

References

1) http://www.guardian.co.uk/society/2006/may/09/health.lifeandhealth


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