

Official Response

SUBJECT: Proposed Palliative Care (Scotland) Bill
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Introduction

This response to the Call for evidence on the above Bill has been prepared by the following Christian denominations:

- **The Salvation Army:** The Salvation Army has 82 Corps/ centres in Scotland with approximately 4500 members, and are part of the United Kingdom Territory with the Republic of Ireland. The Salvation Army is at work in 120 countries. The three-fold mission of the Salvation Army as detailed in its Mission statement is 'Called to be disciples of Jesus Christ, the Salvation Army in the United Kingdom Territory with the Republic of Ireland exists to save souls, grow saints and serve suffering humanity.'
- **The Church of Scotland:** The Church of Scotland has around 984 active ministers, 1,179 congregations, and its official membership at approximately 489,000 comprises about 10% of the population of Scotland. In the 2001 national census, 42% of Scots identified themselves as 'Church of Scotland' by religion. The Church of Scotland seeks to inspire the people of Scotland and beyond with the good news of Jesus Christ through enthusiastic, worshipping witnessing, nurturing and serving communities

A number of people from each of these groups, many of them with professional expertise in areas relevant to this response, have contributed to the writing of this response.

Introduction

In broad terms the denominations represented welcome 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 Do you agree or disagree with the general principles of the Bill?

The proposed Palliative Care (Scotland) Bill has the potential to significantly reduce the cost of inappropriate treatment and bed-blocking in general hospitals, and to enhance the support given to patients and their families in the last stages of their lives. Indeed, its provisions would be a welcome and long overdue incentive to "joined up" palliative care in the community, where those involved in

giving support - medical professionals and carers, social work providers and spiritual carers, even if not formally coordinated, are at least talking to each other and recognise the importance of working together.

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. 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.

Q2 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”?

The rationale for establishing the provision of palliative care as a specific statutory duty, sending a clear signal that palliative care is a core service, not just an added extra, is to be applauded. Establishing a statutory duty would enshrine the provision of palliative care into law in a much more robust way than the Government's Living and Dying Well could be enforced. However, we feel that consideration should be given to the question as to whether a statutory duty is really the most appropriate way of ensuring that palliative care is available to those who require it.

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. Rural areas present particular problems for any palliative care model primarily focused on centralised units such as hospitals or hospices.

The proposed duty to provide care not only covers patients, but also the family members of patients. The requirement to assess needs and ensure appropriate care promptly would probably require generalist GP practices to refer more people to psychiatric nurses or consultants, social workers, and to either specialist spiritual counsellors or parish clergy – and to use relevant people with such expertise readily available within the local community. Although this could have some resource implications for the churches, it is important to stress the need for health practices to make use of resources within the community.

Greater awareness and recognition that good palliative care can and should be provided within the local community may change the culture of indiscriminate aggressive response for the treatment of cancer and heart failure in general hospitals; and in care homes for the elderly, from where too often, elderly patients with terminal illness are admitted to general hospital wards for the last few hours or weeks of their lives.

Q3 Do you have any comments on the provisions concerning reporting and indicators contained in the Bill?

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 tend to mask such differences.

In addition, we would express concern that the national “Living and Dying Well” action plan introduced 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.

We would also have concerns that some of the indicators currently included in the list may be 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)

There may be some concern that the implementation of the bill's requirements might produce a focus on targets that would distort priorities and other health provision. In fact, the requirements of this bill would build on existing programmes and good practice – at minimal cost:

The Scottish Government's End of Life Strategy over the past year has encouraged GPs (with the inducement of £100 per patient):

- 1) to identify those who need palliative care;
- 2) to assess their needs holistically and plan appropriate care;
- 3) to notify out of hours services to preserve continuity of information;
- 4) to be alert for when the terminal / last days phase approaches, and to consider a holistic care framework to die well.

GPs and nurses involved seemed to welcome this approach with its focus on talking about the wishes and expectations of patients and families and being more ready to meet personal needs.

This Bill is realistic in that it does not try to provide more hospices but recognises that the overwhelming majority of people would chose to die in their own homes with adequate support and pain relief.

Q4 Are you content with the definitions contained in the Bill, particularly that of “palliative care”?

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.

We would re-emphasise the need for palliative care to be concerned with 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

Q5 Do you have any comment on the costs identified in the Financial Memorandum?

Many geriatricians and community palliative care experts have expressed the view that if palliative care was improved, if patients received consistently more appropriate and agreed treatment, care and support, and if family and friends got better support, this would reduce the stress experienced by all participants, and

therefore lead to fewer demands for expensive inappropriate treatments. Thus additional costs may be less than anticipated.

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.

Conclusion

In general terms the denominations represented 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 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.

All members of the Church are called to share Christ's love and compassion; to care for and support those facing death. Incapacitating illness should not be trivialised, yet God made us for relationship, both with Him and in supporting communities which value all their members. People fear not only pain but indignity and becoming a burden to their loved ones. Caring for the dying can be a relentless and often painfully heavy experience. Christianity teaches not only the immense value of each human life but also that we are to "carry each other's burdens...doing good to all people".

The law's prohibition of killing protects the most vulnerable in our society, who may otherwise be made to feel that they have become a burden to their family, their friends or the state. Greater priority must be given to improving palliative care not just in care homes, hospitals and hospices but also for the sick in their own homes, and so we welcome this Bill.

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