

## **Call for written evidence on Palliative Care (Scotland) Bill**

### **Compassion in Dying's response**

#### **Compassion in Dying**

Compassion in Dying is a charity that focuses on research, education and advice on all aspects of the end-of-life process (for adults). Our charitable objectives are to conduct research and to provide advice, information and guidance to all those affected by the end of life; including patients, carers and health professionals.

#### **1. Do you agree or disagree with the general principles of the Bill?**

Overall, Compassion in Dying supports the Bill and is encouraged that it aims to give legislative effect to the Living and Dying Well strategy, improving access to palliative care regardless of location, diagnosis, or other variables, and further embedding palliative care in everyday practice. Alongside raising awareness of palliative care across Scotland, the Bill is important in that it will create a specific duty for Scottish Ministers to provide or secure palliative care for all persons diagnosed with a life-limiting condition.

The proposed indicators set out in the Bill would collate much-needed data on the effectiveness and impact of palliative services, from examining where and why people die, to the education and training of health care professionals. However, Compassion in Dying believes the proposed indicators could go further, gathering more information and increasing awareness of the end-of-life choices that patients and carers can make and importantly, *ensuring these wishes are acted upon*.

If implemented properly, this Bill could have a positive impact on the lives of people in Scotland.

#### **2. Do you believe there should be a specific duty on the provision of palliative care in the NHS (Scotland) Act 1978, over and above the general duty of “providing a comprehensive and integrated health service”?**

Compassion in Dying supports the Bill's attempts to promote a culture of palliative care and provide concrete measures for its effectiveness. We agree that a specific duty should be placed on Scottish Ministers to provide or secure palliative care for every person diagnosed as having a life-limiting condition and for their family. However, whilst we welcome this move to address imbalances in palliative care provision across the country, and the traditional reliance on voluntary services, we do not believe that any one healthcare service should have priority over another. Palliative care needs to be valued and embedded in the wider culture and daily delivery of healthcare, but not at the expense of other services.

We fully agree with the point made by Dr McLaren in the Policy Memorandum who is *concerned to find a way that palliative care is increasingly woven into the day-to-day care of clinicians and care professionals much earlier in disease trajectories rather than end of life becoming the main focus of palliative care*<sup>1</sup>.

If the Bill becomes law it would be helpful if the Scottish Parliament could provide a clear explanation of what the duty imposed on Scottish Ministers to provide or secure palliative care to the extent that it meets the “reasonable needs”<sup>2</sup> of individuals will actually mean to a person with a life-limiting condition. For example, if a person cannot access appropriate palliative care services in their local area, would the Scottish Ministers’ duty to provide or secure care cause them to move the individual to a different area, or to provide a specialist nurse in their area, or to provide relevant training for a local nurse or doctor? Members of the public will also need to be clear on what impact this new duty has on procedures for raising comments, concerns or complaints about the palliative care they are receiving or want to receive, in order to avoid confusion and distress for patients and carers, and duplication of work between Health Boards, MSPs and Scottish Ministers.

### **3. Do you have any comments on the provisions concerning reporting and indicators contained in the Bill?**

Compassion in Dying believes that a yearly report, which details the effectiveness of the delivery of palliative care according to pre-defined indicators, would ensure that these services can be audited and continuously improved. We are encouraged that the indicators are patient-centred, recognise that patient choice is important and go beyond standard quality markers such as ‘numbers of GPs signing up to GSF’<sup>3</sup>. We welcome the provision in the Bill allowing indicators to be amended or added to over time.

*Indicator 1:* Information to be provided on the number of persons with a life-limiting condition who have received palliative care and the number of family members who have received palliative care.

Compassion in Dying agrees with this indicator. We would like to see it extended to also record the number of persons with a life-limiting condition who have not received palliative care, in order that the *proportion* receiving palliative care can also be determined.

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<sup>1</sup> Dr McLaren, 16 February 2009, Consultation response 39

<sup>2</sup> Palliative Care (Scotland) Bill Explanatory Notes para 15

<sup>3</sup> Kennedy S, Seymour J, Almack K, Cox K (2009) Key stakeholders’ experiences and views of the NHS End of Life Care programme: findings from a national evaluation *Palliative Medicine* 23: 283-294

*Indicator 2:* Information on the average time it takes for persons diagnosed as having a life-limiting condition to receive a first assessment of their palliative care needs and also the longest time it has taken for a first assessment.

Compassion in Dying agrees with this indicator.

*Indicator 3:* Information on the average time it takes for persons with a life-limiting condition whose palliative care needs have been assessed to receive palliative care for the first time and also the longest time it has taken.

Compassion in Dying agrees with this indicator.

*Indicator 4:* Information on the number of persons who are in receipt of palliative care who have received a community care assessment.

Compassion in Dying agrees with this indicator.

*Indicator 5:* Information on the proportion of carers, caring for a person with a life-limiting condition, who have received a carer's assessment.

Compassion in Dying agrees with this indicator. However it would be useful to have clarification over what the Bill means by 'carer' and 'family member' (the latter being usefully defined in the Explanatory Notes) as there is often a distinction between the two in health and social care guidelines.

*Indicator 6:* Information on the place and cause of death of any person with a life-limiting condition who has received palliative care should be collated.

Compassion in Dying agrees with the inclusion of this indicator as it would provide useful 'stand-alone' data as well as providing the context data in order for indicators 7 and 8 to prove meaningful.

*Indicator 7:* Information on the number of persons who have been in receipt of palliative care and died at their preferred place of death, where such a preference has been recorded in the patient's medical records.

Compassion in Dying agrees with the inclusion of this indicator as it is essential to evaluate whether patients have died in their preferred place. But we believe this indicator could go further and evaluate the impact of patient choice at the end-of-life in more detail.

Firstly, preferred place of death is only one end-of-life preference. Others options include: do not hospitalise; refusal of artificial nutrition and hydration or antibiotics; do not resuscitate; and receiving only comfort care. Compassion in Dying believes that it is vital for all these choice options to be incorporated into care and the evaluation of care.

Secondly, the mechanisms currently in place for recording such preferences (and then evaluating whether they have been respected) need to be addressed. Treatment preferences listed in Advance Decisions, also known as advance directives or living wills (which do not have statutory force in Scotland but are supported by common law, and in theory by one of the general principles of the Adults with Incapacity (Scotland) Act 2000 - *that the wishes of an adult should be taken into consideration when acting or making a decision on their behalf*), and other tools for recording patient preferences are not always recorded in medical records. Indicator 7 should be flexible enough to investigate where such preferences have been recorded (by asking GPs, looking at medical records and asking family) and if they have been acted upon. If data cannot be gathered from these sources then this *lack of data* would provide the evidence-base for improving the methods by which patients can record their preferences.

This indicator should also be used to measure how many people have shared/recorded their electronic Palliative Care Summary (ePCS). As the ePCS must include a reference to a person's care plan or Advance Decision, it is important that the initial list of indicators explicitly cover use of the ePCS system. As the system becomes more imbedded in health care in Scotland, an indicator measuring how far people's wishes as set out in the ePCS are respected, could be developed.

*Indicator 8:* Information on the number of persons who have died in hospital despite expressing a preference to die elsewhere, where such a preference has been recorded in the patient's medical records. In such cases, reasons must be given to explain why a person who has been in receipt of palliative care died in hospital despite having expressed a contrary perspective.

This indicator has similarities to indicator 7, addressing why patient preferences have or have not been acted upon. We are encouraged by the inclusion of categories of reasons why patients had died in the hospital setting: "unexpected change in symptoms" "inability to relieve pain" and "any other reason" (in which case the reason must be stated). These will provide valuable data which can be used to improve patient care.

Similarly to indicator 7 we believe that indicator 8 must move beyond *dying in hospital* as a lone indicator.

Compassion in Dying believes that it would make sense to combine *expanded* (i.e. measuring a variety of patient preferences for end-of-life care) indicators 7 and 8 into one indicator. This could be done alongside an examination of the mechanisms for recording such preferences (beyond simply medical records) and an additional sub-indicator which examined whether these preferences had impacted on care and/or been acted upon by

healthcare professionals. We believe this would capture comprehensive information on patient care and choices and could be used to improve practices in Scotland.

*Indicator 9:* Information on the nature of the psychological, social and spiritual help and support given to persons with a life-limiting condition and their family members.

Compassion in Dying agrees with this indicator but considers it important that it should form a part of indicators 2, 3, 4 and 5 and not stand alone as a measure. This would ensure that the numbers of people receiving this care are reported on, and emphasise that psychological, social and spiritual support is an integral part of palliative care.

*Indicator 10:* Information to be provided on the number of persons with a life-limiting condition who have received palliative care and the number of family members who have received palliative care who have completed a survey conducted on behalf of the Scottish Ministers of Health Boards on the standard of palliative care.

Compassion in Dying agrees with this indicator and we would be interested to know how this will be done. We would encourage that this work gathers information from patients, carers and healthcare professionals on the *awareness* and *practice* of patient choices and rights.

*Indicator 11:* Scottish Ministers to report on the number of persons who have received education and training in providing palliative care. This may include staff from a range of disciplines who provide palliative care. This needs to be monitored closely as the Bill anticipates that generalists will provide more palliative care in the future.

Compassion in Dying agrees with this indicator and stresses the importance of all potential health and social care professionals being included for this indicator.

The Policy Memorandum accurately reflects that the boundaries between palliative care and end-of-life care are blurred: *palliative care can be provided during the early part of the illness and support is given to family members to help them come to terms with the death of a family member...and...end of life care is care provided in the period shortly before death and should be the continuation of good care provided over the long trajectory of the illness* (p 9). These proposed indicators are quite rightly concerned with the whole journey from assessment of palliative needs until choices are made about place of death etc. One practical way of demonstrating the importance of this *journey* would be to invest monies in promoting patients' end-of-life choices at an appropriate stage (for example, soon after diagnosis or before they reach the

end-of-life stage), ensuring they get recorded and can then be acted upon. Training should include information on tools for expressing end-of-life choices, so that the relevant professionals understand the choices that patients can make about treatment and their responsibilities under statutory and common law in this area.

**4. Are you content with the definitions contained in the Bill, particularly that of 'palliative care'?**

Compassion in Dying agrees with the definition of *palliative care* contained in the Bill, which focuses on treatment which controls and relieves pain, discomfort or other symptoms caused by or related to a life-limiting condition, and providing psychological, social or spiritual help and support with the intention of improving quality of life. We also support the inclusion of support for family members in the definition

**5. Do you have any comment on the costs identified in the Financial Memorandum?**

It is vital that dedicated monies reach their intended target as set out by the Scottish Government via the Living and Dying Well strategy.

Lessons can be learned from England where research carried out by Help the Hospices during the summer of 2009 indicated that 26 out of 28 PCTs in England had either been unable to identify any additional funding to support the implementation of the End of Life Care Strategy locally, or had taken a conscious decision to use the additional resources on other priorities<sup>1</sup>. In other words, specific funding had not reached the services it was intended for.

This Bill does not assign funding to the Living and Dying Well Strategy, but it is vital that Government funding of the Strategy continues, in order that it can be fully delivered, and in order that Scottish Ministers can fulfill their obligation to provide or secure palliative care for every person diagnosed as having a life-limiting condition and their family.

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<sup>1</sup> <http://www.communitycare.co.uk/Articles/2009/07/13/112079/Help-the-Hospices-issues-warning-over-end-of-life-care.htm>