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CHURCH AND SOCIETY COUNCIL**

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## Official Response

**SUBJECT:** Proposed Palliative Care (Scotland) Bill  
**REQUESTED BY:** Roseanna Cunningham MSP, The Scottish Parliament, Edinburgh, EH99 1SP  
**REFERENCE:** OR - 03 - 09  
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The Church and Society Council of the Church of Scotland welcomes the opportunity to respond to the current consultation on the Proposed Palliative Care (Scotland) Bill.

### **Introduction**

In broad terms the Church and Society Council of the Church of Scotland welcomes all efforts to improve the quality of care available to all Scotland's citizens. We find ourselves in general agreement and support of the aims of this proposed Bill, and would like to endorse much of what is presented. We do, however, have some concerns; these are detailed below.

### **Q1 What are your views on using this definition of palliative care for Scotland in the proposed Bill?**

As the WHO definition used makes clear, we would emphasise the need not only for physical issues to be addressed in improving palliative care, but also that psychological, social and spiritual issues be seen as being important. We recognise and encourage the efforts of the relevant authorities in Scotland in seeking to improve all aspects of palliative care.

### **Q2 What are your views on the whether all progressive, life-limiting conditions should lead to an entitlement to palliative care?**

It is widely acknowledged that palliative care for non- malignant conditions is generally poorer than for those with other, but no less life-threatening, conditions of a non-cancerous nature. Financial aid, hospice facilities, and nursing support can be harder to access for sufferers from some of these "Cinderella" conditions. Much support for the terminally ill depends on charitable funding rather than the NHS. The hospice movement is one example of this, and support organisations such as Marie Curie Cancer Care,

Macmillan Cancer Support, and the Maggie's Centres also rely upon charitable giving. Unfortunately, some of these facilities are provided for cancer sufferers only.

The "Living and Dying Well" action plan for palliative and end of life care in Scotland, produced in 2008 by NHS Scotland, recognises the need to address this problem, and gives a useful classification system for non-cancerous illnesses with poor prognosis.

- The first category is those with Organ Failure. This includes heart disease (mainly heart failure), chronic lung disease, end-stage kidney failure, and neurological conditions. The three most significant illnesses in the last group are Motor Neurone Disease, Multiple Sclerosis, and Parkinson's disease.
- The second category comprises patients with frailty (multiple conditions leading to increasing impairment of function), Dementia, and Stroke.

None of these conditions can be described as curable, and thus sufferers are approaching the end of life, though that point may be months or even years away. Many cancerous conditions are now treatable and some curable; in addition, many cancers progress at a relatively predictable rate, allowing both patient and health care staff to develop plans for many aspects of care. On the other hand, people with conditions such as organ failure or dementia can only look forward to their health deteriorating at an unpredictable rate.

Most patients in these categories require frequent hospital admission as time progresses. They cannot enjoy holidays as they may be uninsurable for travel, they are unemployable, and they cannot plan for an uncertain future. In addition, notwithstanding the recent encouraging action by the Scottish Parliament seeking to improve the legal processes for those exposed to asbestos, many people with chronic lung disease and their families continue to be locked in legal struggles for compensation over a perceived cause of their illness, with settlements often outstanding at the time of death.

The main needs are for day-time support, and in the later stages night-time also; for good continuity of nursing and medical care; for adequate respite care; and, ultimately for many, a residential placement which allows partners to visit on a regular basis. Sadly, in much of rural Scotland this last need cannot be met, and many life partners are separated during their final months together. The Living and Dying Well plan is to be welcomed, addressing as it does the need to recognise the special requirements of families affected by these conditions. It also sets out to apply good models of practice such as the Gold Standards Framework and the Liverpool Care Pathway to non-cancer patients, ensuring a truly holistic approach. Palliative care practitioners are well aware of these needs and are striving to improve access to hospice beds. The recent initiative by Marie Curie Cancer Care and the British Heart Foundation to set up a pilot centre in Glasgow for heart failure patients and their families is also a very welcome development indeed.

While we welcome the proposal that all progressive, life limiting conditions lead to an entitlement to good palliative care, we recognise the practical issues surrounding this—including the need for increased resources, and also the less predictable course of many of the conditions under consideration

**Q3 A list of indicators of high-quality palliative care has been provided. What other indicators should be included and why?**

We would re-emphasise the need for palliative care to be about more than simply the alleviation of physical symptoms. In particular, care for the psychological, social and spiritual aspects of the end of life need to be taken into consideration. While acknowledging that many of these factors are perhaps more difficult to measure or assess objectively than others, we would urge that these also be included in any list of indicators. We would encourage the wider use of plans such as the Liverpool Care Pathway and the Gold Standards Framework, which emphasise care for non-medical needs.

We also see some problems with defining "high-quality care" in terms of "assessment, documentation, and management" (para 24). While this type of audit could be carried out in the specialist setting of a Hospice, in a general hospital or a home situation it might be more difficult to achieve effectively.

In addition, we would have some concerns about some of the indicators currently including the list as being relatively "blunt instruments" in assessing the real quality of care being given. For example, simply looking at the number of patients transferred to hospital in the last weeks of life may misinterpret some of the reasons for these transfers (e.g. carer fatigue).

**Q4 What are the funding implications of this proposal? Please provide detailed costings.**

We appreciate that widening the net of palliative care has potentially significant financial implications. However, we would also urge recognition of the fact that many of the important aspects of palliative care are non-material: for example, care and compassion, a listening ear, and spiritual care. We recognise that many health care staff provide such non-material aspects of care, often under conditions which are far from ideal. We welcome the inclusion of hospital chaplains in many specialist palliative care teams, and would encourage their involvement in non-hospital settings.

In addition, we would encourage the recognition of the contribution that many non-professionals make to many aspects of care: this would include spouses and other family carers, friends, neighbours and church contacts, for example.

**Q5 What other organisations etc. will be affected by the proposal and in what ways?**

Much of the thrust of this legislation is aimed at NHS facilities. Scotland has an ageing population, and the number of people living (and consequently dying) in care homes is increasing; it is estimated that between 15- 20% of deaths in the UK occur in care homes. There is evidence to suggest that there is suffering among those dying in care homes for a variety of reasons, including:

- lack of access to palliative care education
- high turnover of staff

- low staffing levels
- an emphasis on rehabilitation which makes dying peripheral, despite the fact that those living in care homes are increasingly frail with complex needs on admission.

The majority of care home residents die within two years of admission. Although care home staff training is largely co-ordinated by the Scottish Commission for the Regulation of Care, maintenance of levels of trained, competent and motivated staff is largely the responsibility of individual care homes. Emphasis in training is usually given to nutrition, hydration and pain control; spiritual care is often considered less important.

Changing practice in care homes takes time as it involves a change in the culture of care. This requires adequate resources in terms of practice development projects which are long enough to allow changes to be embedded and sustained. A key recommendation of a recent feasibility study on the use of the Gold Standards Framework in Care Homes was the need for greater availability of palliative care support and more formal links between care homes and providers of specialist palliative care.

While acknowledging the practical difficulties of “rolling out” the proposed targets to facilities outside the NHS, we would argue that the end of life care of a significant minority of the people of Scotland is given in such settings, and would urge that consideration be given to seeking to improve palliative care in all facilities, not just in the NHS.

**Q6 Please provide any other comments on the Bill’s proposal to place a requirement on all Health Boards to provide high-quality palliative care to everyone in need of it.**

Our main concern would be that this simply become a “box-ticking” exercise- that Health Boards and other relevant authorities expend resources (financial, and also in terms of staff time) ensuring that targets are “met”, and that as a result actual delivery of care to individual patients might slip down the list of priorities. It must also be recognised that the care needed by each person is different, and that statutory targets may

In addition, we would express concern that the national “Living and Dying Well” action plan introduced only last year has not had sufficient time to “bed in”, and that further legislative change at this stage may be unduly onerous on staff, many of whom are already stretched to capacity. Perhaps some form of phased or delayed introduction of any new statutory requirements might be considered, taking into account lessons learned over the next 3-5 years.

**Conclusion**

In general terms the Church and Society Council of the Church of Scotland would endorse and support much of what is suggested in this proposal. We note that similar initiatives are also being undertaken at the European level, with the recent adoption of Resolution 1649 (2009) on “Palliative care: a model for innovative health and social policies” by the Council of Europe Parliamentary Assembly. We look forward to the draft of the Bill being brought before the Parliament, and to all aspects of the palliative care provided to all of Scotland’s citizens improving as a result of the legislation