

What do we mean by palliative care?

A discussion paper

It is necessary to revisit the National Council's definitions of palliative care in the light of the following factors:

- The development by the Department of Health of a supportive care strategy for cancer services in England and Wales.
- The commitment in the NHS Cancer Plan for England to securing agreement on the core elements of specialist palliative care that should be available to all patients.
- The development of national standards for palliative care in the context of cancer services and the Care Standards Act.

This paper discusses the possible options for change and their implications.

Introduction

In March 2000 the National Council approved a set of definitions of the principal elements of care provided to meet the full spectrum of palliative care need. Three elements were defined: General Palliative Care, Intermediate Palliative Care and Specialist Palliative Care.

General Palliative Care

This was defined as palliative care provided by all the usual professional carers of the patient/family as an integral part of routine clinical practice. It is provided for patients and families with low to moderate complexity of palliative care need in all care settings.

Intermediate Palliative Care

This was defined as palliative care provided by professional carers working full-time in palliative care but not accredited as specialists in palliative care. It is provided in hospices, some nursing homes, some community hospitals and patients' homes. It is provided for patients and families with low to moderate complexity of palliative care need.

Specialist Palliative Care

This was defined as palliative care provided by accredited specialists in palliative care who are working in multi-professional specialist palliative care teams. It is provided in specialist palliative care units, some hospices and patients' homes. It is provided for patients and families with high complexity of palliative care need.

Intermediate Care in the NHS

Since agreement on those definitions was reached the NHS has launched a national initiative to provide and develop intermediate care facilities. Intermediate care is defined by the NHS as a whole system approach to a range of multidisciplinary, multi-agency services designed to promote independence by:

- Reducing avoidable hospital admissions to acute hospitals
- Facilitating timely discharge from acute hospital and promoting effective rehabilitation
- Minimising premature or avoidable dependence on long term care in institutional settings

While it is clear that palliative care services can make an important contribution to intermediate

care as defined, it is also clear that the term 'intermediate', as employed in the set of palliative care definitions, needs to be changed in order to avoid confusion with the NHS use of the word.

Palliative Care 2000: Commissioning Through Partnership

Council's guidance on commissioning argued that it was necessary to draw a distinction between those providers who offered specialist palliative care and the smaller traditional hospices (usually in the voluntary sector) that offered services with neither the same degree of medical specialisation nor the full range of multi-professional specialist support.

The guidance recognised that such hospices tended to focus on patients with problems less complex than those cared for by the specialist services. It suggested that some of those hospices would adhere to such a role either through choice or in the expectation that resources would not be available to develop full specialist palliative care services.

It was also recognised that whatever their degree of specialisation in palliative care those hospices would continue to make an essential contribution to the palliative care service for the population they serve. That view is reflected in Chapter 9 on the Service Components and their Functions in which the essential service components of a palliative care service for a given population are described in terms of their functions.

Past approaches to defining palliative care

Despite the guidance that all the essential service components should be supplied in a co-ordinated way to provide a total palliative care service, it is probably fair to say that some providers of individual components still regard themselves more as independent providers than as contributors to an integrated service. That factor alone may contribute to the widespread view that individual providers should be categorised either as specialist palliative care providers or as something different e.g. intermediate palliative care providers.

It is also suggested that the preoccupation with definitions up to now has largely been focussed on what is being provided rather than on what perhaps should be provided. The intention has been to make the definitions inclusive of whatever provision currently exists. The difficulty in that approach resides in the fact that services that specialise in palliative care vary considerably in the degree to which they employ specialists in palliative care to deliver those services.

In consequence, the approach adopted in this paper is based on defining what should be provided.

A new approach to defining services

The National Council's Project Team on national standards and performance indicators has drafted a set of national policy objectives for palliative care and has used them as the base from which national standards for specialist palliative care services can be derived. The first of these objectives concerns Fair Access.

To ensure that all patients with palliative care needs, together with their carers, have equitable access to a range of specialist palliative care services appropriate to those needs.

If that objective is to be achieved it will be necessary to ensure that all health care providers have formal arrangements for accessing such services. In other words any patient in whatever setting will need to be assured of the following:

- That their normal professional carers are able to and do assess their palliative care needs across the dimensions of physical, psychological, social and spiritual care
- That their professional carers have the knowledge and skills to deliver basic palliative care themselves and to know when it is appropriate to refer to specialist palliative care services
- That any health care provider that does not have a full multi-professional specialist palliative care team of its own has formal arrangements in place for accessing a named team from another health care provider

There is probably a broad consensus that such criteria should apply to all health care services that do not specialise in palliative care. However, if the objective of equitable access is to be achieved for all patients, then the criteria will also need to apply to services that specialise in palliative care but do not have a full multi-professional specialist palliative care team.

That means that any health care provider, NHS or voluntary, that specialises in palliative care, would either have to provide a full multi-professional specialist team of its own or have formal arrangements with such a team for providing those specialist elements that it did not have. It is envisaged that when Supportive and Palliative Care Networks are fully established in England, they would be responsible for ensuring that such arrangements are in place.

Examples of services that would need to make such arrangements include:

- NHS hospital support teams/nurses
- community based Macmillan nurse teams
- voluntary hospices that do not have a full multi-professional specialist palliative care team

- community hospitals with designated palliative care beds
- Marie Curie Nursing Service
- Hospice at home type schemes

It is suggested that if this approach to defining what should be provided is acceptable, definitions need to be developed only for the following:

- Palliative care
- General palliative care
- Specialist palliative care
- General palliative care services
- Specialist palliative care services

The concept of the 'palliative care approach' would not be needed nor would a replacement for 'intermediate palliative care' need to be found.

Palliative care defined

The World Health Organisation definition of palliative care, produced in 1990, is still relevant today although the remit of palliative care is now considered to be applicable to patients with a non-cancer diagnosis as well as those with cancer.

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.

Palliative care:

- *Affirms life and regards dying as a normal process*
- *Neither hastens nor postpones death*
- *Provides relief from pain and other symptoms*
- *Integrates the psychological and spiritual aspects of patient care*
- *Offers a support system to help patients live as actively as possible until death*
- *Offers a support system to help the family cope during the patient's illness and in their own bereavement*

General palliative care defined

General palliative care can be defined quite simply as palliative care provided by the patient and family's usual professional carers as a vital and integral part of their routine clinical practice. It is informed by a knowledge and practice of palliative care principles.

Those principles comprise:

- Focus on quality of life which includes good symptom control

- Whole person approach taking into account the person's past life experience and current situation
- Care which encompasses both the person with life-threatening illness and those that matter to that person
- Respect for patient autonomy and choice (e.g. over place of care, treatment options, access to specialist palliative care)
- Emphasis on open and sensitive communication, which extends to patients, informal carers and professional colleagues

General palliative care is provided for patients and their families with low to moderate complexity of palliative care need, whatever the illness or its stage, in all care settings

General palliative care services defined

A General Palliative Care Service comprises a health and social workforce that meets the following requirements. It should be able to:

- Assess the palliative care needs of each patient and their families across the domains of physical, psychological, social and spiritual need.
- Meet those needs within the limits of their knowledge, skills and competence
- Know when to seek advice from or refer to specialist palliative care services

In order to meet those requirements the health and social care workforce will need appropriate training and guidance. In particular it will need the following:

- Training in basic palliative care including symptom management
- Skills in assessing the palliative care needs of patients and families
- Training in communication skills
- Guidance on when to refer to specialist palliative care services

Specialist palliative care defined

Specialist palliative care can be defined quite simply as palliative care provided by health and social care professionals who specialise in palliative care and work within a multi-professional specialist palliative care team.

Specialist palliative care services defined

Specialist Palliative Care Services may be defined in terms of their core service components and their functions and the composition of the multi-professional specialist teams that are required to deliver them. The core service components may be provided by a range of NHS and voluntary

providers that specialise in palliative care and together contribute to an integrated specialist palliative care service for the population of a Supportive and Palliative Care Network (or other forms of managed clinical networks). The service should be available in all care settings for patients with moderate to high complexity of palliative care need. It is anticipated that the Network would be responsible for designating which services are best able to care for those patients with the most complex needs.

Each provider will need to employ a full multi-professional specialist team or to have formal arrangements for accessing from such a team the specialist elements not available in its own team. This is to ensure that all patients being cared for by a service specialising in palliative care have ready access to palliative care specialists according to assessed need. It would no longer be tenable for example for a Macmillan community nurse team not to have or not to use formal arrangements for accessing a consultant in palliative medicine.

The Core Service Components

It is not yet possible to provide definitive advice on what core service components should be provided for any given population since that is likely to be subject to evidence-based Guidance on Supportive and Palliative Care that is to be produced by NICE towards the end of this year. It may however be anticipated that the core services will include the following:

- Specialist palliative in-patient care
- Specialist palliative home care
- Specialist palliative day therapy
- Specialist palliative hospital support
- Education in palliative care

The Multi-professional Specialist Palliative Care Team

Again because of the work on Supportive and Palliative Care Guidance to be produced by NICE it is not yet possible to be precise about the core membership of the multi-professional team required to deliver each of the core service

components. However, it can be expected that the core membership will include:

- Consultant in palliative medicine
- Senior nursing staff with specialist qualification in palliative care
- Social worker, physiotherapist, occupational therapist with palliative care experience and/or qualification
- Chaplain

Summary

This discussion paper suggests that what differentiates general palliative care from specialist palliative care is the identity of those who deliver the care rather than any difference in the definition of palliative care itself.

It also suggests that all services that specialise in palliative care should either have a full multi-professional specialist team of their own or have formal arrangements with such a team for accessing those specialist staff they do not have. All such services would therefore come under the umbrella of a specialist palliative care service that Networks should ensure is well integrated.

If those two proposals are acceptable then there is neither further need for the concept of the palliative care approach nor for any differentiation in definitions between units and teams in the degree to which they have specialist teams of their own.

Discussion

Readers of this discussion paper are invited to submit their views on the suggestions set out above. They should be sent, as soon as possible, to Jayne Thomas at the National Council for Hospice and Specialist Palliative Care Services, 34-44 Britannia Street, London WC1X 9JG or by email to j.thomas@hospice-spc-council.org.uk