Introduction

1. This Memorandum has been prepared by the Scottish Government to assist consideration by the Scottish Parliament Health and Sport Committee of the Palliative Care (Scotland) Bill, which was introduced by Gil Paterson on 1 June 2010.

Background

2. The aim of the Bill is to place a statutory requirement on the Scottish Ministers and through them, NHS Boards to provide palliative care for every person with a condition, illness or disease that is progressive, fatal and cannot be reversed by treatment; for that person’s family members and, also sets up reporting arrangements which requires Scottish Ministers to report annually on the provision of palliative care. The Bill specifies indicators with the aim that the quality of care provided can be monitored.

3. The Bill reflects the Scottish Government’s expectations contained within ‘Living and Dying Well’ Scotland’s first national action plan for the provision of palliative care which aims to ensure that palliative and end of life care is available for patients, their families and carers, however the Bill places a legal duty on the Scottish Ministers to provide such care. ‘Living and Dying Well’ ensures that palliative and end of life care will be available regardless of diagnosis or location and wherever possible, allows for the patient to be treated at the location of their choice. This may also mean that the patient can chose to die at home if this is their wish and is practicable in accordance with their clinical needs.

4. To make this a legal duty, the Bill amends Section 48 of the National Health Service (Scotland) Act 1978 making it an additional requirement of Scottish Ministers to ensure the provision of palliative care to persons with a life-limiting condition and to their families and goes on to make it a further legal duty on the Scottish Ministers to report to the Scottish Parliament providing details of palliative care provision. One of the objectives of the Bill is to raise the priority of palliative care services in line with ‘Living and Dying Well’ by creating a specific duty on Scottish Ministers to provide or secure palliative and end of life care for anyone who needs it.

5. The 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 Scottish Parliament which compiles the information submitted by frontline providers to enable the Scottish Parliament to scrutinise, compare and contrast the delivery of palliative care services nationwide.
Consultation

6. The consultation exercise on these proposals was originally undertaken by Roseanna Cunningham MSP and on her appointment to the Scottish Government, Gil Paterson MSP took over the process which ran from 14 November 2009 to 9 March 2010 and considered the consultation responses. A total of 370 copies of consultation document were issued to organisations, MSPs and MPs with an interest in the issue and further copies were provided in response to individual requests. The consultation document was also made available from a link on the proposals for Members’ Bills webpage on the Scottish Parliament website.

7. The consultation exercise resulted in 106 formal responses being received, the breakdown being as follows, 59 individual responses were received, 23 from health professionals, 9 from hospices and charities, 5 from forums and groups, 4 from church organisations, 3 from societies and 3 from local authorities.

Financial Impact

8. The Financial Memorandum to the Bill indicates that the financial implications of the provisions are based on the costs of implementing the recommendations contained within ‘Living and Dying Well’ and also on what information is currently being collected by NHS Boards.

9. The Audit Scotland report into palliative care service in Scotland, which is referred to in the Financial Memorandum, indicated that palliative care associated with primary care and more general acute care was undertaken by generalists and that these costs are more difficult to determine as they are embedded in the existing work of staff working in health and social care. Information on the cost of generalist palliative care provision is not held centrally with this funding included in Board allocations.

10. Additional funding of £3m has been provided for generalist palliative care provision through Action Point 14 of ‘Living and Dying Well’ which stated that additional funding would be provided to support improvements in generalist palliative care through a Direct Enhanced Services (DES) for palliative care which was launched in November 2008. GP Practices were able to add patients with palliative and end of life care needs (irrespective of diagnosis) onto their Quality and Outcomes Framework palliative care register. A further £1.12m over the 2008-09 and 2009-10 financial years was provided for the development and implementation of the actions set out in ‘Living and Dying Well’ individual NHS Board delivery plans across all care settings.

11. Funding for specialist palliative care which relates to care provided through specialist teams by the NHS and specialist care commissioned from hospices is quoted as amounting to £59m in 2006/07 of which £32.8m was met by public donations to individual hospices. The remainder is provided by NHS Boards through the current funding agreement which allows for NHS Boards to fund hospices up to 50% of agreed running costs (HDL(2003)18 Funding of Specialist Palliative Care Provided by Independent Voluntary Hospices in Scotland) and which is currently under review.
12. The funding details provided in the Financial Memorandum reflect spending by the Department of Health (England) and whilst a figure of £198m for 2010/11 is quoted, a survey conducted by the National Council for Palliative Care found that 35% of Primary Care Trusts who responded were unable to identify how much they spend on end of life care in 2009/10. The assumption that a simple 11% comparison can provide corresponding expenditure in Scotland is potentially not reflective of the true position. It should also be noted that stemming from the requirements of ‘Living and Dying Well’, Delivery Plans were produced by NHS Boards in Scotland. A one-off amount of £25k was provided to each NHS Board to support this work. However, as indicated there will be initial set up and running costs associated with the production performance indicators and reporting systems. It will be necessary for NHS Boards to consider the financial implications of additional statutory requirements which extend beyond the range of services currently provided.

Scottish Government’s Position

13. The Scottish Government is not planning on bringing forward legislation in respect of the provision of palliative and end of life care and the UK Government has no plans to introduce such legislation. We consider there are sufficient existing legal powers and policy arrangements to ensure the development of palliative and end of life care services in common with other NHS services. The Bill recognises and acknowledges the messages and recommendations contained within ‘Living and Dying Well’, the Scottish Government’s action plan for the provision of palliative and end of life care in Scotland.

14. ‘Living and Dying Well’ sets out the Scottish Government’s vision of how this care should be provided and fully commits NHS Boards to the provision of palliative and end of life care, regardless of diagnosis or location and has been accepted by NHS Boards and voluntary sector and local authority stakeholders. The proposal to make this provision a statutory obligation may limit the flexibility of NHS Boards to plan and provide palliative and end of life care services in accordance with local circumstances.

15. Since the publication of ‘Living and Dying Well’ in October 2008, NHSScotland with key stakeholders, has been working to implement the actions set out in the action plan. All NHS territorial and applicable special NHS Boards now have a delivery plan against each of the actions. We are currently preparing an update to ‘Living and Dying Well’ that incorporates the reports from a series short life working groups supporting the implementation of ‘Living and Dying Well’ as well as the various related work programmes. This paper will include a number of additional actions for NHS Boards and key stakeholders to review/implement through their ‘Living and Dying Well’ delivery plans.

16. Alongside this, further examples of the development work continue including an educational care package through NHS Education Scotland. The NHSScotland Do Not Attempt Cardiopulmonary Resuscitation Policy was published in May 2010 and the national roll out of the electronic palliative care summary (ePCS) continues. Linkages have been made to related work programmes including Care Homes, dementia, reshaping older people’s services and the Healthcare Quality Strategy for NHSScotland. As we finalise the outputs from the working groups, the key
recommendations, as well as potential measures to demonstrate continuous, sustainable improvement will be developed and implemented as part of the NHS Quality Improvement Scotland Implementation and Improvement Programme for Palliative and End of Life Care.

17. The Bill reflects the existing policy agenda established in the Better Health, Better Care Action Plan and the NHSScotland Healthcare Quality Strategy which will be delivered through Scotland’s national action plan for the provision of palliative and end of life care (‘Living and Dying Well’). Palliative care has moved rapidly to become a substantive area of development; and an issue which has received significant attention from the Scottish Parliament Audit Committee, Audit Scotland and the media.

18. Current legislation and administrative arrangements have been used as the basis for the implementation of the action plan. From a policy perspective we are confident that the proposals underpinning the Bill are already accommodated within ‘Living and Dying Well’, our existing strategic plans and implementation arrangements.

Conclusion

19. In summary, current legislation already imposes duties to secure the care and treatment of illness and enables a range of facilities and the finance for these to be provided. This applies to palliative and end of life care as it applies to other treatment. The proposed Bill goes a step further however and would make it an express statutory obligation for Boards to provide this care. Existing work in relation to the implementation of ‘Living and Dying Well’ is expected to lead to a more equitable and improved service being provided and which will be maintained through NHS Board lead officials and palliative care delivery plans.

20. This Bill will place special duties, both in relation to service provision and reporting, on Ministers/Health Boards in relation to palliative care which is just one of many types of care provided by NHSScotland. The Bill could initiate the situation where advocates of particular types of care seek to get a corresponding duty placed on Ministers/Boards as a means of securing priority for their favoured service resulting in a small number of services being marginalised.

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