Palliative Care (Scotland) Bill

Marie Curie Cancer Care

I am delighted to have the chance, on behalf of Marie Curie Cancer Care, to submit Stage One Evidence on the Palliative Care Bill.

As you know, this charity is passionate about and has long promoted the improvement of palliative and end of life care services. In addition to providing care and support for people at the end of their lives, we are also committed to addressing the inequities of access to and provision of care and support for these people, and their families and carers. Through the delivery of care in our hospices and within people’s homes we continue to work alongside many others to remove the obstacles to dying in the place of an individual’s preference.

Therefore we welcome the intentions of the Palliative Care Bill. In particular, we welcome the commitment to the universal provision of high quality palliative care continued support for collaborative, inclusive working across organisations and sectors to jointly drive and deliver what people and the end of their lives, and their families and carers need.

We see the intentions of what is in the Bill as one piece of the jigsaw of improvement on which the NHS and partnership organisations has embarked. Against this background, we support the way in which Palliative Care Bill supports individuals’ preferences at the end of their life through continued improvements in the delivery of high quality palliative care.

We understand that there are challenges around ensuring sustained momentum in further improving palliative care services, particularly in light of significant pressures on public services. Whilst we acknowledge that there are practical challenges to achieving this ambition, we believe that it should still be possible to access high quality palliative and end of life care, in the place of your choice even in times of economic uncertainty.

Of course, it is crucial that access to and provision of high quality palliative and end of life care is supported by consistent practice. For example, people’s ability to exercise the right to choose to die at home is dependent on them being able to make informed decisions, which reflect their preferences, and taking into account their needs and those of their families and carers.

The provision of high quality palliative care is most meaningful when people understand and know how to access these services. In this respect, it is therefore very important that we continue implementing the Living and Dying Well strategy and the findings emerging from this programme of partnership work.

The attached note makes some comments as invited on the Palliative Care Bill based on the consultation questions provided. The charity is happy for these comments to be published in accordance with usual procedures.
Marie Curie is delighted to support patients and their families and carers through the nursing service and hospice care. We offer our support to the Scottish Government in its continued commitment to ensure that people at the end of their lives have the high quality care and support they need at the end of their life in the place of their choice.

**Introduction**
Marie Curie Cancer Care believes that everyone with cancer and other illnesses should have the high quality care and support they need at the end of their life in the place of their choice. Marie Curie Cancer Care is one of the UK’s largest charities. Every year the charity provides care to around 5,500 patients and their families at home and in hospices in Scotland - free of charge to individuals. This equates to about 50% of all cancer patients who die at home in Scotland and to achieve this Marie Curie Cancer Care employs approximately 2,000 nurses.

As a result Marie Curie Cancer Care spends £15 million directly on palliative care in Scotland per annum. Our services are delivered in partnership with funding from the NHS, other voluntary sector providers and our supporters. Care and support is always free of charge to patients, families and carers.

**Background to Marie Curie Cancer Care**
Employing more than 2,700 nurses, doctors and other healthcare professionals, it expects to provide care to around 32,000 terminally ill patients in the community and in its hospices this year and is the largest provider of hospice beds outside the NHS. Around 70 per cent of the charity’s income comes from the generous support of thousands of individuals, membership organisations and businesses, with the balance of our funds coming from the NHS.

**Marie Curie Cancer Care’s Services**
The charity is known for its network of Marie Curie Nurses working in the community to provide end-of-life care, totally free for patients in their own homes. Marie Curie Cancer Care has two hospices in Scotland, one in Edinburgh and one in Glasgow. Through the hospices, the charity offers specialist care for people with cancer and other illnesses and their families. The hospices provide a combination of day services, in-patient care, care in the home, social, spiritual and family support and bereavement support. Marie Curie Cancer Care hospices actively promote quality of life and provide support for their families, completely free.

**Supporting the choice to die at home**
Research shows around two thirds of people in Scotland would like to die at home if they had a terminal illness, with a sizeable minority opting for hospice care. However, more than 50 per cent of cancer deaths still occur in hospital, the place people say they would least like to be. Since 2004 Marie Curie Cancer Care has been campaigning for more patients to be able to make the choice to be cared for and die at home.
Research
The charity undertakes palliative care research to find better ways of caring for people at the end of life. The charity has three centres for palliative care research: The Marie Curie Palliative Care Research Unit at University College London, The Marie Curie Palliative Care Institute in Liverpool and The Marie Curie Palliative Care Institute in the Wales Cancer Trials Unit. The charity also funds seven fundamental scientific research groups which investigate the causes and treatments of cancer. This research was previously carried out at the Marie Curie Research Institute in Oxted, Surrey. The programmes are now located in universities around the country, and will receive funding from the charity until 2012.

CONSULTATION QUESTIONS

Question 1: Do you agree or disagree with the general principles of the Bill?

Marie Curie Cancer Care supports the intentions behind the Bill and for continued implementation of the outcomes and ongoing work within Living and Dying Well. We are committed to improving the care provided to patients and their families at the end of their lives and consider the ongoing interaction between patients, palliative care providers, umbrella organisations, MSPs and the Scottish Government to be invaluable in achieving this goal.

We support the Scottish Government’s publication of Living and Dying Well and its aim to ensure that high quality palliative and end of life care is available in a consistent, comprehensive and appropriate manner across all care settings in Scotland. We are very much engaged in and fully supportive of the implementation of Living and Dying Well and welcome measures to monitor and further progress, such as appointment of a National Clinical Lead, NHS Board Executive Leads and a National Advisory Group. The work of these bodies is progressing well, and Marie Curie Cancer Care is participating closely to ensure that the relevant bodies learn and benefit from our experience and expertise.

The many organisations that make up Scotland’s palliative care community are using the Living and Dying Well strategy implementation process to develop ways of working that optimise effective delivery of palliative care in Scotland. This process is a work in progress; for example, the report of the outputs of the Living and Dying Well short life working groups will be published in September 2010. The recommendations coming out of this work will provide clear evidence to help inform further planning and addressing key areas of work in order to improve the access to and provision of high quality palliative and end of life care in all settings, across all agencies.

We ask that those considering the Palliative Care (Scotland) Bill look at all activity currently underway within the Living and Dying Well Programme and to use the evidence and findings emerging to directly inform any and all further work in driving further improvements in caring for people at the end of their lives.
Question 2: Do you believe that 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 continued progress of the Living and Dying Well strategy suggests that it may not be necessary to create a specific duty on the provision of palliative care. Marie Curie Cancer Care suggests that the Scottish Government examine the outcomes from the Living and Dying Well strategy in order to ensure that the creation of any additional statutes sits alongside this process, which is currently working well and provides a wealth of evidence and insight. It is worth noting that additional to the Scottish Government’s strategy the General Medical Council’s new guidance for doctors, ‘Treatment and care towards the end of life: good practice in decision making’, came into effect on 1 July 2010.

Question 3: Do you have any comments on the provisions concerning reporting and indicators contained in the Bill?

Marie Curie Cancer Care welcomes the call for robust, statutory reporting and the wide involvement of all those involved in providing care and support to people at the end of their lives. The collation of high quality information, analysis and reports – in conjunction with solid needs-based assessment of the population are crucial to effectively inform the planning of services. We would like to suggest the possibility that the existing reporting processes established through the implementation of the Living and Dying Well strategy are extended and reinforced. For example, the NHS Quality Strategy includes National Quality Outcome Measure “Percentage of last 12 months of life spent in preferred place of care” with the explicit purpose of capturing the outcomes of the impact of work within Living and Dying Well.

Question 4: Are you content with the definitions contained in the Bill, particularly that of ‘palliative care’?

Marie Curie Cancer Care welcomes the definition of palliative care set out in the Bill, particularly as it accords with that set out in Living and Dying Well. We recognise that the Bill will place a statutory duty on Scottish Ministers to provide for universal access to palliative care, which may, in future, require proposals which seek to tackle remaining inequities in access to and provision of services. Marie Curie Cancer Care is fully committed to addressing inequity in access to and provision of care and support for people at the end of life. The quality of care and support should not be dependent on an individual’s diagnosis or condition i.e. cancer vs. non-cancer.

We particularly welcome the term ‘life-limiting illness’ with regard to palliative care, as this means that the necessity of palliative care will be judged according to the need of the patient and their ability to benefit from palliative care.
Question 5: do you have any comment on the costs identified in the Financial Memorandum?

Marie Curie Cancer Care would welcome further clarity on the provisions set out in the Financial Memorandum that increased demand might be met through generalist palliative care and increased care in the community by setting out a more explicit definition of what and who this care might be provided by. For example, the voluntary sector provides a wide range of services in conjunction with other partners, such as the NHS. These services range from hospice-based care to palliative care provided both specialist and generalist staff within the community.

Marie Curie Cancer Care is dedicated to supporting patient choice regarding how and where people are cared for at the end of their life. This includes choice of place of death, which, more often than not, is an individual’s own residence. To this end, our nursing services are mobile and in the community and our nurses aim to be with patients at the time of their death in the place of their choosing. With the amount of people dying set to increase year-on-year, and as people live longer with terminal conditions, the demand for services will continue to grow and we remain committed to supporting the needs of people at the end of their lives in the place of their choice.

Marie Curie Cancer Care would welcome the mandatory collection of information on the nature, the volume and the outcomes of the provision of palliative and end of life care services. We particularly welcome the inclusion of indicator 9, which seeks to collect information on the psychological, social and spiritual support provided to patients and their family members and carers. Evidence demonstrates that care and support of this nature has a significant impact on the health and well-being of people at the end of their life and their family and carers. We ask for further clarity on the reporting duties tied to all indicators, and, in particular the scope of indicator 9.

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