Defining dedicated palliative care

A summary of the views of local independent charitable hospices

About this paper

Help the Hospices understands the importance of putting some boundaries around the scope of the review, and we are pleased to have the opportunity to submit a collective hospice view on ‘dedicated palliative care’.

Help the Hospices is pleased that the review has sought to avoid the unhelpful and distracting debate about specialist versus generalist services.

Following the announcement of the Palliative Care Funding Review, and the stakeholder event held on 3 September 2010, throughout September, we canvassed the views of our member hospices on the definition of ‘dedicated palliative care’. This paper is a composite of the comments we received.

The value of existing definitions of palliative care

Some of our members expressed concern about the prospect of yet another term being used to describe palliative care. While we appreciate the need for the review to put some boundaries around the services that will eventually fall within the new funding system, hospices question the value of creating a wholly new terminology around ‘dedicated’ palliative care.

Internationally recognised definitions of palliative care, such as those developed by the World Health Organization and NICE, remain highly relevant, particularly given they do not seek to define palliative care in narrow health terms. Both definitions reflect the physical, social, psychological and spiritual components of palliative care, which must not be lost in the definition of ‘dedicated palliative care’.

We recommend that the review considers the definition of ‘agreed services’ used by the NHS in Scotland. Although we would not support a wholesale shift to the approach taken by the NHS in Scotland, the framework in Scotland does provide some useful points to consider.

An underlying assumption

Our starting position, and the underlying assumption that underpins the comments in this paper, is that it is the state’s responsibility to be an enabler of good care, and to make sure its citizens have everything they need at a time when they are most vulnerable and to create the climate to enable individuals to take responsibility.
The state’s responsibility and the importance of social care

The terms of reference for the review talk in terms of defining the ‘NHS responsibilities’ for meeting palliative care needs. In our view, this is a dangerous restriction, which overlooks the significance of social and emotional care and support, and would be a significant narrowing of the internationally recognised definitions of palliative care.

We strongly recommend that in defining ‘dedicated palliative care’, the review should use an approach that takes people’s needs as its starting point, not a narrow organisational or provider perspective, and must include the responsibility of local authority resourced social care.

A framework for defining dedicated palliative care

As a framework for defining dedicated palliative care, we would suggest the following components:

**The definition should:**

- be patient and carer focused, based on a person’s needs, and reflect physical, social, psychological and spiritual dimensions
- encompass all those diagnosed with an incurable, progressive and life-limiting condition
- recognise that palliative care is frequently provided in parallel with curative treatment
- include care and support across the spectrum of health and social care
- seek to incorporate those services and individuals that work primarily in providing palliative care
- reflect quality and outcomes in care without adopting crude indicators, such as the location of death
- reflect the fact that care can be delivered at various points along the end of life care pathway described in the End of Life Care Strategy
- facilitate choice in a range of care settings, by including care provided by a spectrum of service providers in the statutory, voluntary and commercial sectors
- reflect the expertise and skill of the care professionals providing the care and support
- recognise the importance of support for carers and the bereaved.
The definition should not:

- use arbitrary time limits, such as the last year of life
- adopt a narrow medical approach that seeks to define ‘dedicated palliative care’ in terms of the presence of medical specialists or treatments
- be based on diagnosis or prognosis
- be restricted to a narrow definition of ‘NHS responsibility’.

Identifying the services to be included in a definition

Help the Hospices believes that the workforce description included in the End of Life Care Strategy provides a useful framework for determining which services should be included in a definition of ‘dedicated palliative care’.

The strategy segmented the workforce into three categories, and we believe there is merit in applying the same logic to identifying the services that should fall within the definition of ‘dedicated palliative care’. The three categories consist of:

1. services focusing exclusively on meeting palliative care needs, such as hospices, hospital palliative care teams, specialist community nursing services, care homes, etc
2. services that play a major role in meeting palliative care needs, such as GPs, district nurses, etc
3. services that play a minor supporting role in meeting palliative care needs.

We recommend that the definition of ‘dedicated palliative care’ should include all services and support provided in the first category.

In our view, dedicated palliative care should include the teams who spend most of their time dedicated to working with palliative care patients and families in all settings.

Reflecting the expert nature of palliative care

In our view, the definition should also include the expert advice and support that palliative care services provide to the rest of the health and care economy. In particular, it is essential that the definition includes the delivery of evidence-based education and training to the wider workforce, and the provision of palliative care advice lines.

We believe dedicated palliative care should include palliative care coordination, and the education, training and support that services provide to other care providers who spend part of their time working with palliative care patients and families.
The potential to use end of life care registers

One of the important outcomes from the implementation of the End of Life Care Strategy has been the development of end of life care registers, particularly those based on the Gold Standards Framework. Member views on the potential value of these registers in supporting a definition of ‘dedicated palliative care’ were mixed. In particular, there was some discussion about their potential value in providing a ‘trigger’ for the definition.

About Help the Hospices

Help the Hospices is the leading charity supporting hospice care throughout the UK. We want the very best care for everyone facing the end of life.

The majority of hospice care in the UK is provided by our member hospices. Care is given free of charge to the patient and their friends and family. It can be at home, in the hospice and in the community and can be for days, months or years. We are here to represent and support our members. We work with our members and other organisations as they strive to grow and improve hospice and palliative care throughout the UK and across the world.

Our services are here to support hospice people and champion the voice of hospice care. They include a wide range of training and education programmes, informative and practical resources for hospice staff, work to influence government policy and support for quality care and good practice.

For more information

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October 2010