End of Life Assistance (Scotland) Bill

Highland Hospice Inverness

Highland Hospice provides specialist palliative care and advice for patients throughout Highland, with advanced, incurable disease and a short life expectancy, regardless of diagnosis. We endorse the WHO definition and principles of palliative care. Our position on euthanasia and assisted suicide has been established in wide consultation with our staff, volunteers, and community supporters, and is endorsed unanimously by our Board of Directors.

For the sake of brevity in this submission we will use the term ‘assisted dying’ to mean either euthanasia or assisted suicide. Similarly reference to ‘the Bill’ will mean the Bill itself and the accompanying Explanatory Notes and Policy Memorandum. We recognise that these accompanying documents have no standing in law, but they are in the public domain and will be influential. It is therefore valid to comment on them.

In addition to this written submission, we would welcome the opportunity to contribute to the oral evidence being gathered by the Committee.

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

We stand resolutely against assisted dying which, contrary to the assertions of the Bill, is at variance with the principles and practice of palliative care.¹ One of the many defining characteristics of palliative care is that death will never be intentionally hastened. Much of our inspiration comes from Dame Cicely Saunders – the founder of modern hospice care - who said that in palliative care, “We do all we can not only to help you die peacefully, but also to live until you die”.² We must do everything possible to maximise the value and potential of life, rather than deliberately ending life. A change in the law to permit assisted dying would create a paradigm shift in the principles of health and social care in our society, away from that fundamental requirement to respect and promote life, embodied in Article 2 of the Human Rights Act 1998. This Bill challenges that fundamental requirement for people with terminal illness or physical disability. Legalised assisted dying would create ethical and legal dilemmas for health care professionals, who have come under increasing scrutiny over recent years in order to assure safe practice. We recognise the strong public opinion in favour of such legislation. However we contend, with good evidence³, that public opinion is obscured by lack of information and opportunity for informed reflection on the implications of a change in the law, and as such, does not provide a safe basis for legislative change, particularly when human life itself is at stake.

This Bill declares its purpose to be the legalisation of the means necessary to enable a person to die with dignity and a minimum of distress. That provision is already made in health care. Palliative care in particular is directed to precisely these objectives. There is no indication whatsoever, in any of the documentation, why the provisions of this Bill meet the purported need.

¹

²

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

Eligibility criteria include terminal illness with an anticipated prognosis of six months or less, or physical incapacity which renders a person dependent on others, plus the finding of life to be intolerable. The six month prognosis is a common figure in proposals for assisted dying, but is an arbitrary figure. Determination of prognosis is notoriously inaccurate in malignant disease and even moreso in terminal non-malignant disease. It would also be difficult for a doctor to determine whether or not the degree of dependence was sufficient for the purposes of this Bill, all the more difficult because each of us is inevitably dependent on others in most aspects of life, even in health. The Bill acknowledges that intolerability is subjective, but gives no indication as to how this should be evaluated. Recent evidence indicates that unbearable suffering is transitory amongst those who request assisted dying and it cannot be relied upon as a firm basis on which to make a decision to end life.

We have major concerns about the imposition of assisted dying in the palliative care environment. In our experience, determined requests for assisted dying are exceptionally rare. Our work includes sensitive exploration of and support for the psychological or spiritual distress which commonly accompany terminal illness. Our patients are able to disclose these issues in the safe knowledge that our only response will be to optimise the quality or quantity of remaining life. The legalisation of assisted dying would compromise that essential trust within the relationship between patients and clinical professionals. It would become impossible to engage freely with patients as we currently do, without the potential for accelerated death being on the agenda. Published experience supports the contention that assisted dying and palliative care are not compatible.

Expert palliative care is usually, but not always successful in ameliorating or alleviating suffering in advanced disease. Continued research and investment in health care is the right approach for those who cannot be adequately helped by current provision. The Bill acknowledges that legal access to assisted dying for some would create the potential for others to come under inappropriate influence or even coercion to consider this action. A right for the minority who determinedly wish assisted dying would threaten the care, safety and security of the majority.

Human dignity is a complex issue, not defined simply in terms of autonomy, dependency or capacity. We refute the implication that a dignified death can only be achieved by assisted dying. Our whole basis of care is dignity, achieved by detailed understanding and implementation of its components in health care.

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

We consider the safeguards to be unfit for purpose. There is no information about the format or management of any of the proposed documentation, or how
it itself should be scrutinised. The requirement for 'discussion of feasible alternatives' to assisted dying is difficult to interpret. What would comprise such discussion and what would be its purpose? Doctors develop expertise in particular areas of medicine, but may at the same time become less familiar with other areas. It cannot be safely assumed that the designated practitioner, whoever that may be, will have sufficient knowledge or expertise to competently discuss feasible alternatives, including palliative care.

The Bill requires two psychiatric assessments, but permits both to be conducted by the same person, who is only required to report that the patient is acting voluntarily and with capacity, and not on how appropriate it is to continue with the process. The final decision as to whether the process should be carried through rests solely with the designated practitioner. In a matter of such consequence, second opinion should indeed be mandatory, but should also be independent and above reproach. Approval of the second request by the same doctor who approves the first can hardly be construed as an independent second opinion! There is no indication of criteria by which the doctor or the independent witnesses should establish that the requesting person is acting voluntarily and without undue influence, what rigour would be required for this, or how any disagreement would be adjudicated. The provision for revocation of the process at any stage, 'however informally', creates a dilemma for the doctor dealing with any expressions of distress by the requesting person. How does a doctor qualitatively evaluate statements or questions in this context? Do indications of hesitation or doubt, or concerns about the family, so commonly expressed by people approaching death, constitute informal revocation? This supposed safeguard may actually inhibit the open and supportive dialogue with the doctor which is so important when approaching death. Moreover, there is no requirement in the Bill that any expression of hesitation to someone else should automatically be passed on to the doctor, rather than suppressed with well meaning or malicious intent.

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

This Bill disregards many of the recommendations of the House of Lords Select Committee specifically intended to guide the drafting of such legislation. It does not draw a clear distinction between assisted suicide and voluntary euthanasia, or set out clearly the actions which a doctor may and may not take in either case. There is no guidance whatsoever on what a doctor may or may not do, or agree to, in bringing about the person’s death. Discussion with one of our local Consultant Psychiatrists convinces us that the Bill does not adequately address the need to identify psychological or psychiatric disorders.

Whilst the wording regarding prognosis in terminal disease is an improvement on previous legislative attempts, the Bill does not acknowledge the everyday clinical realities of prognostic inaccuracy. It does not focus on unrelievable suffering, but only on intolerability. In making provision only for discussion of palliative care, the Bill does not encourage patients to experience such care
before taking a final decision. Finally it makes no allowance for conscientious opt-out for doctors, and we find this particularly objectionable.

This Bill is substantially dependent on doctors. Whilst some UK doctors do favour euthanasia and assisted suicide, the majority are opposed. This Bill places onerous and inappropriate responsibilities on doctors, without prior focussed consultation with the medical profession. As the only professionals implicated in the process, it must be assumed that doctors will be responsible for ensuring that eligibility criteria are met by the requesting person, the witnesses to written requests, and any other person involved. Reliable verification of these criteria, with appropriate background searches, is a legal function for which doctors have neither the time nor expertise. The inevitable involvement of lawyers would escalate the cost to the requesting person which would offset, or more likely overtake any potential savings in the provision of ongoing health care.

The Bill states that actual means of terminating life will best be left to the expertise of doctors. Doctors work to save and preserve life and do not have expertise in its deliberate termination. Furthermore, the provision of health care is based on the establishment of competency. The Bill gives no indication of what competency in life-ending intervention will be required, or how that would be achieved. The same applies to lay personnel who, under the provisions of this Bill, may deliver the life-ending intervention. The Bill makes no comment about personal and professional support for participating personnel, and seems to suggest that training requirements would be nominal. The implication that assisted dying should be just another strand of health care is naive, and misguided about the gravity of any such decision or intervention.

Contrary to assertions that assisted dying is practiced in secret, recent published evidence indicates that doctors in the UK are rarely involved in such practices. The implication that this Bill would legalise something which is happening commonly and covertly, is not justified.

Several evocative anecdotes of suffering are cited. Numerous equally evocative anecdotes could be cited to support the opposite view. The debate on assisted dying will inevitably be passionate, on both sides, but in a matter of such gravity, also needs to be rational and objective, particularly since there is a need to address the acknowledged inadequacies of public opinion.

The Policy Memorandum quoting Dworkin says; “Death – the final act of life’s drama - should reflect our own convictions, not the convictions of others forced on us in our most vulnerable moment.” Although intended to support the Bill, this statement, bearing in mind the relative numbers involved, is a powerful argument against it.

In summary, this Bill does not establish that there is a need for assisted dying, nor does it explain why it provides for a better death than current palliative care services do. Essential detail is lacking, the safeguards are vacuous, crucial questions remain unanswered, and much is left to speculation. It is particularly vague about the ultimate action it seeks to authorise, and it fails to demonstrate an understanding of the principles and practice of medicine. We hope that the
Bill will progress to well-informed Parliamentary debate, and be exposed – and defeated - in that arena.

Maria McGill
Chief Executive
Highland Hospice
10 May 2010

REFERENCES
1. WHO definition of pall care http://www.who.int/cancer/palliative/en/
3. Assisted Dying for the Terminally Ill Bill. House of Lords Select Committee Report, 2005
6. Chochinov. 2007;335;184-187 BMJ
8. Seale. Palliative Medicine 2006; 20: 3-10