Dear Christine,

Health and Sport Committee consideration of the Palliative Care (Scotland) Bill at Stage 1

I would like to thank the Committee for the courtesy extended to me during my evidence giving session.

During the evidence session on my Bill I promised to provide further clarification on the definition of “palliative care” and “life-limiting condition” and the related term of “reasonable needs”. I have also taken the opportunity to address a few points which arose during my evidence and that of the Cabinet Secretary for Health and Wellbeing where further clarification might be useful to the Committee’s consideration of the general principles.

Definition of palliative of care

Concern was expressed that the definition of “palliative care” in my Bill might inadvertently preclude people in need of such care from receiving it. It was also suggested it would be difficult to define palliative care and that this would impact on the determination of who should qualify for palliative care and the collection of performance indicators.

Before addressing the specific elements of the definition of palliative care, I would like to assure the Committee my Bill does not alter the practice that should be followed in the implementation of the Living and Dying Well strategy and in fact my Bill provides greater clarity whilst retaining the necessary flexibility for those tasked with its implementation.

The Bill uses the same definition of palliative care as the Scottish Government’s strategy. The meaning of palliative care is explained in the introduction to that
strategy and refers directly to the definition used by the World Health Organisation (WHO)\(^1\).

In this regard, I note that the Living and Dying Well strategy states that “The key to providing appropriate palliative and end of life care is first of all to identify those likely to benefit from it. An important first step in implementing this Action Plan will be to ensure that triggers for the assessment or review of palliative and end of life care needs are recognised in all care settings at time of diagnosis, at times of changing or complex needs, and at the very end of life.”

It follows that, in order to implement the strategy, practitioners will need to be clear about who needs palliative care, when such needs should first be assessed and at what point such care should be provided. If there is, as has been suggested in evidence to you, uncertainty about these issues, my Bill surely provides that clarity.

In order to fully understand the definition of “palliative care” it requires to be read with that of “life-limiting condition” and “reasonable needs”.

*Life-limiting condition*

As I understand the evidence there were two specific concerns raised in relation to the definition of life-limiting condition:

- Who is included in the definition; and
- Whether the definition precludes curative treatment being provided simultaneously.

Dealing with the first point, the Bill purposely did not list the illnesses which would attract palliative care. This was because it risked inadvertently precluding an illness which might have otherwise attracted palliative care. Instead the Bill uses “life-limiting condition”, a term used in the Living and Dying Well strategy.\(^2\) Section 48C defines “life-limiting condition” as a condition, illness or disease which is progressive and fatal and the progress of which cannot be reversed by treatment. The Committee heard evidence that the definition might not include those with dementia or multiple sclerosis. Both these diseases are progressive, fatal and cannot be reversed by treatment. I can therefore confirm that under the terms of my Bill dementia and multiple sclerosis would be life-limiting conditions. The advice I have is that the definition is specific enough to provide clarity and be sufficiently flexible so as not to exclude people who should receive palliative care.

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\(^1\) The World Health Organisation’s definition of palliative care describes, “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.” For the full definition see: http://www.who.int/cancer/palliative/definition/en/

\(^2\) Living and Dying Well: a national action plan for palliative and end of life care in Scotland http://www.scotland.gov.uk/Publications/2008/10/01091608/0
Irreversible condition

During the oral evidence sessions, some concern was expressed that the definition of life-limiting condition precludes individuals who are still receiving treatment for their disease because their condition might be reversible.

Again, let me provide some reassurance on this point. The Bill does not preclude treatment being given to address the life-limiting condition alongside palliative care, including curative treatment. In diagnosing a person with a life-limiting condition the clinician would have to have regard to the normal disease trajectory for the condition. Unless the condition is completely reversed then an individual would continue to qualify for palliative care. So, for example, a person with cancer can continue to receive curative treatment alongside palliative care. This is the model of palliative care set out in Living and Dying Well. If however treatment does prove successful and the condition cured, or reversed, then the individual would no longer be entitled to or indeed qualify for palliative care.

Reasonable needs

Under section 48A (1) as inserted it is the reasonable needs of the person who is suffering from a life limiting illness which require to be met. The use of the “reasonable” needs” test in the Bill will help ensure that a person with a life-limiting condition will receive palliative care at any point at which they reasonably need it. In some disease trajectories a person may receive palliative care for a period of time, then stop and then start again as their needs vary. The test used in the Bill ensures that this flexibility is possible and is, ultimately, determined by the person’s reasonable needs.

In keeping with the spirit of the Living and Dying Well strategy, the determination of a person’s reasonable needs will be made as a result of discussion with, and input from, the person, carers, relevant health professionals and others providing care and support, such as chaplains, social workers and pharmacists.

The use of a reasonableness test is one that will be familiar to members from other legislation including the Members Interests Act. Members will recollect that in considering this test they accepted that it falls to be determined what would be reasonably required in the eyes of a fair minded and impartial observer. The test is no different here. It ensures that demands for assistance can be judged impartially as to their reasonableness.

This approach to underpinning eligibility, encompassing each of the 3 aspects which must be considered together, avoids a one size fits all approach and recognises the needs of individuals will vary depending upon the nature of their illness, and their personal circumstances. Equally, even for those coming within the definition of palliative care, a life-limiting condition does not require needs to be met which a fair minded and impartial observer would determine are not reasonably required. This is in line with the Living and Dying Well strategy objectives and provides the clarity and consistency required of legislation.

I trust that the above provides some clarification on the definition of palliative care contained in my Bill.
In addition to the points raised above, I wanted to take the opportunity to address a number of points relating to the indicators that were raised during the Committee’s evidence session on 10 November.

**Indicators**

**Information on quality and equity of provision**

In her evidence to the Committee, the Cabinet Secretary for Health and Wellbeing expressed reservations that the information collected by the indicators in the Bill did not measure equity or quality of provision of palliative care. I would like to address this point as I am not convinced that this is an accurate reflection of the indicators.

A number of the indicators do focus on quantitative information, for example, by seeking how many people and family members have received palliative care. This basic information is not currently collected and is essential baseline information. A number of the indicators explicitly require information about the quality of palliative care: for example, by obtaining figures about:

- the average time between the diagnosis and the first assessment of their palliative care needs;
- the average time between the assessment and receipt of such care; and
- the number of people who die at their preferred place of death.

Indicator 9 seeks information on the nature of the psychological, social and spiritual help and support given to family members and persons with a life-limiting condition. This provides information about the quality of care provided as well as providing information that it is taking place.

Finally, indicator 10 seeks information on the number of persons who have completed a survey on the standard of such care. The purpose is to capture information from surveys already undertaken by Health Boards on the standard of palliative care received thereby measuring the satisfaction of patients and their families.

In terms of the equitable provision of palliative care, the Bill requires information to be provided by the Scottish Ministers at Health Board level. Thus each of the 11 indicators measures equity allowing the provision of palliative care to be measured and compared and contrasted on a regional basis.

**Quality Outcome Measures**

Reference was made to the update paper the Scottish Government provided to the Public Audit Committee on the provision of palliative care services and the announcement by the Scottish Government that one of 12 high-level Quality Outcome Measures will relate to palliative care: “the percentage of last 12 months of life spent in preferred place of care.” Even a single measure is to be welcomed, but does not provide baseline information about the number of people receiving palliative care. Nor perhaps more importantly, does it provide reassurance that all in need of
palliative care have been identified and are receiving appropriate care in accordance with Living and Dying Well.

**Role of the Care Commission**

Finally, it was suggested during the evidence session that the data gathered by the Care Commission in its regulatory role might be used to measure the provision of palliative care. I note that paragraph 58 of *Living and Dying Well: Building on Progress*, reports on progress in the development of quality mechanisms in measuring the provision of palliative and end of life care in care homes.

While I welcome this development, it is important to note that such data will not cover those people living outside care homes, for example those who are receiving palliative care in hospital or at home. My Bill is not so restrictive and captures this wider group thus providing much needed information.

I hope this has been helpful.

A copy of this letter goes, via email, to David Cullum from the Non-Executive Bills Unit.

Yours sincerely,

**Gil Paterson MSP**
**Member in Charge**