The Association for Palliative Medicine (APM) is an organisation of over a thousand doctors working in palliative care. We welcome the opportunity to respond to the call for written evidence on the End of Life Assistance (Scotland) Bill.

The APM is opposed to changing the law on assisted dying, and it is therefore inappropriate to respond to the consultation questions beyond stating that we do not agree that a person should be able to request assistance to end their life from a registered medical practitioner. We do, however, wish to comment on a number of issues raised by the introduction of the Bill, and proposed changes to the law on assisted dying in Scotland. In spite of our opposition to the Bill, we welcome the opportunity to debate and explore the complex issues it raises, and wish to acknowledge that the Member’s introduction of the Bill arises out of concern for patients, respect for patients’ autonomy, and the need to protect doctors.

We strongly support the Scottish Government’s Document Living and Dying Well: a national action plan for palliative and end of life care in Scotland¹ with its person centred approach to delivering equity and excellence in palliative and end of life care, on the basis of need, not diagnosis.

The World Health Organisation (WHO) defines palliative care as: “... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”²

Specialist palliative care focuses on people with complex palliative care needs, such as complex pain management or psychological distress, and is provided by a team of professionals who specialise in palliative care. General palliative care forms part of the routine care of patients and support for carers. It may be part of the work of a range of health and social care practitioners including GPs, care assistants and hospital staff.

The prohibition on the deliberate killing of another is one of the cornerstones of the law.³ “Hard cases make bad law”,⁴ and may pave the way to dangerous decisions. A change in the law on deliberate killing, regardless of the

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² World Health Organization definition of Palliative Care, 2004 at www.who.int/cancer/palliative
⁴ Oliver Wendell Holmes J, US Supreme Court Judge (1890-1935)
motivation behind it, is likely to have profound long-term implications for the
way in which society views people suffering from progressive disease or
disability. This change would be based on a few high profile cases, as
opposed to the many thousands of people who have a dignified death
supported by good palliative care.

It is our view that the Bill does not take account of the complexities of the
issues involved, and of the wider implications such legislation would have for
individuals, for health care professionals, and for the way society as a whole
regards the sick and dying. We believe it to be both dangerous and
unnecessary.

“End of life assistance” is defined at section 1(2) of the Bill as meaning
assistance, including the provision, or administration, of appropriate means, to
enable a person to die with dignity and a minimum of distress. The routine
practice of Palliative Care, as outlined in the World Health Organisation’s
definition above, is to provide care and support for patients and their families
to allow death with dignity and a minimum of distress. However Palliative Care
does not encompass assisted dying. The Bill could thus pose serious
difficulties for the practice of Palliative Care.

Listening to patients, and discussing death and dying, is a core part of
palliative care. These open and frank discussions will often include the
question “Have you ever thought life is not worth living?” Such thoughts are
natural, and allow fears and concerns to be explored. The Bill would
fundamentally alter the nature of end of life discussions and advance care
planning, if such conversations were seen as a prompt towards assistance in
ending life, rather than an integral part of good palliative care. Vulnerable
patients might then be reluctant to disclose their fears and concerns to doctors
and other healthcare professionals

Palliative care professionals are well aware of the very real distress
experienced by those facing the uncertainties of progressive disease, with its
potential and actual losses of function and ability, roles and relationships,
independence and autonomy. Suicidal thoughts are common, and must be
recognised as valid, but most people do move on from this position. Depression is also common, and may be missed as a diagnosis. There is a
risk that the Bill would direct people towards choosing death, rather than
exploring why they want to die.

With access to good palliative care, and adequate and timely support for
patients and their families, persistent requests for assistance in dying are

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LaFollette H (Ed) Oxford University Press. Oxford
implications for UK doctors” BMC Fam Pract, 7: 39
physician’ aid in dying: cross sectional survey” British Medical Journal, 337: 1682
9 Dr David Jeffrey, Presentation on the Proposed End of Life Choices (Scotland) Bill, Cross Party Group on
Palliative Care, in the Scottish Parliament; 4th February 2009
infrequent. Where they do persist, we believe the solution lies in providing support and care, to help ameliorate issues such as hopelessness, helplessness, loss of meaning and existential distress, as well as fear and anxiety regarding future pain or distress. Physician-assisted dying is not an appropriate solution.

There is, nevertheless, a small minority of people, who wish to have control over the manner and timing of their own death.10 We acknowledged that the needs of such individuals must be addressed. However, we do not consider that the proposed Bill is an appropriate or proportionate response to those needs, and are deeply concerned that legislation, with such widespread implications for all, should be proposed on the basis of the particular needs of a small group.

Relief of suffering is an important goal of all medical care. Palliative care does not claim to be able to relieve all suffering, especially extreme degrees of psychological and spiritual distress, or where inadequate or poor care has meant a loss of dignity,11 or isolation has disrupted personal relationships, with a consequent "loss of self".12 Effective support and skilled interventions, with open and sensitive communication, must be available to alleviate such suffering, rather than the introduction of legislation to end life. There is a need to improve the communication skills of doctors, and for advance care planning at the end of life to enhance patient autonomy. This Bill may seriously distort the doctor-patient relationship of trust.

Living and Dying Well,13 the Scottish Government’s action plan for palliative and end of life care, focuses on high quality palliative care being available to patients and families regardless of diagnosis, prognosis or place of care. Audit Scotland’s Review of Palliative Care Services in Scotland14 suggests that over 40,000 people in Scotland each year could benefit from palliative care. Healthcare providers across Scotland are improving the identification and assessment of people with palliative care needs, and planning how to effectively and equitably meet those needs, by providing a comprehensive palliative care service.

The recent Audit Scotland report showed particularly significant gaps in end of life support for people with neurological conditions and for those over 75 years.15 All patients who need palliative care should have access to this care at an appropriate level to meet identified needs. The report highlights the need to develop and expand palliative care services at all levels, and encourage research to improve care of the dying.

We are concerned that this Bill may threaten funding for such research, and for developing palliative care services. As Dr David Jeffrey points out: “There is a grim prospect of legalised Physician Assisted Suicide becoming a cheap alternative to the expensive care of chronically ill patients.”

Forecasting death is an inexact science. There is evidence that doctors are often inaccurate in their identification of those whose prognosis is limited, particularly in patients with non-malignant disease such as cardiac or respiratory failure.

Assisted dying has implications for the entire healthcare team. Clinical decisions regarding end of life care are no longer made in isolation. The Bill does not recognise the complexity of care in multi-disciplinary teams, or the practical, professional and ethical implications of such legislation on medical practice, and on the doctor-patient relationship, nor does it acknowledge the role of pharmacists in assisted dying.

There is a danger that the Bill considers death as a moral good. Indeed legislation endorses it as such. If medically assisted death can be regarded as in the best interests of competent patients, there may be a move to extend this moral concept to incompetent patients, who are unable to make these decisions themselves.

We are concerned that health professionals will make assumptions about the quality of life of people with either a degenerative or terminal condition. In Holland, death is considered to be in the best interests not only of competent patients, who request it, but also in incompetent patients, where the doctor judges patients to be suffering, or having a life no longer worth living.

The Bill assumes that individual autonomy is a generally accepted principle on which to base law. The law exists to protect all, and imposes limits to autonomy in order to safeguard others, for example in the carrying of weapons. The right to autonomy is also limited in that it does not include the right to consent to harm from another.

The report of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill stated that “patient autonomy cannot be absolute and there must be some limits set, in the interests of the wider community, as to what a patient can require his or her doctor to do.” Access to good palliative

18 George R (2005)(personal communication) Case against the Assisted Dying Bill, submitted to The House of Lords Select Committee on Assisted Dying,
care, and advance care planning for end of life, may enhance autonomy that is specific to patients’ needs, without violating the autonomy of others.

We have considerable sympathy for individuals facing the inexorable decline associated with a degenerative condition, but are concerned that assisting them in ending their lives would irrevocably alter the ethos of medical care. Individual autonomy cannot be allowed to harm others, or have a detrimental effect on society as a whole. We believe that the proposed legislation would do both.

We are particularly concerned for the large numbers of vulnerable people, such as the frail elderly, and those suffering from degenerative conditions with physical and, or, cognitive decline, who have no desire to end their lives but who find themselves dependent to some extent on the care of others. The fear of becoming a burden to others may lead to requests for physician assisted dying in response to that fear.

There is evidence that professionals can influence people’s end of life choices. For those who are unable to express themselves with confidence, coercion may become very real, and result in “social expectations for individuals to choose physician assisted suicide as soon as their physical capabilities decline to a point where they become dependent on others in an expensive, inconvenient way.” The proposed new law may well increase the mental suffering of vulnerable people.

The scope of the Bill for those who find life “intolerable”, whether permanently physically incapacitated, or terminally ill, would make Scottish legislation wider than most other legislative jurisdictions.

The Policy Memorandum makes reference to the approach of other jurisdictions, including the Oregon Death with Dignity Act (1997) and cites evidence of good practice there. However, palliative care has not developed there, as it has in Scotland and the UK. Oregon does not provide any evidence that physician assisted suicide and palliative care can co-exist. Moreover, research has highlighted that one in six of those who took their own lives were suffering from depression which had not been identified by their doctors. In Oregon, this law is failing to protect the vulnerable. Palliative Care is rudimentary in other countries which have legalised assisted dying.

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27 End of Life Assistance (Scotland) Bill 2010, Para. 4(2) (a)&(b)
including the Netherlands,\textsuperscript{30} in comparison with Scotland, a recognized world leader in palliative care. We consider it misleading to imply that because some form of physician assisted dying has been legalised elsewhere, similar legislation is appropriate in a Scottish context.

The Policy Memorandum to the Bill considers that the provisions in the Bill are compatible with the European Convention on Human Rights.\textsuperscript{31} Article 2 states: “Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.”\textsuperscript{32}

The state is obliged ensure that the law protects everyone’s right to life. There is no reciprocal right to die. In the case of \textit{Pretty v DPP},\textsuperscript{33} the House of Lords held that a right to die could not be read into the right to life protected by Article 2. Mrs Pretty took her case to the European Court of Human Rights in Strasbourg,\textsuperscript{34} which confirmed the decision of the House of Lords on the point that Article 2 did not encompass a positive right to die. Although Article 8 of the European Convention on Human Rights\textsuperscript{35} establishes that competent patients have a right to self-determination and personal autonomy, this right does not extend to the actions of others on the individual’s behalf.

Palliative care is concerned with enabling patients with advanced life-limiting conditions to live with the best possible quality of life until they die. Clinical experience and research demonstrates that the majority of requests for euthanasia or physician-assisted suicide arise as a result of poor symptom control, depression, poor social and family support, and a loss of autonomy. Palliative care concentrates on improving these aspects of a patient’s life and the provision of this care should be the starting point for any debate on assisted dying. When a patient is in the terminal phase, the goal of care is to enhance the dignity of the individual. If this legislation is passed there is a risk that some patients will die against their wishes

The Association for Palliative Medicine opposes this legislation and suggests that the interests of dying patients, their families, and our wider society would be better served by increasing access to high quality palliative care, improving the communication between healthcare professionals and patients, gaining a better understanding of the needs of dying patients and informing the public about these highly complex issues in an honest way. We do not believe that the proposed changes to Scots law are a necessary or proportionate response to the fears and concerns of the small group of individuals who would seek to use such legislation.

The APM would welcome the opportunity to participate in future oral evidence sessions of the Committee.

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\bibitem{31} European Convention on Human Rights (1950)
\bibitem{32} European Convention on Human Rights (1950) Article 2(1)
\bibitem{33} \textit{R Pretty v DPP}\textsuperscript{33} [2002] 1 AC 800
\bibitem{34} \textit{Pretty v UK} (2002) 35 EHR 1
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\end{thebibliography}
The Association for Palliative Medicine Ethics Committee on behalf of the Association for Palliative Medicine: Dr Eleanor Grogan (Chair), Dr David Oliver, Dr Tim Harlow, Dr Rob George, Dr Rosaleen Beattie, Dr Craig Gannon, Dr Ian Cairns, Dr Rosie Bronnert

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