

## Definitions of Supportive and Palliative Care

This *Briefing* sets out a range of working definitions for supportive and palliative care that have been developed by the National Council over the past year. The process began in May 2001 with the publication of the *Briefing* 'What do we mean by palliative care?' It was followed in January 2002 by circulation of a Consultation Paper on Definitions of Supportive and Palliative Care. This paper has been developed in the light of the responses to the consultation paper and was agreed by the Board of Trustees in June for submission to the National Institute for Clinical Excellence in relation to its work on developing guidance on supportive and palliative care.

This paper focuses simply on recommended definitions for supportive and palliative care. It also describes the relationship between the concepts of supportive and palliative care.

### Aims of the Review of Definitions

Before setting out what those definitions might be it is necessary to reiterate what the aims of the Consultation Paper were.

- To achieve greater clarity about what is meant by palliative care in contemporary Government policy – in particular to differentiate between supportive and palliative care
- To renew the debate about the difference between what is called specialist palliative care and other forms of palliative care
- To discover whether there is a broad consensus about the meaning that can be attached to supportive and palliative care within current Government policy
- To influence NICE in its work in producing evidence based guidance on supportive and palliative care.

It is clear therefore, from that list of aims, that the Council's role has been to initiate a national debate about definitions rather than to produce the final word on definitions. The debate will continue in response to the NICE consultation process from July onwards. In many senses the Council's review of definitions will have enabled a more informed reaction to whatever NICE proposes.

### Scope of the Definitions

The review of definitions arises out of the commitment in the NHS Cancer Plan for England to develop a supportive and palliative care strategy for cancer. There is as yet no comparable commitment in similar terms for other disease or patient groups. Accordingly, the concept of 'supportive care' for these other groups has a much less firm foundation in policy than for cancer services. For that reason the proposed definition for supportive care in this paper is intended to relate only to cancer services. It is suggested that the development of a definition of supportive care that would encompass all disease and patient groups would require a wider consultation than that undertaken in this review.

The definitions of palliative care are however intended to be applicable to palliative care services that may be required for any disease or patient group.

### Scope of the Consultation

The responses to the Consultation Paper have come very largely from the palliative care world. Only around 5% have been received from clinicians from outside palliative care. There remains therefore a question as to whether further consultation is required of primary care and of the specialties covering the principal disease and patient groups. At this stage, given that NICE is

due to consult widely in September on its draft guidance on supportive and palliative care, further action by the Council may not be necessary.

There may also be a deficit in respect of patient and user views but again that may be made good during the NICE consultation period.

### Conclusions drawn from the response to the Consultation Paper

- There is considerable support for a review of definitions at this time
- The proposed definition of supportive care is broadly acceptable. Many have argued that it is simply a definition of 'good care'.
- The WHO definition of palliative care does require updating.
- There is broad agreement on what parts of the definition require amendment.
- There is considerable support for the distinction made between 'generic' and 'specialist' palliative care services
- There is a recognition that supportive care and palliative care as defined overlap but there is a wide divergence of views about how they overlap
- There is a similar diversity of view about the substitution of 'generic palliative care' by 'supportive care'
- The suggestion for dropping the epithet 'specialist' in specialist palliative care services is a step too far for most respondents.

The proposed definitions that are set out below reflect these conclusions.

### Palliative Care

The following definition is an adaptation of the WHO definition of 1990.

***Palliative care is 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 illness in conjunction with other treatments.***

Palliative care:

- ***Affirms life and regards dying as a normal process***
- ***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 environment***

### Palliative Care Services

Palliative care is delivered by two distinct categories of health and social care professionals.

- The patient and family's usual professional carers
- Professional carers who specialise in palliative care some of whom are accredited specialists e.g. consultants in palliative medicine, clinical nurse specialists in palliative care

It should also be recognised that the informal carers of the patient also provide palliative care.

### General Palliative Care Services

General palliative care is provided by the usual professional carers of the patient and family with low to moderate complexity of palliative care need.

A general palliative care service comprises a health and social workforce in which all the patient and family's usual professional carers provide palliative care as a vital and integral part of their routine clinical practice. That practice is underpinned by the following principles:

- 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)
- Emphasis on open and sensitive communication, which extends to patients, informal carers and professional colleagues

The patient and family's usual carers 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 workforce will need appropriate training and guidance including:

- Education and training in the basic principles and practice of 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 Services

Specialist palliative care services are provided for patients and their families with moderate to high complexity of palliative care need. They are defined in terms of their core service components, their functions and the composition of the multi-professional teams that are required to deliver them. They are underpinned by the same set of principles as for general palliative care services.

It is expected that NICE will provide definitions of the core service components in its Guidance on supportive and palliative care.

### Key requirements

- a The core service components are provided by a range of NHS, voluntary and independent providers that specialise in palliative care and together contribute to an integrated specialist palliative care service for the population of a managed clinical network e.g. the local Supportive and Palliative Care Network.
- b The service is available in all care settings
- c Each provider contributing to the service will:  
*either*  
employ a full multi-professional palliative care team of its own  
*or*  
have formal arrangements for accessing from such a team the specialist elements not available in its own team

## Supportive Care

### A Definition of Supportive Care

Supportive care is that which helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.

### Key Principles

The key principles underpinning good care comprise:

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

## Principal Domains of Support and Care Need

### Information needs

Patients should receive all the information they want concerning their condition and possible treatment and care options. That information should be up to date, honest, timely and sensitively given.

### Being treated as a human being

Patients should be treated with dignity and respect as an individual person (not just as a disease or as a numbered patient)

### Empowerment

Patients need to have their voice heard, directly or through advocacy, and to be valued for the knowledge and skills that they can bring to their individual situations. They need to be able to exercise real choice about their care and treatment and where it takes place.

### Physical needs

Patients need to have their physical symptoms managed, to a degree that is acceptable to them and achievable within current knowledge.

### Continuity of care

Patients need well informed health and social care professionals who work in the community and good communication between professionals working within and across the NHS, voluntary and independent sector service providers.

### Psychological needs

Emotional support for the patient and those caring for them and giving time to listen and understand concerns

### Social needs

Patients need support for their carers and family, advice on financial and employment matters and provision of transport.

### Spiritual needs

Support for patients to be able to explore the spiritual issues that are important to them.

## Relationship between Supportive Care and Palliative Care

The last stage in this review of definitions is to consider the relationship between supportive and palliative care in the light of the recommended definitions for palliative and supportive care.

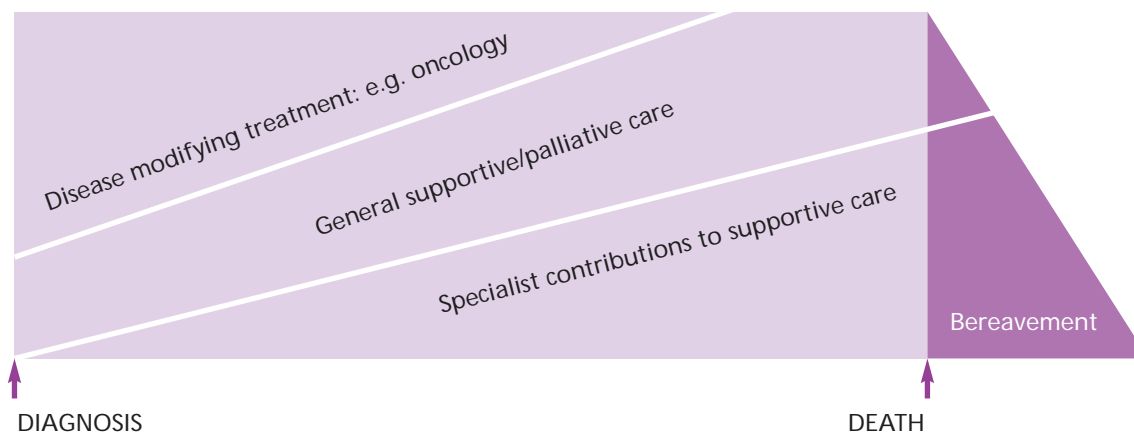
The definition proposed for supportive care is very broad and is essentially a definition of care need. It is much more inclusive than the term 'best supportive care' that is often used to describe the care needs of a patient with apparently incurable disease. It includes all aspects of patient and family care needs other than the processes of diagnosis and treatment that have curative aims. It also acknowledges that patients have supportive care needs from the point of pre-diagnosis.

The principles that underpin supportive and palliative care are broadly the same. It is also clear that the domains of patient and family need are also very similar. There is therefore considerable overlap between supportive and palliative care in terms of need. For the usual professional carers of the patient and family this may be best acknowledged by regarding the care they give as general supportive/palliative care. As long as they are able to meet the requirements set out in a) below, there would seem to be no utility in analysing where the overlap occurs and where it does not.

- a The usual professional carers of a patient and their family should be able to:
  - Assess the care and support needs (including palliative care) of each patient and family across all the domains of need
  - Meet those needs within the limits of their knowledge, skills and competence
  - Know when to seek advice from or refer to specialist services
  
- b The specialist services comprise all those that may contribute to the supportive care of a patient and their family. They include:
  - Specialist palliative care services
  - Specialist psychological and psychiatric services
  - Social care services
  - Palliative interventions e.g. palliative radiotherapy, palliative surgery
  - Specialist pain services
  - Information, advice and resource centres

Some of these services will have functions beyond supportive care e.g. psychological services.

The specialist services as listed above supplement the general supportive/palliative care services provided by the usual professional carers of the patient and family. The diagram below illustrates this.



**Note 1** General supportive/palliative care is provided by the patient's usual professional carers

**Note 2** The specialist contributors to supportive care are listed in b) above