

Response to Lords debate on Palliative Care

About this briefing

On 31st January 2007 the House of Lords debated the issue of palliative care provision in response to a question laid down by Baroness Jay of Paddington:

“Baroness Jay of Paddington asked Her Majesty’s Government how they assess the effectiveness of palliative care services; and on what basis decisions to fund additional services are taken.”

The subsequent debate saw a range of views put forward regarding the issue of palliative care provision and touched on the issue of choice at the end of life, with respect to assisted dying.

Help the Hospices believes it is extremely welcome for palliative care to be debated in such a broad and informative context, but was concerned that some sentiments expressed in the debate seem to come from a misunderstanding about the nature of palliative care. This briefing seeks to contribute to the ongoing debate, and to provide further insight in to the issues raised.

Both Houses of Parliament are due to debate Private Members Bills on palliative care on Friday 23rd February 2007. In the House of Lords, Baroness Finlay’s Palliative Care Bill is due to receive its second reading, while in the House of Commons, the Provision of Palliative Care Bill, tabled by Jim Dobbin, MP, is also timetabled to receive its second reading. Hospices might want to consider contacting their local MP, or any members of the House of Lords with whom they have contact, to share their thoughts on the Bills. We hope that the contents of this briefing will help you to do so.

If you have any comments or questions please contact Hazel Cheeseman, Policy and Public Affairs Officer, Help the Hospices, h.cheeseman@helpthehospices.org.uk.

Measuring the effectiveness of holistic palliative care

Concerns were raised by a number of peers during the debate that assessing the effectiveness of palliation was not feasible using current commonly understood notions of what palliation might mean. Baroness Jay cited what she described as ‘mission creep’¹ from an original objective of clinical pain relief to one which encompassed: “psychological, social and spiritual help and support.”² She was concerned that such interventions could not be effectively evaluated.

The origins of modern palliative care were not as narrowly defined as Baroness Jay implied and were, instead, built on the notion that end of life care should be holistic. Dame Cecily Saunders, the founder of the modern hospice movement and a pioneer in palliative medicine, saw pain that was physical at the end of life as compounded by ‘total pain’, pain which is emotional, social and spiritual. Far from ‘mission creep’, the wider adoption of this notion of pain is moving society some way towards fulfilling the objectives of those original visionaries. Aside from what the original objectives of

¹ HL Deb 31 Jan 2007 c307

² HL Deb 31 Jan 2007 c307

palliative care might have been, the notion that the holistic elements of palliative care should be divorced from each other seems to contradict the current trend in government thinking. Elsewhere in medical and social care, the Government extols the virtues of 'joined up thinking' and is actively seeking to create holistic models of care. It would seem strange in this context then to dismantle one of the few active examples of such an holistic approach in our current system.

Research would suggest that it is both relevant and necessary to address the needs of patients beyond pain relief. These other aspects of palliative care can be seen as not merely additional to clinical outcomes but in fact be part of achieving them:

*"King et al reported that 71% of people who entered their acute hospital study had an important spiritual belief, even though many did not express that in a religious way. Other studies confirm this proportion and are beginning to show the importance of spiritual belief in predicting clinical outcome, the management of death distress, end of life despair, and assessing quality of life in oncology patients."*³

Elements beyond the clinical removal of pain are not only important to the way in which patients experience palliative care (studies show that patients identify a wide range of non-medical interventions as important⁴) but their effects are also measurable. Quasi scientific methods can be used to assess outcomes, for example the use of 'proxys' or the recently developed McGill Quality of Life Questionnaire (MQOL)⁵.

Similar claims were made that there was a gap between the rhetoric of what palliative care professionals claimed to be able to deliver and the reality of the suffering of patients. It was stated that: "We need to be more honest and open about real clinical practice – about what it can and cannot achieve." (Baroness Murphy)⁶.

Baroness Murphy, in her critique of the limitations of palliation, described a variety of symptoms that are not easily controlled by palliative intervention. However, good palliative care can in fact make a significant contribution. For example, Baroness Murphy raised the issue of side effects from opiates. While such side effects are possible it will not be necessary for all patients to receive pain relief via opiates and even those who do can have the side effects moderated by good palliative interventions such as using a variety of drug therapies. Baroness Murphy also described a variety of unpleasant symptoms that patients can experience, but again much of what she described can be controlled through good palliative intervention, significantly limit their impact. For example, the use of specialist dressings and antibiotics to treat necrotic flesh can help to reduce unpleasant odours.

³ Speck, P., Higginson, I. and Addington-Hall, J. (2004) [Editorial: Spiritual needs in health care: May be distinct from religious ones and integral to palliative care.](#) *British Medical Journal*, 329, 123-124.

⁴ Aspinal, F., Hughes, R., Dunckley, M. and Addington-Hall, J. (2006) [What is important to measure in the last months and weeks of life?: A modified nominal group study.](#) *International Journal of Nursing Studies*, 43, (4), 393-403.

⁵ SR Cohen, BM Mount, MG Strobel, F Bui - Palliat Med, 1995 - ncbi.nlm.nih.gov
The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease.

⁶ HL Deb 31 Jan 2007 c316

Others in the debate suggested that there that there might be an absence or resistance to 'rigorous analysis'⁷ of the palliative care processes from those currently within the movement. Hospices and palliative care teams undergo comprehensive reporting and inspection processes, and any suggestion that that palliative care is not 'rigorously' analysed would come as a surprise to many professionals. Although there is much acknowledgement that the level of academic research and evaluation of palliative care services is far below that of other medical fields, this situation endures not because of a resistance to intellectual interrogation of palliative care practice but to chronic under funding and the relative youth of the discipline⁸.

While it is true that there are limits to the effectiveness of palliative interventions, as there is with any intervention medical or otherwise, there is much evidence that palliative care as a holistic model can significantly improve outcomes for patients, carers and relatives. Such outcomes can produce better wellbeing in our society and 'better deaths'. These are outcomes which should be aspired to. Measuring the effectiveness of interventions at the end of life cannot and should not be a simple measure of direct cause and effect, dependant as it is on personal experiences. As Albert Einstein said: "*not everything that matters can be measured, and not everything that can be measured matters.*"

The extent and nature of palliative care provision

The debate raised some questions about the appropriate level of specialist palliative care. Lord Joffe asserted that what he describes as the 'Rolls-Royce'⁹ model of palliative care (holistic specialist palliative care) is 'far more expensive'¹⁰ than the less comprehensive alternative.

There is agreement that there is a need for more research into palliative care, and there is evidence that would suggest that specialist interventions can cost more. However, the evidence also indicates that such interventions can have outcomes which ultimately reduce the cost burden on the NHS:

*"...when compared to conventional care, there is evidence that specialist teams in palliative care improve satisfaction and identify and deal with more patient and family needs. Moreover, multiprofessional approaches to palliative care reduce the overall cost of care by reducing the amount of time patients spend in acute hospital settings."*¹¹

Quite apart from the question about whether specialist interventions cost of save the NHS money, there is a bigger question about the standard or care which can and should be acceptable at a minimum for all those at the end of life. There is evidence that

⁷ HL Deb 31 Jan 2007 c317

⁸ The Cancer Experiences Research Collaborative (CECo): building research capacity in supportive and palliative care. Christopher Bailey, Roger Wilson, Julia Addington-Hall, Shelia Payne, David Clark, Mari Lloyd-Williams, Alex Molassiotis, Jane Seymour, *Progress in Palliative Care*, 13:6, 2006

⁹ HL Deb 31 Jan 2007 c318

¹⁰ HL Deb 31 Jan 2007 c318

¹¹ Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature ... - J Hearn, IJ Higginson - *Palliative Medicine*, 1998 - pmj.sagepub.com

specialist palliative care interventions can significantly alter the experiences of people at the end of life beyond what they experience through generalist practice:

“In the interviews patients indicated that they had experienced changes in physical, emotional and interpersonal status, in spiritual outlook, and in their preparation for death. They also described the impact of the palliative care unit environment.”¹²

Definition of choice

The debate appeared to closely associate the issue of patient choice at the end of life specifically to the choice of when to die. This represents only one aspect of choice which, were the law to change, would still continue to effect only a small proportion of those at the end of life. There are much broader considerations relating to choice for the majority, covering such issues as type and location of care, which must not be ignored.

The validity of palliative care is sometimes questioned by those who advocate a change in the law around assisted dying. Help the Hospices does not seek to take a view on either side of the debate about assisted dying. However, advocating for increased provision of high quality palliative care should not be seen to place it on one side of that specific debate. Better palliative care should be the priority for all those concerned with end of life care, as without it, choice for those suffering from terminal illness becomes non-existent.

Inaccuracies regarding hospice care

The debate included several statements about hospice care which also require clarification.

Figures quoted suggested that hospices were only involved in 4% of patient deaths. While it is true that only 4% of patients die in a hospice, this is because the role of the hospice is to get people well and stable enough that they can go home and die. In 2005/06 home care teams saw more than 140,000 patients. It is misleading to evaluate the effectiveness of hospice care simply on the basis of the number of people who die in a hospice, as this provides a very limited picture of the contribution that hospices make.

In his closing statement, Lord Hunt quoted a Help the Hospices survey which stated that the Government contributes 38% of hospices expenditure. This figure is not correct. Help the Hospices is not aware of a study they have conducted with this conclusion. Based on the information provided by independent charitable hospices, we maintain that the average government contribution is 33% of hospice expenditure, but recognize that this figure varies wildly across the country.

¹² Changes in quality of life following admission to palliative care units
SR Cohen, P Boston, BM Mount, P Porterfield - Palliative Medicine, 2001