

Palliative Care for Adults with Non-malignant Diseases

Developing a National Policy

Introduction

In its Strategic Agenda for 2001 to 2004 Council set out a number of principles that it believed should underpin the functions of planning, commissioning and delivery of palliative care services. Foremost among them was the following:

'Every person with advanced, progressive and incurable illness should receive palliative care, appropriate to their assessed need.'

In respect of people with a diagnosis of non-malignant disease the Strategic Agenda identified several key actions:

- To work with national charities and other bodies concerned with specific disease and patient and user and carer groups to develop recommended service models for those with a non-cancer diagnosis
- To appraise existing service models and encourage the development of pilot services
- To collaborate with the health departments in England, Wales and Northern Ireland in developing this agenda

- To seek additional NHS funding for these service developments.

The purpose of this paper is to set out a range of ideas for taking forward this commitment to extend access to palliative care to this large patient group. In doing so a view is taken of what the ultimate goal might be and consequently it links with the proposal to develop a vision for palliative care that goes well beyond the period of the current Strategic Agenda that was limited to 2001/2004.

Background

Over the last five years Council has taken several steps that were designed to encourage greater access to specialist palliative care services by those with a diagnosis other than cancer. In particular it has published a series of papers and guidance documents with the following aims:

- To gain wider recognition of the palliative care needs of the different disease and patient groups
- To understand where the barriers might lie in meeting identified palliative care need

- To suggest in the light of that, ways in which those needs might nevertheless be met at least to some extent by existing services.

Those publications are:

- *Reaching Out: Specialist Palliative Care for Adults with Non-malignant Diseases*, 1998
- *Palliative Care 2000: Commissioning through Partnership*, 1999
- *Positive Partnerships: Palliative Care for Adults with Severe Mental Health Problems*, 2000
- *Wider Horizons: Care of the Dying in a Multicultural Society*, 2001

Additionally Council has sought to ensure that palliative care is included, where relevant, in each new National Service Framework produced by the Department of Health. There is accordingly a reference to the palliative care needs of those with heart failure in the NSF for Coronary Heart Disease and also an important section on end of life care in the NSF for Older People.

There has also been much activity by leading researchers and clinicians in palliative care to promote and extend palliative care for the non-cancer patient.

Despite these efforts there is as yet no sign in the annual collections of national data for palliative care that access to specialist services has

increased. The Minimum Data Set collection for 2000/01 reveals the figures set out in Table 1, below.

The question arising from this is whether current access adequately meets the needs of those with non-malignant disease. Council's publication *Reaching Out* is unequivocal in its conclusion that it does not.

'There is convincing evidence that many patients who die from non-malignant disease have unmet need for symptom control, psychosocial support, open communication, control over their final days and choice about the care they receive. These patients and their informal carers, facing considerable distress in the final months of life, need palliative care. For many, adoption of the palliative care approach to their care will be adequate. For others, with complex needs, specialist palliative care will be appropriate.'

Assessment of Palliative Care Need

The following questions arise in the consideration of how to assess aggregate palliative care needs of a population:

- How many people per year with advanced progressive illness are likely to have palliative care needs?

TABLE 1 – Access to Specialist Palliative Care Services 2000/01

Service Component	Cancer Patients as % of all patients gaining access	Non-cancer Patients as % of all patients gaining access	Number of New Non-cancer Patients
In-patient	95.2%	4.8%	2000
Home Care	96.2%	3.8%	3600
Day Care	94%	6%	1100
Hospital support	94%	6%	6000

Notes to the Table

- There is likely to be considerable multiple counting of individual patients who may access two or more service components. The total number of new patients will accordingly be much less than the total of the figures in the last column.
- Access has hardly changed since 1994/95 when data collection began of nationally defined data items.

- What proportion of those people are likely to need intervention from specialists in palliative care?
- What are likely to be the principal domains of support and care need?

How many people need palliative care?

It is probable that for most people most palliative care needs will arise during the last year of life. The starting point for this consideration is therefore mortality data.

In the year 2000 according to ONS there were 537,877 death registrations in England and Wales, 256,698 male and 281,169 female. Analysis of those deaths by age group is shown below:

TABLE 2 – Death registrations by age group

Age Group	Male deaths	Female deaths	Total deaths
Under 1	1,902	1,497	3,399
1-4	345	247	592
5-14	490	351	841
15-24	2,226	907	3,133
25-34	3,849	1,702	5,551
35-44	6,135	3,853	9,988
45-54	13,355	9,108	22,463
55-64	28,003	17,722	45,725
65-74	60,801	42,318	103,119
75-84	87,449	89,651	177,100
85 & over	52,143	113,813	165,956

The principal causes of death are set out below.

TABLE 3 – Principal causes of death

Disease group	ICD Codes	Number of deaths	% of Total Deaths
Neoplasms	140-239	134,490	25.0%
Endocrine Nutritional Metabolic Disorders	240-279	7,246	1.3%
Mental Disorders	290-319	10,771	2.0%
Diseases of Nervous System & Sensory Organs	320-389	9,638	1.8%
Diseases of the Circulatory System	390-459	207,618	38.6%
Diseases of the Respiratory System	460-519	93,982	17.5%
Diseases of the Digestive System	520-579	22,115	4.1%
Diseases of the Genito-Urinary System	580-629	7,282	1.4%
Symptoms Signs & ill defined conditions	780-799	13,682	2.5%
Injury & Poisoning	800-999	17,141	3.2%
TOTALS		523,965	97.4%

The number of deaths after excluding from Table 3 deaths caused by neoplasms and injury and poisoning is 372,334. Some of these deaths will be preceded by short or no identified terminal periods. Some will be sudden deaths but many will be preceded by a recognised period of predominantly palliative care need. However, whatever the exact numbers may be in each of those categories, the number of people dying from progressive non-malignant disease who will need palliative care is very large, perhaps as many as 300,000 per year. Most of these will be older people as Table 2 indicates. Most of these will be suffering from diseases of the circulatory or respiratory systems.

As indicated above in Table 1 less than 10,000 people with non-malignant disease are currently gaining access to specialist palliative care services. This is 2 to 3% of the total number of people dying from non-malignant disease whereas the proportion of people with cancer gaining access to at least one specialist palliative care service in the last year of their lives is at least 75%.

Aggregate palliative care need is likely to vary considerably from one part of the country to another. One of the key factors likely to influence need is the proportion of older people in the population. For Local Authority populations the proportion of people aged 60 and over varies from 35% in Christchurch to 13% in Milton Keynes. These proportions are reflected in the incidence of deaths for all causes – 1,635 per 100,000 population in Christchurch and 706 in Milton Keynes. The highest incidence of deaths per 100,000 population of 1,690 is to be found in Tendring and the lowest of 667 in Kensington & Chelsea.

If these factors are good indicators of palliative care need then it may be concluded that those areas of the country with the highest proportions of older people in the population may need twice the resources of those with the lowest proportions. However such indicators are somewhat crude in the sense that within them lies the implicit assumption that the palliative care needs of each principal disease group are similar both in the nature and amount of their palliative care needs. More work will be required to understand how the needs of each group may vary e.g. because of differing patterns of symptoms and disease trajectories.

How many people need access to specialist palliative care services?

There is much evidence that a multi-professional specialist palliative care team can improve outcomes for people with cancer in a variety of settings e.g. at home, in hospitals, in hospices. However, there is no evidence to suggest that all patients with cancer need access to such a team. There is also no evidence to suggest that a specific proportion of patients need access. All that is known is that currently at least 75% of people with cancer do gain access. There is no evidence to suggest that this proportion is either too low or too high.

Given this uncertainty it would appear doubtful that any firm lessons can be learned from the cancer experience that would inform judgements about what proportion of those with advanced progressive disease other than cancer require access to a specialist team. Added to that is the further uncertainty about what might be the most effective ways of meeting the palliative care needs of the non-cancer groups.

Accordingly, it is not tenable to attempt to derive what specialist palliative care services might be needed for the non-cancer patient from the cancer experience. In particular, it is not appropriate to draw the simplistic conclusion that because 75% of people with cancer in the last year of their lives do gain access that a similar proportion of those with non cancer also need access.

What are the principal domains of support and care need?

The National Institute for Clinical Excellence is in the process of developing evidence based guidance on service configuration for supportive and palliative care in the context of cancer services. It is probable that this guidance will also be useful for informing the development of services for the non-cancer groups of patients.

In the most recent draft of the NICE guidance reference is made to work undertaken by Cancerlink that highlighted the following domains as key components of good supportive care. In this guidance the term supportive care is taken to embrace palliative care.

- **Being treated as a human being.** People want to be treated as individuals, and with dignity and respect.
- **Empowerment.** The ability to have their voice heard, to be valued for their knowledge and skills, and to exercise real choice about treatments and services are central to patients' and carers' wishes.
- **Information.** Patients and carers should receive all the information they want about their condition and possible treatment. It should be given in an honest, timely and sensitive manner.
- **Having choices.** Patients and carers want to know what options are available to them from the NHS, voluntary and private sectors, including access to self-help and support groups and complementary therapies.
- **Continuity of care.** Good communication and co-ordination of services between health and social care professionals working across the NHS and social sectors is essential.
- **Equal access.** People want access to services of similar quality wherever they are delivered.
- **Meeting physical needs.** Physical symptoms must be managed to a degree acceptable to patients.
- **Meeting psychological needs.** Patients and carers need emotional support from professionals who are prepared to listen to them and are capable of understanding their concerns.
- **Meeting social needs.** Support for carers, advice on financial and employment issues and provision of transport are necessary.
- **Meeting spiritual needs.** Patients and carers should have support to help them explore the spiritual issues important to them.

While it is likely that the needs of disease and patient groups other than cancer will be broadly similar to those of people with cancer, it can be expected that there will be important variations between the different disease groups. Such variations may arise because of differing patterns of symptoms and disease trajectories. For

example respite care or social care may be more important for one group than another.

Definitions of Supportive and Palliative Care

In its evidence to NICE the National Council provided a set of proposed definitions for the following:

- Palliative care
- General palliative care services
- Specialist palliative care services
- Supportive care.

It also provided a view about the relationship between supportive and palliative care. While these definitions have been developed in the context of cancer services, it is likely that they would also be applicable to other disease and patient groups. Readers should refer to Council's *Briefing Number 11 Definitions of Supportive and Palliative Care*. Its content is reflected in the sections of this paper that follow.

Models of palliative care service provision

As the Council works through its non-cancer agenda it has become clear that the palliative care services required for any disease or patient group should be delivered by two distinct but complementary 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.

The patient and family's usual professional carers

The usual professional carers provide general palliative care to patients and families with low to moderate complexity of need. They need to 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 that is relevant to each distinct disease or patient group 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.

While much of the education, training and guidance required would be common to all disease or patient groups, some of it would not, e.g. because of different disease trajectories, different patterns of symptoms. There would accordingly be a need to develop elements of a training programme that were specific to the principal disease groups, e.g. coronary heart disease, neurological diseases. This would need to be undertaken in collaboration with the medical specialties concerned, specialists in palliative care, the relevant national charities and the policy leads in the Department of Health.

The scale of the continuing programme of education and training would be huge since potentially it would involve all professional staff engaged in health and social care in whatever setting.

Specialist palliative care services

The specialist services that have been developed primarily for people with cancer comprise the following core components:

- Specialist palliative in-patient care in hospices or specialist palliative care units
- Specialist palliative community care provided mainly by teams of clinical nurse specialists to people in their place of residence – more intensive support for limited periods can often be provided by the Marie Curie Nursing Service and 'hospice at home' type services
- Specialist palliative day care/therapy
- Specialist palliative hospital support teams
- Bereavement support services
- Education and training in palliative care.

The level of intervention of the community and hospital based teams may vary according to the needs of the patient and the usual professional carers of the patient and family. The levels of intervention are as follows:

Level 1 Advisory Role – The team provides advice and information to professional colleagues in respect of a specific patient but has no direct contact with the patient.

Level 2 Advisory Role Plus – Team members have a single contact with the patient/carer and provide advice and information to a professional colleague.

Level 3 Supportive Role – Team members have several contacts with the patient and/or carers to provide planned support and advice for a well defined problem followed by discharge of the patient back to the referrer.

Level 4 Continuing Role – The team's role is ongoing, usually to deal with complex continuing problems and may involve repeated assessments and interventions.

Level 5 Lead Role – As for Level 4 and the team acts fully for the General Practitioner or hospital consultant in providing care for the patient and carers.

While it is probable that services modelled on these lines would provide effective care and support for some people from any disease or patient group, it is uncertain what the most cost-effective models of service would be for specific groups. Given that the palliative care needs of different groups may vary in important respects, this may have an effect on the precise configuration of the services needed to meet those needs. The factors influencing these variations include:

- The extent to which it is possible to enhance the palliative care skills and practice of the usual professional carers of the patient and family
- The relative importance for each disease or patient group of the physical, psychological, social and spiritual needs, e.g. respite care may be more important for one group than another or social care
- The different disease trajectories and different patterns of symptoms experienced
- The development of integrated care pathways that are relevant to (or in some cases specific to) the various disease groups
- The relative importance of providing access in each of the care settings
- The professional mix in the teams for each disease group may vary as also may the proportions of each profession in the team.

It follows that in order to develop a national policy for development of specialist palliative care services for the non-cancer patient, it will be necessary to achieve a comprehensive understanding of the palliative care needs of each of the principal disease/patient groups. It is only then that it will be possible to provide guidance on the service models that may be most cost-effective in meeting those needs. The next section sets out a recommended process for reaching that objective.

A Plan for Developing a National Policy

It is proposed that a national policy be developed for each of the principal disease or patient groups rather than to attempt to produce a policy for people with a non-cancer diagnosis as a whole. This would involve bringing together the key players for each of these groups to discuss how best to address the supportive and palliative care agenda for each group. This is likely to include the following:

- The specific medical specialty
- The national charities with key interests in the disease/patient group
- User involvement
- Palliative care specialists
- Social services
- Department of Health policy leads
- Primary care.

In view of the fact that National Service Frameworks have been published for Coronary Heart Disease and for Older People, the priority would be to develop guidance for these groups. Following that, the priorities would appear to be people with diseases of the respiratory system and neurological diseases, the latter being the subject of an NSF in preparation.

Initially it is proposed that two parallel groups be established for CHD and for Older People but recognising that there will be some overlap between them since the scope of Older People embraces potentially all disease groups.

The Agenda

While the Agenda for each group will need in some respects to be specific to the particular disease/patient group, it will also need to include the following topic areas:

- Assessment of the aggregate palliative care needs of the disease/patient group for any given population

- Identification of the principal domains of support and palliative care needs of individual patients/carers
- Identification of the palliative interventions that may be most effective in meeting these needs
- Assessment of the forthcoming NICE guidance on supportive and palliative care for its relevance and appropriateness for the group of patients and other users concerned
- Identification and review of any current models of delivering palliative care to the patient group concerned e.g. use of integrated care pathways, clinical nurse specialists in palliative care working jointly between cardiology and palliative care teams
- Assessment of the education and training needs in palliative care for those working in the specialty concerned
- Development of guidance on what service configurations would be most cost-effective in meeting patient and carer need
- Assessment of the resource implications of such guidance.

Overarching themes

Continuing education and training in palliative care for the usual professional carers of the patient and family is a topic that will be common to all the disease/patient groups. As stated above on page 6 while much of the education and guidance would be common to all disease/patient groups, some of it would not. While the disease specific requirements could be expected to emerge from the disease specific groups, the common elements may not. There may therefore be a case for

establishing a third group that would identify the education and training required by every health or social care professional to equip them with basic palliative care skills and knowledge.

Implementing the Plan

The Plan outlined above is wide in its scope and could not be achieved by the National Council on its own. Even if it had the resources required it would still be necessary to work in partnership with other key national organisations to deliver this agenda. There are accordingly two preliminary actions that Council needs to take before the proposed agenda can start to be undertaken. They are:

- To establish working partnerships with the key players for the priority disease/patient groups. Some work has been undertaken in this respect but it will need to be followed through.
- To secure project funding for the work outlined above. It may be that the ability of the Council to secure funding will be enhanced by bids based on partnerships with the key national players.

Council would be pleased to receive any comments on this *Briefing*. In particular it would be helpful to receive information about initiatives to extend specialist palliative care services to disease groups other than cancer.

Comments/information should be sent to Peter Tebbit, National Palliative Care Development Adviser at the address above, or by email to p.tebbit@hospice-spc-council.org.uk