INTRODUCTION

1. This document relates to the Palliative Care (Scotland) Bill introduced in the Scottish Parliament on 1 June 2010. It has been prepared by the Non-Executive Bills Unit on behalf of Gil Paterson MSP, the member in charge of the Bill to satisfy Rule 9.3.3A of the Parliament’s Standing Orders. The contents are entirely the responsibility of the member and have not been endorsed by the Parliament. Explanatory Notes and other accompanying documents are published separately as SP Bill 50–EN.

POLICY OBJECTIVES OF THE BILL

2. The founding father of the National Health Service, Aneurin Bevan, famously promised that care for us would go from the cradle to the grave and, in the 60 years since, the cradle has been properly looked after. Developments in obstetrics, maternity services and neonatal care have all ensured that at the beginning of life most people are well cared for, but until relatively recently there has been less attention to the end of life process.

3. At present there is a wide variation in the provision of palliative care across Scotland. This is due to a number of factors such as health boards’ differing priorities.

4. The objective of the Bill is to secure access to palliative care (including end of life care) for everyone in Scotland with a progressive life-limiting condition and their family members. The Bill aims to secure this by:
   - placing Scottish Ministers under a statutory obligation to provide palliative care for those with life-limiting conditions and their family members; and
   - setting up reporting arrangements so that the palliative care provided can be monitored by Scottish Ministers and the Parliament.

5. These reporting arrangements require Scottish Ministers to report on the provision of palliative care in relation to a number of key indicators established in the Bill. Scottish Ministers will be required to lay an annual report before the Parliament which compiles the information submitted by frontline providers to enable the Parliament to scrutinise, compare and contrast the delivery of palliative care services nationwide.

6. The effect of the Bill will be to:
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- give legislative effect to the key intentions of the Scottish Government’s Living and Dying Well strategy;
- raise the priority of palliative care provision within the National Health Service; and
- standardise and collate information held on the delivery of palliative care services in line with suggestions by Audit Scotland and the Public Audit Committee.

7. By complementing the intentions of the Living and Dying Well strategy the Bill will also assist in:

- making access to services more equitable; and
- improving and maintaining palliative care services.

BACKGROUND

What is palliative care?

8. Palliative care is the term used to describe the care that is given when cure is not possible. Palliative care is a proactive approach involving a multi-professional team. As well as controlling pain and other distressing symptoms, it applies a holistic approach to meeting the physical, practical, social, emotional, psychological and spiritual needs of patients and their families facing progressive illness and bereavement. Palliative care aims to help patients and their families maintain the best quality of life through their life-limiting illness and allows people to have “a good death”, where the wishes of the patient and their family are respected.

People most likely to need palliative care services

9. Over 55,000 people die in Scotland each year. 80% of those deaths in Scotland occur in patients aged 65 years and over, and 60% in those aged over 75 years. By 2031, the number of people aged 75 and over is projected to increase by 75%.

10. Many elderly people will need palliative care services because of a combination of morbidity and mortality factors. Conversely, however “older people are often described as the “disadvantaged dying” because they are less likely to receive care.” Audit Scotland confirms this perception, stating in its report “people over 75 years are less likely to receive specialist palliative care than people aged 45-74 years”.

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1 Living and Dying Well: A national action plan for palliative and end of life care in Scotland – the Scottish Government, October 2008
2 See para 24 (Audit Scotland Review) and paras 28 & 29 (Public Audit Committee Inquiry) of this Policy Memorandum
3 Review of Palliative Care Services in Scotland, Key Messages Audit Scotland, August 2008, para 12
6 British Medical Association Scotland, 27 February 2009, Consultation Response 16, page 1
7 Review of Palliative Care Services in Scotland, Key Messages, Audit Scotland, August 2008, para 11
11. In considering the provision of palliative care services it is important to recognise other groups may also benefit from equitable provision of palliative care services. The Association for Children’s Palliative Care advises that “Many children and young people with life-limiting conditions are not currently accommodated within palliative care services, so tend to receive piecemeal and crisis intervention rather than co-ordinated care.” Additionally there is a growing number of children and young people with life-limiting conditions who are surviving longer, who may also have palliative care needs, for example those living with cystic fibrosis can now have a life expectancy of 30 to 40 years.

Provision of palliative care

12. Palliative care can be provided through specialist or generalist services.

13. Specialist palliative care is provided by multi-disciplinary teams whose members have trained specifically in palliative care. These include for example, consultants in palliative medicine, clinical nurse specialists, chaplains, social workers, pharmacists and other appropriate health professionals. Care focuses on complex needs such as pain management or psychological, social or spiritual needs. Specialist palliative care can be provided at home, or in care homes hospitals or hospices. Alongside the public sector, the voluntary sector is a key provider of specialist palliative care, such as St Margaret of Scotland Hospice in Clydebank which has provided invaluable information to the member to inform the development of the policy behind this Bill.

14. The other category of palliative care is general palliative care, which is part of the routine care of patients and support of carers. It can be provided in the patient’s home, a care home, in GP practices or as part of the general care provided in community or acute hospitals. It may be part of the work of a range of health or social care workers including GPs, district nurses, social workers or care assistants, as well as hospital staff.

15. Not every person with a life-limiting condition will need to access specialist palliative care. However, the most recent figures show that around 90 per cent of specialist palliative care is delivered to patients with cancer although cancer accounts for less than 30 percent of deaths. People suffering from other progressive conditions such as cystic fibrosis, dementia, end-stage heart failure, Parkinson’s disease, HIV/AIDS, motor neurone disease, multiple sclerosis, muscular dystrophy, renal failure and variant Creutzfeldt-Jakob disease (vCJD) may also have complex palliative care needs but are less likely get specialist palliative care.

Access to palliative care services

16. Since 2001, all health boards have completed a palliative care needs assessment of their area to determine requirements of the local population, developed a palliative care strategy, or established a palliative care managed clinical network. They must also take account of a number

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8 Association of Children’s Palliative Care (ACT), 19 February, Consultation Response 30, page 2
9 Scottish Children’s and Young People’s Palliative Care Network (SCYPPCN), Consultation Response 21, page 2
10 Review of Palliative Care Services in Scotland, Key Messages Audit Scotland, August 2008, para 12
11 Review of Palliative Care Services in Scotland, Key Messages Audit Scotland, August 2008, para 5
of specialist palliative care standards published by NHS Quality Improvement Scotland (NHS QIS).  

17. In January 2004 NHS QIS published a report detailing their review of individual services’ performance against the standards. The review found that none of the specialist palliative care units were providing 24 hour access to their in-patient service, although this is an essential criterion of the standard. It was also found that only four out of 19 sites were providing 24 hour access to their advice service, another essential criterion. Additionally, none of the sites met the “desirable” criteria of providing 24 hour access to services in the community. The report concluded that high demand, and short supply of specialist staff to provide cover for these services, together with the complexity of providing specialist palliative care services between NHS Scotland and voluntary hospices, meant there should be a review of provision to ensure equitable access to services across Scotland.

18. There is also some evidence to suggest that certain groups of people may find it more difficult to access palliative care services. There might also be a lack of take-up of palliative care services generally and in particular by some ethnic and social groups due to perceptions that palliative care services are primarily for patients with cancer. Also there may be a reluctance to refer or be referred for palliative care because of a misunderstanding of what benefits this service can offer. For instance, many people associate hospices purely with end of life medical care for the patient, whereas they also provide psychological, spiritual and respite care for the patient and their carers:

“Lack of awareness among [black and ethnic] communities of the potential benefits and the perception, among older people and professionals alike, that palliative care is only for cancer rather than for conditions which are more prevalent among people from black and ethnic minority backgrounds, such as heart disease and strokes. The disparities may also be attributable to general social and material deprivation rather than ethnicity alone.”

Recent reports and inquiries

19. Historically, palliative care services have arisen from voluntary sector fundraising efforts with voluntary hospices operating since the 1960s. Scotland has 15 voluntary hospices (including

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13 Specialist Palliative Care; National Overview - January 2004, pg. 32, NHS QIS: http://www.nhshealthquality.org/nhsqis/controller?p_service=Content.show&p_appliCCpMenuId=0&pElementID=0&pContentID=1162
14 Specialist Palliative Care; National Overview - January 2004, pg. 77, NHS QIS: http://www.nhshealthquality.org/nhsqis/controller?p_service=Content.show&p_appliCCpMenuId=0&pElementID=0&pContentID=1162
15 “The common causes of mortality in people with profound and multiple learning disability (PMLD) are different to those of the general population. The most common causes of death for this group of people are respiratory failure, which relates to pneumonia and aspiration, swallowing and feeding problems, and gastro-oesophageal reflux disorder. […] However, at present, people with PMLD are excluded from receiving good quality palliative care as most of the specialist services for palliative care are directed at people with common forms of cancer. Rarely, if ever, would people with PMLD who are at end of life for respiratory failure or cardiovascular disease be offered palliative care” PAMIS, 5 March 2009, Consultation Response 22, page 1
16 British Medical Association, Consultation Response 16, page 1, quoting from The Policy Research Institute on Aging and Ethnicity’s publication, The Ethics of Caring for Older People 2009
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2 national hospices for children). It has only been relatively recently that palliative care has begun to be provided within mainstream health provision, so for the health service it is a new phenomenon. Recent reports and inquiries seek to improve the planning and delivery of palliative care services in Scotland.

Palliative and end of life care in Scotland: The case for a cohesive approach

20. A short life working group of the Scottish Partnership for Palliative Care produced a report based on widespread consultation.

21. The group make several recommendations which it believed would begin the development of an integrated and cohesive approach to palliative care services. These centred on:

- supporting continued and expanding use of the principles of the Gold Standards Framework Scotland in all care settings;
- encouraging a uniform approach to achieving the goals of the Liverpool Integrated Care Pathway for the Dying Patient in all care settings; and
- clarifying some of the issues relating to out of hours service provision, Do Not Attempt Resuscitation policy and joint working by health and social care.

22. This report was submitted to the then Scottish Executive in May 2007, which led to a commitment by the Scottish Government in Better Health, Better Care: Action Plan (December 2007) to implement the report’s recommendations.

Review of Palliative Care Services in Scotland

23. Audit Scotland reviewed the planning and delivery of palliative care services across Scotland. The review analysed levels of palliative care activity, how services were planned and resourced, and the scope for improvements in the efficiency of services. This included an examination of whether health boards, Managed Clinical Networks, Community Health Partnerships, independent hospices and local authorities have a joined-up approach to planning and delivering palliative care.

24. In August 2008 Audit Scotland issued its report. Some of the key findings were:

17 Roseanna Cunningham MSP Herald Article “Mainstream medicine must embrace palliative care”, 18 November 2008
20 The Liverpool Care Pathway is an integrated care pathway that is used at the bedside in the last hours and days of life. http://www.mcppcil.org.uk/liverpool-care-pathway/
significant variation in the availability of specialist care services and how easily patients with complex needs can access these. Specialist palliative care remains primarily cancer focused;

most palliative care is provided by generalist staff in hospitals, care homes or patient’s own homes. Palliative care needs were not always recognised or well supported. Generalists needed increased skills, confidence and support from specialists;

palliative care needs to be better joined up, particularly at night and weekends. Support was not widely available for those caring for someone with palliative care needs;

in 2006/07, £59 million was spent on specialist palliative care. Almost half of this came from the voluntary sector. It is not possible to say how much is spent on general palliative care. Health boards and their partners need to plan now to meet the predicted increase in demand from an ageing population;

the Scottish Government should work with health boards, councils, voluntary hospices and the Information Services Division (ISD Scotland) to ensure information is collected consistently across all services and used to improve planning and to help provide joined-up care for patients.22

The Scottish Government’s Living and Dying Well Strategy

25. In October 2008 the Scottish Government published its strategy for ensuring that palliative and end of life care can be available to all persons in Scotland with life-limiting conditions. The Living and Dying Well strategy seeks to “ensure that good palliative and end of life care is available for all patients and families who need it in a consistent, comprehensive, appropriate manner across all care settings in Scotland.”23

26. This strategy also provides a basis for implementing the recommendations of the Scottish Partnership for Palliative Care 2007 report and takes account of the key messages and recommendations in the Audit Scotland review.

27. The Scottish Government has also set up a number of short-life working groups as a result of the strategy. These will develop recommendations in areas identified as needing further development work. The outputs of the groups will include:

- national palliative and end of life guidelines and referral criteria for primary care staff and non-specialist hospital staff to refer patients to specialist palliative care services;
- recommendations on appropriate service configurations to meet the needs of adolescents and young people with palliative and end of life care needs;
- recommendations on delivering palliative and end of life care in acute settings; and

• consideration of national standards for generalist and specialist palliative and end of life care.

Public Audit Committee Inquiry

28. The Parliament’s Public Audit Committee considered the Audit Scotland report and the Government’s Living and Dying Well Strategy. In relation to delivery of palliative care services, the Committee’s report\(^{24}\) stated that “consistent and accurate data collection, carried out on a national basis, is critical to enable reliable planning and monitoring of service delivery”\(^{25}\). The Committee was concerned that there are no specific actions within the Government’s strategy on recording consistent information across health boards, but noted that there is an expectation that this would follow\(^{26}\).

29. The Scottish Government responded\(^{27}\) to the points raised in the Committee’s Report. In relation to data collection the Government listed future data improvement work. The Committee has continued its interest in Scotland’s palliative care services and agreed to note the response and agreed the issues to be included in the progress report it will receive from the Scottish Government in September 2010.

KEY ASPECTS OF THE BILL

Duty to provide palliative care

30. The Bill adds force to these recent policy developments by underpinning the Scottish Government’s Living and Dying Well Strategy. It provides the necessary momentum to achieve equitable access as envisaged by that strategy. It does this by placing a specific statutory duty on Scottish Ministers to provide palliative care available to every person diagnosed as having a life-limiting condition and to family members of such persons.

31. Under the National Health Service (Scotland) Act 1978 Scottish Ministers and health boards have duties which relate in general to the provision of palliative care. For example section 36 relates to the provision of accommodation and services and section 37 provides for arrangements to be made in respect of the prevention of illness, care and after-care.\(^{28}\) A duty to provide palliative care could, effectively, be read into the 1978 Act. However the scope of that duty is limited in that it need only be carried out “to such extent as considered necessary to meet all reasonable requirements”. The insertion of a specific duty within the 1978 Act will ensure greater consistency of delivery of palliative care throughout Scotland. Further it is to be noted that the duty as set out in the Bill is absolute; the scope of the duty cannot be limited by Ministers as is the case with the existing general provisions discussed above.


\(^{26}\) Public Audit Committee Report, 1st Report 2009 (Session 3), Review of Palliative Care Services in Scotland, SP Paper 189, para 16

\(^{27}\) Public Audit Committee, 6th Meeting 2009 (Session 3) 25 March 2009, item 2, paper PA/S3/09/6/7 http://www.scottish.parliament.uk/s3/committees/publicAudit/papers-09/paup09-06.pdf

\(^{28}\) Responsibility for these and other functions have been transferred to health boards under the Functions of Health Boards (Scotland) Order 1991 (SI 1991/570)
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32. Palliative care services should be part of mainstream care as highlighted by one palliative care specialist 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.”

33. Support for this legislation is typified by another palliative care specialist who agrees there should be a requirement to provide palliative care, “This should be understood as a culture change within health professions…also…acute hospitals that palliative care is a key part of safe and effective patient care in life limiting illness.” Other health professionals agreed, stating that palliative care should “Not be viewed as an add-on but rather as an essential part of patient care.” Sense Scotland also welcomed the proposals on palliative care outlined in the Bill. They agreed that this was an essential area that for too long has been on the periphery of medicine and clinical care.

34. Creating a specific duty sends a clear signal that palliative care is a core service. Palliative care is not just an added extra but is an integral service to be provided to those who need it, not simply whenever possible. A statutory obligation introduces the need for action and raises the priority of palliative care provision within the National Health Service. As a result Scottish Ministers and the wider National Health Service will have to promote the necessary mainstreaming, co-ordination, training and system design changes advocated in the Living and Dying Well strategy.

35. The Bill does not require the Scottish Ministers to provide treatment, help or support where there is already a duty on another person to do so. This means that the Bill does not transfer responsibilities between the Scottish Ministers and local authorities or between the Scottish Ministers and health boards in relation to the provision of services which could amount to or be viewed as palliative care services.

Definitions

36. Central to the operation of the Bill are the definitions of “palliative care” and “life-limiting condition”.

Palliative care

37. There are many definitions of palliative care. Palliative care is sometimes defined as solely being care that alleviates pain and other symptoms. Such definitions of care include any other support for either the patient or their family, for example that provided by a psychologist. Many aspects of palliative care are applicable earlier in the course of a disease and palliative care can, and often should, be provided alongside disease modifying treatment. Some definitions either implicitly or explicitly allow for this. Palliative care is still sometimes defined as solely being for people with cancer, but is more usually defined as being for people facing a life-

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28 Dr McLaren, 16 February 2009, Consultation Response 39
30 Dr J Martin Leiper FRCP, Consultant in Palliative Medicine, NHS Tayside, 28 November 2008, Consultation Response 27, page 1
31 Julie King, Consultation Response 62
32 Sense Scotland, 28 February 2009, Consultation Response 29
threatening illness. It is not generally defined as being for people with chronic diseases such as diabetes.

38. Palliative care can often be confused with end of life care. Alzheimer Scotland illustrates what it sees as the difference: “For people with dementia palliative care continues throughout the illness and is more evident in some stages of the illness than others. 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.”

This view on the role of end of life care is shared by the Scottish Partnership for Palliative Care. The diagram below, while focussing on those with cancer, represents the change in views about the role of palliative care. Traditionally palliative care was only provided towards the end of the illness trajectory. Now 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.

Traditional view

| Anti-cancer treatments | Palliative/terminal care |

Current view

| Anti-cancer treatments | Palliative care | Grief |

Diagnosis — Death

39. The World Health Organization (WHO) defined palliative care in 2002 as—

“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.”

40. This definition is internationally recognised and is supplemented by a further nine elements of palliative care highlighted by the WHO:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;

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33 Alzheimer Scotland, February 2009, Consultation Response 32, page 1
34 Scottish Partnership for Palliative Care, Palliative and end of life care in Scotland: the case for a cohesive approach, May 2007, page 9, para 1.2 terminology
35 Journal of the Royal Society of Medicine, 2001 September; 94(9): 437-441 PMCID: PMC1282181
36 World Health Organisation Definition of Palliative Care, http://www.who.int/cancer/palliative/definition/en/
• 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.

41. In England, a working definition of palliative care was introduced and accepted by the National Institute for Clinical Excellence (NICE) in 2004. This definition however excludes quality of life concerns of the person and their family, which the WHO definition addresses.37

42. It is for these reasons that the definition in the Bill is founded on the agreed WHO definition with one exception as explained in the following paragraphs.

43. Determination of the reasonable palliative care needs of persons with a life-limiting condition and their family members is likely to be a holistic assessment. This will include consideration of physical, psychological, social and spiritual needs, and will involve relevant health professionals and others providing care and support, such as chaplains, social workers and pharmacists.

44. It is recognised that a range of family members may be in need of support and care as a result of their connection with the person with a life-limiting condition. Provision of care is qualified by the requirement that such care and support must be based on the reasonable needs of the person. In assessing the reasonable needs of family members, consideration may be given to the nature and frequency of the association that the family member has with the person with the life-limiting condition.

Life-limiting condition

45. It is the intention of the Bill that palliative care should be made available to both adults and children from the point of diagnosis of the life-limiting condition onwards. Palliative care need not be provided on a continuous basis but should be provided when it is needed. Defining what conditions attract palliative care for the purposes of the Bill is crucial in the application of the legislation.

46. The Bill does not rely on a list of illnesses which would attract palliative care services. Any list might unintentionally preclude certain conditions or groups like the elderly who could

37 Sense Scotland, 28 February 2009, Consultation Response 29, page 2
have a combination of morbidity and mortality factors. This addresses the point highlighted by the Association for Children’s Palliative Care who advise that “Some children and young people with palliative care needs do not have a named or recognised condition.”

47. The WHO definition refers to “life-threatening illness” in relation to the description of the type of illness which would require palliative care services, whereas the consultation on the Bill used the term “life-limiting condition”. This is because the term “life-threatening” is considered to encompass more conditions than “life-limiting”, as it does not necessarily mean that the condition is irreversible. For example, a cancer could be life-threatening, but if treated successfully need not be life-limiting. Life-limiting conditions do not include chronic diseases such as diabetes which may not be reversible but if treated need not be life-limiting.

48. The definition of a life-limiting condition used in the Bill would encompass any person with a condition, illness or disease which (a) is progressive and fatal; and (b) the progress of which cannot be reversed by treatment.

**Reporting on the provision of palliative care services**

49. The Bill requires Scottish Ministers to lay a report annually before the Scottish Parliament containing information relating to the 11 indicators set out in the Bill. A report will provide information in relation to each indicator for the whole of Scotland and contain a breakdown of the information as it relates to the area covered by each health board.

50. Currently information on the delivery of palliative care services is not held in a consistent format across health boards and the wider National Health Service. Nor is information collected and published in one place. Reporting this information will enable Scottish Ministers and the Parliament to scrutinise, compare and contrast the delivery of palliative care services nationwide. The transparency of this approach will also allow best practices to be highlighted throughout the National Health Service.

51. The indicators cover information such as the place of death, waiting time for palliative care, provision of palliative care training, care assessments and patients and families’ views on the service they have received. Indicators can be modified and added to by the Scottish Ministers to keep pace with developments with the Living and Dying Well Strategy.

**CONSIDERATION OF OTHER POLICY ISSUES**

**Funding**

52. Information about the potential costs that arise in the implementation of this Bill was sought from respondents to the consultation. The majority of those responding considered the proposal would require funding but could not quantify those costs. None argued against the proposal on cost grounds. The Financial Memorandum provides best estimates of potential costs.

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38 Association for Children’s Palliative Care (ACT), February 2009, Consultation Response 30, page 1
53. Inevitably providing access to palliative care to all with a life-limiting condition will result in some cost, but it is not possible to disaggregate the costs of delivering the Scottish Government’s Living and Dying Well strategy from the effects of a new statutory duty to provide palliative care. The member also believes any cost must be balanced against equality and moral issues. This policy should be considered as being our moral duty in much the same way as the policy on free personal care for the elderly. Such an approach helps avoid perceptions of “the elderly and terminally ill as a burden either financially or otherwise.”

54. Like free care for the elderly, the Government’s Living and Dying Well Strategy and this Bill demonstrates Scotland’s forward thinking approach to health policy. This approach is advocated by the Parliamentary Assembly of the Council of Europe, which recently issued Resolution 1649 (2009) Palliative Care: a model for innovative health and social policies. The Assembly noted that, especially in the final stages of life and in spite of the high standards and the costs involved, contemporary medical care fails to meet the basic needs of many people (e.g. seriously ill patients, chronically ill patients and patients requiring high levels of individual care). Against the background of the increasing domination of health and social policies by economics, growing numbers of people do not have a strong enough lobby to defend basic rights. The Assembly noted that palliative care enables people who have serious illnesses, are suffering pain or are in a state of great despair, to exercise self-determination. The Bill’s approach therefore although based on meeting needs, contributes to a person’s rights more broadly, for example, human, civic and participation rights.

55. This approach is further supported by the Scottish Council on Human Bioethics: “The Bill may ensure that money could be allocated to health boards to provide adequate Palliative Care. This may mean that some funding is directed away from other specialities. However, this would be in keeping with a general move away from surgical interventions and towards a more holistic and caring approach to health.” Another respondent put the policy in perspective “health boards are publicly funded and therefore the needs of the people at end of life should and must be met in the same way as any other time in life where treatment is required.”

56. With the provision of accessible, high quality palliative care services on an equitable basis savings could be achieved. One of the principal advantages of a planned and high quality palliative care service would be to reduce unnecessary and expensive hospital admissions. Another potential saving could be in relation to prescribing budgets. Good prescribing in palliative care is important but the use of non-drug measures is as important as medication. By relieving suffering from other symptoms through the provision of psychological, social and spiritual care as part of the provision of palliative care services could lead to less need for medication. Provision of support for families as part of a palliative care package could also reduce the amount spent on family counselling and bereavement services currently as the patient is more likely to have had a “good death”. Potential savings are considered in more detail in the Financial Memorandum.

39 Dan and Eileen Tinney, 29 January 2009, Consultation Response 80
40 Council of Europe, Parliamentary Assembly, Resolution 1649 (2009) Palliative Care: a model for innovative health and social policies, Adopted January 2009
http://assembly.coe.int/Mainf.asp?link=/Documents/AdoptedText/ta09/ERES1649.htm
41 Scottish Council on Human Bioethics, Consultation Response 14, page 6
42 Julie King, 9 March 2009, Consultation Response 62
IMPLEMENTATION

57. The provisions of the Bill come into force on Royal Assent. The reporting period is linked to financial year with the initial report covering the part of the financial year remaining after the Bill comes into force. This will provide some linkage between activity on palliative care services and funding.

ALTERNATIVE APPOACHES

58. The alternative option to the Bill would be to do nothing and rely solely on the Living and Dying Well Strategy to deliver palliative care. This approach was rejected, however, because additional benefits will accrue from providing a statutory duty to provide palliative care to those with life-limiting conditions. This duty directly contributes to people with palliative care needs getting access to the care they need by prioritising palliative care services.

CONSULTATION

59. Consultation on palliative care proposals was originally undertaken by Roseanna Cunningham MSP. On her appointment as a Minister of the Scottish Government, Gil Paterson MSP took over the proposal and considered the consultation responses.

60. The consultation document accompanying the draft proposal for the Palliative Care Bill was issued on 14 November 2008 and the consultation ran until 9 March 2009.

61. 370 copies of the consultation document were issued to organisations, MSPs and MPs. Further copies were posted or e-mailed in response to individual inquiries. The consultation document was also made available from a link on the Proposals for Members’ Bills web pages on the Scottish Parliament website. The summary of responses can also be accessed online.

62. There were 106 responses to the consultation document. These were from the following groups:

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<td>Individuals</td>
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<td>Health professionals</td>
<td>23</td>
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<td>Hospices and charities</td>
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<td>Forums or groups</td>
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63. The main areas consulted on were:

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43 Proposed Palliative Care (Scotland) Bill, Consultation Paper
http://www.scottish.parliament.uk/s3/bills/MembersBills/pdfs/PalliativeCareConsultation.pdf

44 Proposed Palliative Care (Scotland) Bill, Summary of Responses
what definition of palliative care should be used within the Bill;  
whether all progressive, life-limiting conditions should lead to an entitlement to palliative care;  
what indicators should be used to monitor the quality of palliative care being provided;  
potential funding implications;  
what other organisations etc. might be affected by the proposal and why.

64. The majority of the responses, 64%, expressed support for the proposal, while a further 21% neither opposed nor endorsed the proposal.

65. Twenty-three respondents believed that the World Health Organisation definition of palliative care set out in the consultation paper was appropriate and comprehensive. Some, however, felt that there were omissions from the definition in particular; they felt there was insufficient consideration of spiritual care while others argued that the definition was too focussed on the period immediately before death and more consideration should be given to care from diagnosis.

66. Support for extending the provision of palliative care to all progressive life limiting conditions was almost universal amongst respondents. A few took the opportunity to stress that it should be supplied on the basis of need rather than diagnosis. The only response questioning the proposal did so on the basis that the respondent felt that in extending the provision of palliative care, it was no longer exclusively about palliative care, but pain relief more generally.

67. In relation to the list of indicators to measure the quality of palliative care provided the most common additional indicator suggested was in relation to the provision of social and emotional care. Another suggestion related to measuring the satisfaction of the patient’s relatives. With regard to the use of indicators, a few respondents questioned the impact of the indicators, suggesting that their effect may increase bureaucracy. There was also a suggestion that there should be scope within the reporting framework to detail why certain indicators had not been met, as there may be issues outwith the control of clinicians.

68. There was a general feeling amongst those who responded to the question posed on costs that providing the level of palliative care set out in the proposal would be costly, however, none of the respondents were able to provide detailed costings. Some indicated that the greatest cost would come from the requirement to offer palliative care in the community, enabling people to be cared for and die at home. Other costs highlighted included additional staffing and support to the voluntary sector and training. However, almost none argued against the proposal on cost grounds, with a number stating that palliative care should be an integral part of the health service and not an add-on and as such any increased costs should be considered necessary.

69. In looking at those who would be affected by the proposal for the Bill, the group highlighted as benefiting most significantly were patients, followed by their families.
EFFECTS ON EQUAL OPPORTUNITIES, HUMAN RIGHTS, ISLAND COMMUNITIES, LOCAL GOVERNMENT, SUSTAINABLE DEVELOPMENT ETC.

Equal opportunities

70. The Bill strengthens the Living and Dying Well strategy, which is founded on equal access to palliative care for all those with life-limiting conditions. It contains a clear undertaking to tackle inequalities, supporting “an approach to care which is person centred and based on neither diagnosis nor prognosis but on patient and carer needs. It advocates an approach which recognises the diversity of life circumstances of people who will need palliative and end of life care and which is responsive to these circumstances, whether they relate to age, disability, gender, race, religion/belief or sexual orientation.”

71. The provisions in the Bill are aimed at supporting the strategy which seeks to improve services for vulnerable groups such as older people, people with life-limiting conditions and their carers. The greater numbers of older people requiring palliative care services in the future means that the Bill’s provisions are of particular relevance to older people. Advances in healthcare also mean more children with life-limiting conditions are living longer with associated palliative care needs. Raising the profile of palliative care services via the Bill could also benefit some ethnic and social groups.

Human rights

72. The provisions of the Bill are considered to be compatible with the European Convention on Human Rights. Two main issues were considered in this regard. First, the Bill makes provision which will necessitate the collection of information on the provision of palliative care. The collection of information by the State can, in some circumstances, give rise to issues under article 8 (right to respect for private and family life) of the Convention. Any interference with the rights protected by this article must be in accordance with and prescribed by law, for a legitimate aim and must be necessary and proportionate. To the extent that the collection of this information would impact on article 8 rights it is considered that each of these tests is met.

73. Consideration was also given to whether or not the reporting requirements would trigger article 8 issues, however, the view is taken that they do not. This is because the indicators on which information will be provided do not require the publication of information about individuals. Further, specific provision is made in the Bill confirming that the reporting requirement does not authorise the disclosure of information relating to any person, living or deceased.

Island communities

74. The Bill has no differential impact on the island communities. In practical terms this means that in line with the Government’s Living and Dying Well strategy access to palliative care services will improve for those living in island communities as currently these areas are less well served.

This document relates to the Palliative Care (Scotland) Bill (SP Bill 50) as introduced in the Scottish Parliament on 1 June 2010

Local government

75. Included in the Bill’s indicators are two which relate to care assessments carried out by local authorities. Local authorities will be expected to work with health boards in providing the required information.

Sustainable development

76. The Bill has no significant impact on sustainable development although it will contribute to sustainable communities in meeting the palliative care needs of patients and their families.
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PALLIATIVE CARE (SCOTLAND) BILL

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