

PALLIATIVE CARE FUNDING REVIEW

NCPC SUBMISSION TO INTERIM REPORT: “DEDICATED PALLIATIVE CARE” - A DEFINITION, OCTOBER 2010

1. CONTEXT

1.1 Purpose of review

The government has established the Palliative Care Funding Review with the following terms of reference:

- To make recommendations on a funding mechanism for dedicated palliative care which is fair to all sectors, including the voluntary sector
- Encourages the development of community-based palliative care services.
- Supports the exercise of choice by care users of provider and of location of palliative care provision.

It is clearly essential that all the work of the Review is set within the context of current health and social care commissioning and funding reforms to ensure that its final recommendations complement rather than conflict with other funding mechanisms and approaches. However, the initial task is to define “dedicated palliative care.” We believe that this should be done separately from considering the funding mechanism for the reasons set out below and consequently we welcome the Review team’s decision to take this task first.

1.2 Approaching from the point of individual need

The starting point for defining dedicated palliative care should be the needs of the person or people receiving the care, rather than the services delivering it. Consequently, this submission focuses on how we might define dedicated palliative care. It raises some areas which will need to be considered for the development of a funding mechanism. It does not, however, consider the implications of any

particular definition of dedicated palliative care on what a funding mechanism should look like or on which services might be involved in the delivery of care. We will look at these areas in more detail at a later stage to support the second phase of the Review's work. This is to avoid the risk of the definition being confined by the roles, functions and structures of existing services and professions, rather than enabling a refreshed approach which puts individual people at the heart of shaping services to meet their own needs and preferences in the setting of their choice. This focus on individual needs is vital if the Review is to be successful in facilitating the emergence and development of new community-based palliative care services and providers.

There will be occasions when a service falls within the final definition of dedicated palliative care but is provided by a non palliative care professional. This might either be within a generalist's role, such as a GP, District Nurse or social worker (other than a specialist palliative care social worker), or as part of another specialism, e.g. within a neurologist's work or a heart failure specialist nurse's role. It is important to remember that the majority of *end of life care* at least is not provided by staff whose working lives are dedicated to end of life care (see End of Life Care Strategy). This is another reason why the definition of dedicated palliative care must be based on the person's needs first rather than who provides the care or the care setting if the definition is really going to support choice of care. This does, however, create further challenges for the final funding mechanism to ensure it does not result in double payments and is clear as to how it complements other funding mechanisms, such as PbR and the QOF (see also 1.3 below).

Once there is an agreed definition of dedicated palliative care, we suggest there will be two stages necessary before developing the final funding mechanism:

- identifying the most common dedicated palliative care needs of people and their carers;
- determining what kinds of services are best able to meet those needs and developing standard service specifications.

There is more detailed discussion of these stages in NCPC's *End of Life Care: A commissioning perspective*, Peter Tebbit, 2007. We will consider these areas further in our contribution to the second stage of the Review. Service specifications will help address the question of which aspects of care provided by a non specialist palliative care service should be funded under the mechanism proposed by this review. Consideration of triggers and transition between different components and providers of dedicated palliative care will be essential to ensure a person's care does not become disjointed.

1.3 The wider reform context

It is essential that the Review should be mindful of the impact of the broader commissioning and funding structures being developed for health and social care on any emerging funding mechanism for dedicated palliative care. This will include both the introduction of personal budgets in health and social care, and also the recommendations of the Commission on the Funding of Care and Support, chaired by Andrew Dilnot. The overall objective of the government's reforms to health and social care, including palliative care, is to improve people's choice and control over the services they receive until the end of life. Considerable care must be taken to ensure that reform does not result in a multiplicity of new mechanisms that are incompatible, confusing or excessively bureaucratic. The

government will need to ensure that the final mechanisms adopted across health and social care are joined up, consistent and transparent, so that people can understand how they can exercise choice.

Considering one aspect of reform in isolation from the others risks unforeseen problems arising in the future. This may be an issue for the government rather than any one Review or Commission, however we suggest it would be helpful for the Review and the Dilnot Commission explicitly to acknowledge the whole of the wider agenda in their final recommendations, and will be writing in a similar vein to the Commission.

1.4 Pathway Approach

Any future funding mechanisms must also be able to follow the person along their whole pathway and make costings for that whole pathway, including social care and reflective of people's multiple conditions. The Motor Neurone Disease Association's Year of Care Pathway is a useful comparison.¹ Having a pathway approach should help to address questions of which aspects of care under claimed under 'dedicated palliative care' and which under, for example, neurology. It will be important to test any definition against a potential care pathway for people with a variety of, as well as multiple, conditions and consider how one might measure outcomes of dedicated palliative care.

1.5 The wider role of palliative care

It should also be acknowledged that there will be roles currently provided by 'palliative care services' (particularly specialist services) which may not be specifically referenced in a definition of dedicated palliative care but which will still need to be provided. These will include work which does not involve direct care service provision to people. The chief example of this is the essential role specialist palliative care services and staff provide in educating their non specialist palliative care colleagues. If the Review is to succeed in its aim to support increased choice by care users, account must be made for the need for education and training and resources to provide it. Without this, it will not be possible to develop the community capacity necessary to meet the aims of the Review and of the End of Life Care Strategy, nor of wider agendas such as QIPP. The proposed devolution of responsibility for education and training to provider level in the NHS White Paper increases the need for strong recommendations about its provision and funding to avoid it being viewed as an avoidable extra.

2. "DEDICATED" PALLIATIVE CARE

The key requirement of the definition is that it should enable a "national choice offer" for palliative care to be available to everyone with palliative care needs. An important aspect of that is to enable people to live, receive care, and die in the setting of their choice, which will in most cases be a community setting: their own home; some type of supported housing; or a care home.

¹ See http://www.mndassociation.org/for_professionals/sharing_good_practice/mnd_year_of_care.html

2.1 The NICE Guidance

We suggest that the starting point should be the 2004 Improving Supportive and Palliative Care for Adults with Cancer NICE guidance. The Review must clearly go wider than that to cover all conditions and to include children and young people. This will not only help avoid further variation in definitions between the two age groups, but also support transition care to be less disjointed than is often the case at present. It must also clearly include health and social care for it to reflect people's needs as they experience them, rather than be constricted by service structures.

The NICE guidance discussed "specialist" as well as "general" palliative care. We see "dedicated palliative care" as broader than "specialist palliative care." It therefore follows that the definition of dedicated palliative care should include everything that is included within "specialist palliative care." (See Appendix). This should be reflected in service specifications developed as part of the Review.

The NICE Guidance defines palliative care as follows:

The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the course of the illness in conjunction with other treatments.

The last sentence is particularly important to keep in mind. None of the NICE definition, the WHO version (2002), nor the ToR for the Dedicated Palliative Care Review refer to *end of life care* nor are they restricted to care for the dying. The definition of dedicated palliative care, therefore, should not assume dedicated palliative care is synonymous with end of life care. A person may have palliative care needs at diagnosis; for years before they approach the end of life; and/or alongside receiving curative care. If this is not acknowledged in the definition, any subsequent funding mechanism will jeopardise the provision of (dedicated) palliative care to people at an earlier stage in their condition. The recent evidence on the benefits of early palliative care interventions for people with lung cancer published in the New England Journal of Medicine reinforces this point.²

We believe that dedicated palliative care should cover the following needs of people living with progressive and or life-threatening conditions, or who are approaching or at the end of life:

- Services that are currently provided, and services that should be provided to enable people to be cared for and die in their place of choice (NB not just die in place of choice)
- All long-term life-threatening conditions (NICE guidance is only adults with cancer)
- Symptom control, psychological, spiritual & social support
- Advance care planning

² Temel, Jennifer S et al, "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer", N Engl J Med 2010;363:733-42. Copy attached.

- Need for 24/7 care to enable people to remain in their place of choice, in particular symptom control, nursing care, and specialist advice
- Key worker or co-ordinator (see EoLC strategy)
- Cohesion with services outside the scope of the funding review – seamless transition across all – funding the gateway to other services
- Integration of their health and social care, so that their whole care is planned holistically and consistently.

2.2 Creating a definition

An initial proposed definition has been one based around care provided by staff (specialist and non) who are devoting their working lives to end of life care such as those working in hospices, specialist palliative care teams (hospital and community) or for other dedicated services such as Marie Curie Nursing Service). There is much that is attractive about this idea but we believe it may be too limited in its reach.

It sounds too close to “specialist” palliative care to be broadening understanding. If somebody is spending their working life doing palliative care, presumably they are in reality a specialist or is it to be suggested that “specialist” should require accreditation or certification? Although palliative medicine is a recognised specialty, certification is less developed across other disciplines. The NICE Guidance said that ‘generalist’ or ‘specialist’ status will depend on the circumstances in which they work (see extract below). We believe that dedicated palliative care should be broader than specialist, i.e. should include everything within specialist palliative care plus some more. Dedicated palliative care will include the *purpose of a particular intervention/referral* being done at a given moment rather than being defined by the professional’s core job description e.g. a GP might provide dedicated palliative care in a session or a clinic but their working life would not be devoted to end of life care.

Instead, we propose the following definition of dedicated palliative care:

Care which enables people with progressive, and/or life threatening conditions or who are approaching the end of life to live according to their wishes and preferences wherever possible. The management of pain and other symptoms of non curable conditions and provision of psychological, social and spiritual support is paramount. It includes support for the person to plan their future care in anticipation of further deterioration and support for the person’s family and loved ones. Dedicated palliative care can be provided in any setting. It is not time bound but may be provided at any stage of the person’s care pathway and that of their carer(s).

We would be very happy to discuss any of the above and look forward to contributing to the ongoing work of the Review.

The National Council for Palliative Care
28 October 2010

APPENDIX

From NCPC website (drafted by Peter Tebbit)

Specialist Palliative Care Services are defined as follows:

Specialist Palliative Care Services

These services are provided by specialist multidisciplinary palliative care teams and include:

- Assessment, advice and care for patients and families in all care settings, including hospitals and care homes.
- Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams
- Intensive co-ordinated home support for patients with complex needs who wish to stay at home.
 - This may involve the specialist palliative care service providing specialist advice alongside the patient's own doctor and district nurse to enable someone to stay in their own home.
 - Many teams also now provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'.
- Day care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies.
- Advice and support to all the people involved in a patient's care.
- Bereavement support services which provide support for the people involved in a patient's care following the patient's death.
- Education and training in palliative care.

The specialist teams should include palliative medicine consultants and palliative care nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

FROM THE NICE GUIDANCE

The professionals involved in providing palliative care fall into two distinct categories:

- those providing day-to-day care to patients and carers
- those who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example), some of whom are accredited specialists.

Although palliative care encompasses many of the elements identified as 'supportive care', there are well-defined areas of expertise within specialist palliative care to which patients and carers may need access, such as interventions to respond to:

- unresolved symptoms and complex psychosocial issues for patients with advanced disease
- complex end-of-life issues
- complex bereavement issues.

Importantly, both palliative and supportive care are often provided by patients' family and other carers, and not exclusively by professionals.

Supportive and palliative care services

Supportive and palliative care services should be delivered, as much as possible, where patients and carers want them – in the community (including a patient's own home, but also care homes and community hospitals), in hospital, or in a hospice.

Patients, families and other carers should play the central role in making decisions about the care they receive. They may need support from health and social care professionals to help them to make decisions, to plan and evaluate their care, and to explore whether earlier decisions might need to be changed.

User empowerment must therefore underpin good supportive and palliative care. Not all patients have close family and carers, however. Health and social care professionals should be sensitive to the needs of patients and be prepared to encourage their potential to contribute to their own care.

A wide range of service providers is involved in delivering supportive and palliative care services, including those in primary care, secondary care and the voluntary and social sectors. Many work within multidisciplinary teams. Patients and carers also draw significant support from friends, family, support groups, volunteers and other community based non-statutory resources.

Providing supportive and palliative care should be an integral part of every health and social care professional's role, but for most, such care is likely to form only a small part of their workload. Many of these professionals are clearly 'generalists' in the field (general practitioners (GPs) and district nurses, for example), while others are specialists who may have received specific training and

qualifications in supportive and/or palliative care or acquired substantial practical experience. These specialists, frequently dedicating all or most of their time to the care of people with cancer, include:

- site-specific cancer nurse specialists
- cancer counsellors
- cancer information nurses/other professionals
- specialist allied health professionals
- physicians in palliative medicine and palliative care nurse specialists.

For others, their 'generalist' or 'specialist' status will depend on the circumstances in which they work. A local authority social worker, for example, may be a generalist working with a wide range of clients, while a social worker employed by a hospice will be working as a specialist in palliative care.

Patients' needs tend to fluctuate across the patient pathway, and services should remain flexible to address changes during each person's experience of cancer. The relative contributions of those involved in supportive and palliative care, including the contributions of patients and carers, are also liable to change.