

## **Submission by the Scottish Partnership for Palliative Care to Margo MacDonald MSP's consultation on the proposal for an Assisted Suicide (Scotland) Bill**

*This submission starts by setting out some background information before moving on to address the specific questions contained in the consultation document.*

### **About the Scottish Partnership for Palliative Care (SPPC)**

The Scottish Partnership for Palliative Care (SPPC) is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership includes all 14 territorial health boards, all 14 of Scotland's voluntary hospices, 17 major national health charities, 7 professional associations and 1 local support organisation. The membership of the Partnership is detailed at [www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk). Through a collaborative approach, the Partnership supports and contributes at national level to the development and strategic direction of palliative care in Scotland and the promotion of service improvement at local level. The Partnership's aims are to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis.

### **SPPC Position Statement on Legalisation of Assisted Suicide in Principle**

The SPPC is not able to adopt a position on the principle of whether or not assisted suicide should be legalised. This is because the topic raises issues of a moral, personal and ethical nature upon which many of our member organisations (for example our member NHS Boards) are institutionally unable to hold a position.

However, the SPPC holds the view that in contemplating legislating in this area MSPs should give careful regard to:-

- Any possible damage to the practice and provision of palliative care. Palliative care benefits many thousands of people in Scotland each year.
- The protection of vulnerable people. All people are potentially vulnerable, depending on events and circumstances, especially towards the end of life.

The content of this consultation response is guided by these twin considerations. The submission aims to support the deliberation of MSPs both by providing relevant factual information and also by directing the attention of MSPs to questions of practical relevance to these twin considerations. MSPs are also encouraged to examine the report and

recommendations of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill

<http://www.publications.parliament.uk/pa/ld/ldasdy.htm>

### **About Palliative Care**

Palliative care is the term used to describe the care that is given when cure is not possible. The word comes from the Latin 'palliatu' (*covered or hidden with a cloak*) and is used to mean 'relieving without curing'<sup>1</sup>.

Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards<sup>2</sup>. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement<sup>3</sup>. The World Health Organisation (WHO) defines palliative care thus:

"Palliative care is 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. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."<sup>4</sup>

Specialist palliative care focuses on people with complex palliative care needs (e.g. complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (e.g. consultants in

palliative medicine and clinical nurse specialists 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, district nurses, care assistants and hospital staff<sup>5</sup>.

There is a common misconception that the use of opioid medicines to control pain in palliative care shortens life in dying patients. In appropriate doses the opioid medicines (e.g. morphine) do not shorten life. There is no robust evidence to support the assertion that medical staff use opioid medicines to shorten deliberately the life of patients<sup>6</sup>.

The views, feelings and wishes of patients change over time and may alter frequently during the course of an illness. Patients who have a desire for an early death or who express a wish to get assistance to commit suicide because of distressing physical or psychological symptoms often change their minds when these symptoms are addressed through appropriate palliative care<sup>7</sup>. However, palliative care cannot *always* successfully address all symptoms.

A few people will have an enduring wish for suicide and such individuals have a need and a right to be respected, affirmed and valued, regardless of the legality or otherwise of assisted suicide.

*Living and Dying Well* (2008) is the Scottish Government's ambitious action plan for palliative and end of life care. The plan describes how palliative care will increasingly be available to patients and families regardless of their diagnosis, prognosis or place of care. Work is progressing across Scotland to improve the identification and assessment of people with palliative care needs, and to better meet those needs identified. Audit Scotland's *Review of Palliative Care Services in Scotland* (2008) suggests that over 40,000 people in Scotland each year could benefit from palliative care.

### **Society-wide approaches to better death, dying and bereavement**

Whilst death, dying and bereavement are inevitable it is possible to reduce the harm/trauma associated with these experiences. How people experience death, dying and bereavement is only in part dependent on palliative care services, and indeed on health and social care services in general. Other factors include access to adequate legal and financial planning, supportive workplace practices and the extent to which people are able to get support from family, friends and the wider community. The extent to which Scottish society is able to acknowledge and be open about death, dying and bereavement is an important determinant. The Scottish Partnership for Palliative Care has established Good Life, Good Death, Good Grief – an

initiative to promote more openness on these issues in Scotland. More information is available at [www.goodlifedeathgrief.org.uk](http://www.goodlifedeathgrief.org.uk).

**Q1. Do you support the general aim of the proposed Bill (as outlined above)? Please indicate “yes/no/undecided” and explain the reasons for your response.**

The SPPC is not able to adopt a position on the principle of whether or not assisted suicide should be legalised. This is because the topic raises issues of a moral, personal and ethical nature upon which many of our member organisations (for example our member NHS Boards) are institutionally unable to hold a position.

However, the SPPC holds the view that in contemplating legislating in this area MSPs should give careful regard to:-

- Any possible damage to the practice and provision of palliative care. Palliative care benefits many thousands of people in Scotland each year.
- The protection of vulnerable people. All people are potentially vulnerable, depending on events and circumstances, especially towards the end of life.

**Q2. What do you see as the main practical advantages of the legislation proposed? What (if any) would be the disadvantages?**

See response to Q1

**Q3. Do you consider that these suggested eligibility requirements are appropriate? If not, please explain which criterion or criteria you would like to see altered, in what ways, and why.**

### **Clarity of Criteria**

It is important that the eligibility criteria are very clear for two reasons. Firstly the criteria must be clear so that members of the Scottish public know whether or not they are eligible for assisted suicide. Secondly the criteria need to be clear so that those assisting a suicide (including medical and pharmacy staff) can be sure of their responsibilities and rights and also confident that they will not be subject to prosecution subsequent to the suicide should the eligibility of the individual be challenged.

### **Capacity**

Severe mental disorder resulting in lack of capacity may be readily detectable. However, a potentially very common combination of factors affecting a requesting person (mild depression, mild cognitive impairment, multiple morbidities and an internalised perception that they are a burden to relatives or others) may be much more difficult to identify. The criteria should be clear as to whether such a person should or should not be eligible for assisted suicide. If such a person should not be eligible for assisted suicide then any

legislation should contain adequate provisions for the identification and exclusion of such individuals.

### **A Qualifying Person Must Have a Terminal Illness or Terminal Condition**

The term “terminal illness” is insufficiently precise to form part of clear eligibility criteria. Similarly the term “terminal condition” is insufficiently precise to form part of clear eligibility criteria. Since neither term is clearly defined in the proposal it is also unclear what the difference between the terms is intended to be.

The experience of palliative care practitioners is that it is difficult to predict accurately when a particular person may die. Prognostication (predicting the course of a disease including how long an individual may have left to live) is more difficult in some conditions and for some individuals than others<sup>8</sup>.

A particular medical condition (defined by a diagnosis) may or may not cause the death of a particular individual. A condition such as multiple sclerosis (MS) may lead directly or indirectly to the death of an individual. However, a person with MS may live for fifty years and die **with** but not **of** multiple sclerosis, or they may die of MS within a few years of diagnosis. Any proposed legislation should be clear as to whether or not a person may be deemed to have a “terminal condition” by virtue of having been diagnosed with a particular condition. If proposed legislation states that a person may be deemed to have a “terminal condition” by virtue of having been diagnosed with a particular condition then a list of such conditions would need to be identified.

It may be more meaningful to speak of an individual reaching “a terminal phase of their illness” based on a combination of their diagnosis or diagnoses and whether their illness is in an advanced stage. However, the term “advanced stage” does not itself have a clear definition unless linked to specified levels of need or life expectancy.

Any legislation should be clear about the level of experience/expertise it deems necessary to determine whether the requesting person has a “terminal condition/illness”. For example would a neurologist be required to determine this for patients with neurological conditions or would it be adequate for a general practitioner to make this determination?

It is common for older people to have several chronic and progressive conditions concurrently<sup>9</sup>. Any legislation would need to reflect this in the definitions used within the eligibility criteria.

### **Life Intolerable**

How an individual is experiencing their life is obviously centrally important, a concern for service providers and must be respected. However, the purpose of the criterion that a qualifying person must “find their life intolerable” is

unclear. This would appear to be an entirely subjective criterion and not one which is capable of assessment by any third party. A more objective criterion could be “unrelievably intolerable” – in this circumstance a third party would assess whether a full range of measures which might normally be expected to relieve feelings of intolerability (care, support, treatment) had been undertaken. The assessment would be about the adequacy of the relief measures rather than the individual’s feeling about their life.

### **Undue Influence**

It should be an explicit eligibility criterion that the person requesting assistance to kill themselves is not acting under any undue influence. However, the current proposal does not list the absence of undue influence as an eligibility criterion.

### **Q4. What is your general view on the merits of pre-registration (as described above)? Do you have any comments on what pre-registration should consist of, and on whether it should be valid for a set period of time?**

The declaration made in pre-registration is the only stage in the proposed process where witnesses assert the voluntary nature of the request, the absence of undue influence and that the requestor understands the nature of their intention. For this reason consideration should be given to a time limit between pre-registration and the first request. It might be simpler and more rigorous to include witness re-confirmation of these assertions in the first written request.

Any legislation should provide guidance to medical/clinical professionals as to how the existence of a longstanding pre-registration should be regarded during the assessment of eligibility. Is a longstanding pre-registration to be regarded as evidence supportive of eligibility? Is a more recent pre-registration to be regarded as less strong evidence? How should assessing clinical professionals deal with a longstanding pre-registration which has not been updated for many years?

### **Q5. Do you have any comment on the process proposed for the first and second formal requests (for example in terms of timings and safeguards)?**

#### **Assessment**

Any legislation should provide clear guidance to health care professionals as to the standards of diligence required when assessing eligibility as part of the request process. Consideration should also be given as to whether assessing clinicians require any particular skills, expertise and knowledge beyond those universally required of all medical practitioners.

As stated above any legislation should be clear about the level of experience/expertise it deems necessary to determine whether the requesting

person has a “terminal condition/illness”. For example would a neurologist be required to determine this for patients with neurological conditions or would it be adequate for a general practitioner to make this determination?

The proposal does not require the assessing practitioner to have any prior knowledge of the requesting person or their social and family circumstance. It could be argued that assessment is more difficult in these circumstances.

Any legislation should be clear and explicit about the extent of the responsibility of the assessing doctor to ensure that alternatives to assisted suicide are explored.

### **Timescales**

The proposed timescales offer very limited time for the exploration of alternative options. One main option would be access to specialist palliative care. The timescales contained in the proposal may not be compatible with access to specialist palliative care. The proposed legislation could create situations in which palliative care practitioners are required to balance the needs of other seriously ill patients and their families against those who may kill themselves (regardless of their clinical condition) if not given immediate access to palliative care. This would have implications for individual practitioners and service organisation.

The lack of any stipulated timescale between the provision of evidence of absence of undue influence (contained in the declaration) and the rest of the processes and timescales is a weakness in the safeguards. Similarly, where specific time limits elapse and the person is “required to return to the start of the formal process” consideration should be given to whether the start of the process is the pre-registration/declaration (with its reference to absence of undue influence) or the first request. The current proposal is to revert to the first request, which does not contain any declaration about absence of undue influence.

MSPs should consider whether the cooling off periods, deadlines and revocation arrangements contained in the proposal could create an undesirable dynamic in which some vulnerable individuals might feel impelled to proceed.

### **Appeal**

Any legislation should be clear whether a patient requesting assistance should have a right of appeal should they be assessed as ineligible and what the process for any appeal might be.

### **Provision of Medication**

The proposal is not clear as to who will prescribe the lethal medication. Any legislation should be clear about the role of non-medical prescribers.

## **Conscientious Objection**

The proposed legislation broadly reflects GMC guidance on dealing with conscientious objection to a particular medical procedure e.g. abortion. Consideration should be given as to whether or not this model is applicable (i.e. whether assisting suicide is or is not a medical procedure) and whether the proposal provides sufficient protection.

### **Q6. Do you think a time-limit of 28 days (or some other period) is an appropriate safeguard against any deterioration of capacity?**

It is difficult to predict when and how fast any individual may experience deterioration of capacity.

### **Q7. Do you agree that the presence of a disinterested, trained facilitator should be required at the time the medication is taken? Do you have any comments on the system outlined for training and licensing facilitators?**

Any legislation should give consideration to dealing with medical complications arising during the assisted suicide. The role of any clinical professionals called to intervene in such a circumstance need to be made clear. What is the duty of care owed in such circumstances?

The proposal appears to envisage a fairly limited, mechanistic role for the facilitators which follows subsequent to, and discrete from, the complex and decisive process of assessment. However, it is easy to envisage complex scenarios being precipitated by the proximity of death and loss at the scheduled time of suicide e.g. sudden uncertainties, conflicts between family members, suggestions of undue influence. Facilitators would need to be equipped to cope with such circumstances.

Any legislation should ensure robust vetting, regulation and adequate training for facilitators.

### **Q8. What sort of documentation and evidence is likely to be required? In particular, how important is it that the process is filmed?**

A robust reporting regime, based on appropriately formal documentation of the whole process, which generates a clear data set, could allow for monitoring, scrutiny, audit, regulation and research into a highly controversial, contested and potentially evolving area of public policy.

### **Q9. What is your assessment of the likely financial implications of the proposed Bill to your organisation? Do you consider that any other financial implications could arise?**

There would be a need to provide training for staff who may be working with patients who may want to discuss assisted suicide. This would apply to all health and social care staff working within specialist palliative care as well as to other much larger groups, for example many hospital staff, general practitioners and arguably most care home staff. Nursing staff might be expected to be one of the groups most frequently approached by patients.



This training would be a very significant cost and be difficult to meet within the current financial climate, where training budgets are under pressure and training opportunities restricted.

The process of assessment and prescription, and the vetting, licensing and regulation of facilitators will incur a cost. Any legislation should be clear as to whether these costs are expected to be met by NHS Boards, voluntary organisations, Scottish Government, individuals or others.

There would be a cost to employers and professional bodies who need to develop relevant guidance for staff.

There would be a need to develop appropriate information resources for the general public and this will have a cost. There would be a need to develop appropriate care for the family and friends of people who had committed suicide, which might give rise to additional costs.

Financial savings could accrue to the NHS and Local Government where a person kills them self and therefore does not require further care and/or treatment from the NHS and social work services. There could also be savings from welfare/social security/pension budgets.

**Q10. Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?**

The eligibility criteria in the proposal are discriminatory, by design. For example anyone who is physically unable to take medication without assistance would not be treated equally by the proposed legislation. Similarly both children aged under 16 and anyone who lacked capacity (for example through Alzheimer's) would not be treated equally by the proposed legislation.

The proposal envisages assistance for suicide being provided by the voluntary sector. This may give rise to differential access to services (for example in remote and rural areas) since the voluntary sector may not have the capacity to deliver a universal service, and by definition has no obligation to provide a universal service.

**Background to Internal Consultation on this Submission**

The membership of the SPPC was consulted on the content of this submission. 44% of nominated member representatives responded to the consultation. Of these responses 98% supported the submission.

Mark Hazelwood, Director,  
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<sup>1</sup> Milligan S and Potts S. Chapter 1.1 The History of Palliative Care. In Stevens E, Milligan S & Jackson S (Eds). Palliative Nursing Across the Spectrum of Care. Chichester, Wiley Blackwell.

<sup>2</sup> National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. London NICE.

<sup>3</sup> Scottish Partnership for Palliative Care (2006) Joined up thinking, joined up care. Edinburgh, SPPC.

<sup>4</sup> World Health Organisation (2002) WHO Definition of Palliative Care.  
<http://www.who.int/cancer/palliative/definition/en/>

<sup>5</sup> National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. London NICE.

<sup>6</sup> George R, Regnard C (2007) Lethal Opioids or Dangerous Prescribers. Palliative Medicine 21:77-80)

<sup>7</sup> . Chochinov HM (2006) Dying, Dignity & New Horizons in Palliative End of Life Care. CA: A Cancer Journal for Clinicians 56(2) 84-103.

<sup>8</sup> Gold Standards Framework (2008) Prognostic Indicator Guidance.  
<http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/PrognosticIndicatorGuidancePaper.pdf>

<sup>9</sup> Karlamanqla A, Tinetti M, Guralnik J et al (2007) Comorbidity in older Adults: Nosology of Impairment, Disease and Conditions. The Journals of Gerontology Series A. Biological Sciences and Medical Sciences 62(2) 296-300.