

National Council for Hospice and Specialist
Palliative Care Services
and
Scottish Partnership Agency
for Palliative and Cancer Care

Reaching out:

Specialist Palliative Care for Adults
with Non-Malignant Diseases

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Foreword



THE SCOTTISH OFFICE

REACHING OUT: SPECIALIST PALLIATIVE CARE FOR ADULTS WITH NON-MALIGNANT DISEASES

We are delighted to write the foreword for this important report from the National Council for Hospices and Specialist Palliative Care Services and the Scottish Partnership Agency for Palliative and Cancer Care.

In the UK we are particularly privileged in having some of the early and courageous innovators who not only established palliative care as a recognised discipline but have continued to push at professional and organisational boundaries to ensure that the principles and practice of palliative care reach all those in need.

These principles of care, which aim to promote both physical and psycho-social well being, which are taken for granted in voluntary and NHS hospices, need to become equally integrated into the whole of our NHS practice. This needs to be achieved for *all those who face life threatening illnesses*.

That is why this report is so important. It reflects and debates these principles which can only be achieved through partnerships and collaboration across care sectors. The report itself is an example of this. It is a collaboration between two national representative bodies, the researcher, Julia Addington-Hall holds a joint post between a voluntary hospice and a London University Medical School and the working party who produced the report is multi-professional representing both statutory and voluntary palliative care sectors.

We warmly commend this report which aims to promote discussion and action and the outcome of that debate should be improved services for a particularly vulnerable group of patients and their families.

A handwritten signature in black ink, appearing to read 'Jay'.

Baroness Jay of Paddington
Minister of State
Department of Health

A handwritten signature in black ink, appearing to read 'Galbraith'.

Sam Galbraith MP
Minister for Health
The Scottish Office

Aims of report

This paper examines the palliative care needs of patients dying from progressive non-malignant diseases and those of patients living with chronic non-malignant diseases.

It aims primarily to promote discussion and action amongst and between:

- providers of specialist palliative care
- health service commissioners
- providers of education to health, social and pastoral care professionals
- health professionals caring for people with a wide range of life-threatening diseases.

Definitions

The NHS Executive in EL (96)85¹ defines the palliative care approach, palliative interventions and specialist palliative care as the principal components of the spectrum of palliative care provision. These definitions follow closely those contained in the National Council's Occasional Paper 8 *Specialist Palliative Care: A Statement of Definitions*.²

The palliative care approach aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles and supported by specialist palliative care. The key principles underpinning palliative care which should be practised by all health professionals in primary care, hospital and other settings 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 the life-threatening disease and those that matter to that person
- respect for patient autonomy and choice (eg 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.

Palliative interventions are non-curative treatments given by specialists in disciplines other than specialist palliative care aimed at controlling distressing symptoms and improving a patient's quality of life, for example through the use of palliative radiotherapy, chemotherapy, surgical procedures and anaesthetic techniques for pain relief.

Specialist palliative care services are those services with palliative care as their core speciality. Specialist palliative care services are needed by a significant minority of people whose deaths are anticipated, and may be provided:

- Directly through the specialist services
- Indirectly through advice to a patient's present professional advisers/carers.

These services provide physical, psychological, social and spiritual support, and will involve practitioners with a broad mix of skills, including medical and nursing, social work, pastoral/spiritual care, physiotherapy, occupational therapy, pharmacy and related specialities.

Executive summary

Patient need

- 1 The UK Departments of Health recognise that palliative care services should be available on the basis of need, not diagnosis. The current situation whereby patients with non-malignant disease have limited access to specialist palliative care is inequitable for both patients and families.
- 2 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.
- 3 There is also evidence that patients with life-threatening non-malignant disease have unmet needs during their disease trajectories. The question for specialist palliative care in relation to these patients is whether it has any unique skills or approaches to bring to their care. Such skills include the emphasis on careful assessment and treatment of symptoms rather than focusing on underlying pathology, expertise in the use of opioid drugs and experience of addressing ethical issues around the withdrawal of active treatment. Palliative care providers must be sure that the patient and family have needs within the remit of hospices and specialist palliative care, and that the goals of intervention are clear.

Meeting the demand for non-cancer referrals

- 4 It should not be presumed that current hospice and specialist palliative care services will be able to accept non-cancer referrals. Major issues to be addressed include:
 - recognition that some existing members of multi-professional specialist palliative care teams may lack the necessary skills and the expertise to extend beyond cancer

- fear of services being overwhelmed by the number of referrals
 - concerns that difficulty in judging life expectancy will lead to beds (and daycare places) being blocked, and domiciliary and hospital support teams being unable to accept urgent referrals because of the proportion of long-term patients in their care
 - concerns that accepting patients with non-malignant disease may lead to reductions in charitable giving
 - the continuing care of patients – whether with a cancer or non-cancer diagnosis – cannot be the sole responsibility of specialist palliative care.
 - concerns about finding resources to support service expansion.
- 5 The experience of palliative care services already accepting patients with non-malignant diseases suggests that services do not necessarily receive an overwhelming number of referrals, and that difficulties in judging life expectancy do not inevitably cause problems. This is, however, dependent on having clear goals for intervention with patients with non-malignant disease, including withdrawing once problems have been resolved, with the proviso that patients will be seen again if new problems within the remit of palliative care develop.

Levels and components of care

- 6 As with cancer patients, it may be appropriate to offer patients with non-malignant disease one of three levels of care:
 - consultancy services – a one-off or time-limited involvement of, usually, one member of the multi-professional team to advise on the management of a specific problem
 - short-term intervention whereby the whole multi-professional team may be involved but will withdraw once therapeutic goals have been reached, or
 - full hospice and specialist palliative care, whereby a limited number of patients who have complex and ongoing needs and who

are close to death are offered the full range of locally available palliative care services.

- 7 Other possible components of service provision for non-cancer patients include the development of disease-specific clinical nurse specialists in palliative care and the encouragement of disease-specific clinical nurse specialists to acquire skills in palliative care.
- 8 In many areas community health and social services are better developed for cancer patients than for those with non-malignant diseases. This may present difficulties for hospices and specialist palliative care in-patient units discharging patients. For example, it can be hard to arrange suitable long-stay accommodation for those unable to go home, particularly for younger patients.
- 9 The implications of extending care to non-cancer patients will be different for different components of specialist palliative care services. Key questions to consider for hospital palliative care teams, domiciliary care teams, day care and inpatient units are listed in box 3 (see page 25).

Education and training

- 10 Education in the principles of palliative care throughout pre-qualification training and via continuing education for all professionals involved in the care of these patients is needed to ensure that all professionals adopt the palliative care approach. This will enable all patients living with or dying from life-threatening diseases, whether malignant or non-malignant, to benefit from the expertise acquired in palliative care over the past 30 years.

Research, auditing and planning

- 11 There is a dearth of research into the palliative care needs of non-cancer patients and into the effectiveness of specialist

palliative care provision in meeting these needs. Hospices and specialist palliative care services currently providing care for these patients, or starting new services, should audit the effectiveness of their interventions with these patients. Plans for the development of any new services for patients with non-malignant disease should be accompanied by plans for a formal evaluation of the effectiveness of the service and its costs at the initial stage.

Funding

- 12 If existing services are to expand to include non-cancer patients, increased funding – whether from charitable sources or from the NHS – will be needed to prevent care for people with non-malignant diseases being provided at the expense of cancer patients. Many hospices and specialist palliative care services are already financially stretched. Expanding services to meet the palliative care needs of patients with non-malignant disease has major resource implications. Cancer charities, an important source of current funding, cannot play a role in financing this expansion. The effects on charitable giving are unknown, but there are anxieties that expansion could lead to reduced public giving. Education of the general public in the suffering of some patients with non-malignant disease may be needed to stimulate compassion and to sustain giving.
- 13 Much of the push towards providing palliative care for patients with non-malignant disease has come from the UK Departments of Health and from health commissioners. Health commissioners are charged with setting priorities which give the best results for their population as a whole as well as meeting individual needs. This report should help commissioners consider: how they can better meet these needs, and future funding and development of these services.

Recommendations for action

Recommendation 1

Local palliative care strategies should be reviewed in the light of government advice and appropriate plans drawn up to improve and resource palliative care for patients with non-malignant diseases.

Recommendation 2

Health authorities and other commissioning agencies should work with specialist palliative care services to:

- define specific priorities of need
- produce and fund a palliative care strategy and plan which takes account of the needs of all patients in their area
- ensure that specialist palliative care services are provided on the basis of patient need rather than medical diagnosis.

Recommendation 3

Hospices and specialist palliative care services should recognise that they have a role to play in the care of patients dying from non-malignant diseases:

- in partnership with other specialists
- through direct service provision, and/or
- by the provision of education or advice to other professionals.

Decisions about moving beyond cancer need to be made locally, based on local need and service provision (for some smaller services it may be appropriate to continue to focus inpatient care on cancer patients).

Recommendation 4

Hospices and specialist palliative care providers should consider their role – but with careful regard to resources available – in the care of patients living with life-threatening diseases and the particular problems which they have the expertise to address.

Recommendation 5

Relevant specialities and other professional bodies as well as educational consortia should address the

education and training implications of providing specialist palliative care for patients with non-malignant diseases.

Recommendation 6

Hospices and specialist palliative care providers should, when accepting referrals for non-cancer patients (as with cancer patients):

- negotiate clear goals with referrers, patients and families
- agree an exit strategy (ongoing open-ended care should only be offered to patients with particularly complex needs).

Recommendation 7

More consultancy services should be developed which offer one-off or short-term involvements to address a specific problem in the management of patients with either malignant or non-malignant diseases.

Recommendation 8

Existing non-cancer organisations should be encouraged to develop their own appropriate service, influenced by the palliative care approach.

Recommendation 9

Hospices and specialist palliative care services should develop clear local guidelines for referrals, negotiated and agreed locally, based on the current availability of skills within the specialist teams and on the types of services provided.

Recommendation 10

Hospices and specialist palliative care services providing care for non-cancer patients should audit their work and disseminate their experiences.

Recommendation 11

The accurate collection of routine data via the minimum data set jointly operated by the National Council and St Christopher's Hospice, London, should continue.

1 Introduction

In 1994, 627,600 people died in the United Kingdom, 25% of whom died from cancer.³ Since 1967, when St Christopher's Hospice, Sydenham – the pioneer of the modern hospice movement – opened, hospice and specialist palliative care services have focused their attention on the minority of adults who die from cancer (Box 1). Nearly one fifth (17.5%) of cancer patients in the UK now die in a voluntary or NHS hospice or specialist palliative care unit, and a further 39% die while in the care of a domiciliary palliative care team.⁴ This is likely to be an underestimate of the proportion of cancer patients currently receiving specialist palliative care, as others would have had domiciliary palliative care, received care from a hospital palliative care team or attended a hospice day unit but died elsewhere. Despite the growth in hospices and specialist palliative care services, population-based studies have shown that some cancer patients are still receiving inadequate care, and have unmet needs for symptom control and psychosocial support.⁵ There is, therefore, no room for complacency about the care of dying cancer patients.

Little attention has, however, been paid to the needs of the majority of people – those who die from other causes. Although leading figures in hospice care, including Dame Cicely Saunders, have long recognised that the principles and expertise of palliative care may be applicable to patients with other life-threatening diseases, their emphasis has been on encouraging those currently providing care for these patients to develop services based on the principles of palliative care, rather than on hospices and specialist palliative care services directly increasing their services to care for these patients.^{6,7} Some patients with neurological conditions, particularly motor neurone disease, receive hospice care and increasingly services are

also providing care for people with HIV/AIDS (initially in dedicated AIDS hospices and more recently in non-specialised units). However, the majority of patients receiving specialist palliative care have a diagnosis of cancer (Box 1).

In 1992 the joint report of the Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committees on the Principle and Provision of Palliative Care⁸ recommended that

“all patients needing them should have access to palliative care services. Although often referred to as equating with terminal cancer care, it is important to recognise that similar services are appropriate and should be developed for patients dying from other diseases”.

A Scottish Office Management Executive letter (MEL (1994) 104)⁹ on contracting for Specialist Palliative Care Services said that

“palliative care is currently provided mainly for people suffering from cancer, but it is increasingly recognised that people with a range of life threatening diseases may also benefit from it”.

This has been supported by the Executive Letter on palliative care EL 96 (85)¹ which says that

“purchasers are asked to ensure that provision of care with a palliative approach is included in all contracts of services for those with cancer and other life threatening diseases ... although this letter is focused on services for cancer patients, it applies equally for patients with other life threatening conditions, including AIDS, neurological conditions, and cardiac and respiratory failure”.

Box 1 – Diagnosis of adult patients who received care from hospices or specialist palliative care services in 1994/1995⁴

	Cancer	Neurological	HIV/AIDS ⁺	Cardiovascular	Other
New inpatients	96.7%	1.3%	0.5%	0.4%	1.2%
New home care patients	96.3%	0.6%	0.6%	0.3%	2.2%
New day care patients	96.3%	2.2%	0.2%	0.3%	0.9%
⁺ Specialist HIV/AIDS services were excluded					

The message that palliative care should be available to all patients who need it has been reinforced by many purchasing authorities who, concerned with the equity of access to services they provide for patients who have life-threatening conditions, have added their voice to the call to provide palliative care for all. In addition patients, families, and patient groups for patients with life-threatening non-malignant conditions such as motor neurone disease, multiple sclerosis and CJD have questioned why hospice care is restricted to cancer patients, and have felt excluded.¹⁰

The question of whether hospices and specialist palliative care services have a role in providing care for people with non-malignant life-threatening diseases, and if so what, is therefore increasingly on the agenda. In 1996 the National Council for Hospice and Specialist Palliative Care Services

(NCHSPCS) and the Scottish Partnership Agency for Palliative and Cancer Care (SPA) set up a joint working party to address these issues.

We first consider whether non-cancer patients have needs for physical, psychological, social and spiritual care, and the extent to which these needs are currently being met. We go on to consider the reasons for and against extending specialist palliative care to these patients. We then describe possible models of service provision, and the educational needs of health professionals both within and outwith specialist palliative care and make recommendations for future research and action.

Throughout the report we differentiate between the palliative care approach and specialist palliative care services (see *Definitions*, page 8).²

2 Palliative care needs of people who die from non-malignant diseases

In 1963 John Hinton published a seminal study which was to play an important role in the initial establishment of St Christopher's Hospice and in the subsequent development of the hospice movement. In it, he described the quality of care received by dying patients, demonstrating considerable unmet need among dying cancer patients.¹¹ However, he also showed that cancer patients were not alone in suffering uncontrolled symptoms in the last days of life. Although pain was less of a problem in non-cancer patients Hinton concluded that discomfort was not greatest in patients dying from cancer: patients dying from heart failure or renal failure or both had the most physical distress. Growing expertise in the control of cancer pain, together with the emotive nature of cancer, undoubtedly largely accounts for the consequent focus of the hospice movement on cancer. However, the unmet needs of people dying from other conditions have been recognised, albeit only peripherally, since the inception of modern hospice care.

Not surprisingly, given the focus on cancer care, there has been relatively little research into the experiences of people dying from conditions other than cancer. Although several studies have reported that cancer patients have more symptoms and more distressing symptoms, particularly pain, in the last months of life,^{12,13} other studies have demonstrated considerable unmet need for symptom control and psychosocial support among patients who die from other causes.^{13,14} Several classic studies which demonstrate deficiencies in care for the dying and which are often interpreted as indictments of terminal cancer care actually included both cancer and non-cancer patients in their sample.^{14,15} A small prospective study of people dying in an acute hospital reported that

“including patients who are dying from non-malignant disease in the study highlighted

certain problems such as nausea, anorexia and pressure sores in this group. It was found that moderate and severe pain occurred as often in these patients as in patients with cancer”.¹⁶

More recently, the SUPPORT study, a major US study of decision making in the last days of life, reported that in the last three days of life two fifths of patients across all the disease categories included¹ had severe pain at least half the time, and at least a quarter had moderate or severe dyspnoea*. Two thirds were reported by family members to have found it difficult to tolerate physical and emotional problems.¹⁷ Other studies have looked specifically at the needs of people dying from kidney failure,¹⁸ motor neurone disease,^{19,20, 21} dementia,^{22,23, 24} stroke,^{25, 26} chronic obstructive pulmonary disease (COPD)²⁷ and heart disease.^{28,29, 30} Taken together these studies demonstrate considerable symptom burden, psychological distress and family anxiety. Further research is needed in order to identify which patients who die from non-malignant disease are especially in need of better symptom control, psychological support and family support in the last days of life, and to document fully differences between their needs and those of the cancer patients traditionally cared for within hospices and specialist palliative care.

However, we consider that there is now ample evidence to demonstrate that cancer is not the only cause of death which results in considerable distress in the final months of life for both patients and families.

* acute respiratory failure/coma/COPD/chronic heart failure/cirrhosis/colon cancer/lung cancer/ multi-organ system failure with cancer/multi-organ system failure

3 Specialist palliative care provision for patients who die from non-malignant diseases

Few patients who die from non-malignant disease die in a hospice or under the care of a domiciliary palliative care team. Hospital palliative care teams play a somewhat larger role in the care of these patients; several inner-city teams reported to the working party that non-cancer patients make up more than a third of their workload. However, these teams were self-selected and therefore may not be representative. We selected 50 teams at random from those listed in the 1997 Directory of Hospices and Specialist Palliative Care Services.³¹ Nineteen replied to a request from the working party for information. The proportion of their workload in 1996 that was made up by patients who did not have cancer ranged from 0% to 12%, with a median of 5%. Several teams reported that non-cancer patients were increasing as a proportion of their workload. The low response rate means that some caution is needed in drawing conclusions from these findings. In addition, we do not know what proportion of patients with non-malignant disease who died in these hospitals were seen by these teams, but, as on average cancer patients made up 95% of their workload despite being only 25% of deaths, it is likely to be a small minority.

Hospices and specialist palliative care services clearly play a minimal role in the terminal care of non-cancer patients.

There is almost no evidence as to the effectiveness or acceptability of specialist palliative care services for patients with non-malignant disease other than those with motor neurone

disease^{19,21} or dementia.^{23,24} However, the dementia studies were based in the USA where the hospice services take a rather different form than in the UK, and these results are therefore of limited applicability to this country.

This report does not look at the substantial needs of people with dementia which will be addressed in a forthcoming Report from the National Council and SPA joint working party on Palliative Care for Adults with Mental Health Problems.

Box 2 shows the place of death in 1990 for patients who died from heart disease and stroke (cancer is included as a comparison group). The majority of these patients died in hospital, with nursing homes also playing an important role particularly for older people. Deficits in the care provided for people who die in hospitals are well documented, and are illustrated by the studies reported above (see for instance,^{14,15 16}). There is evidence that death is not always well managed in nursing homes.³² Deficits in primary care for those patients who die at home and for the majority who spend most of their final months at home although dying elsewhere have also been demonstrated.^{5,14,33} Higginson, in her review of the effectiveness of palliative care services for cancer patients, concluded that there was strong evidence that conventional care alone fails to meet the needs of many patients and families.³⁴ The findings summarised above suggest that the same is true of conventional services for patients dying from non-malignant disease.

Box 2 – Place of death of a random sample of deaths from cancer, heart disease and stroke in the last quarter of 1990 in 20 UK health districts¹³

	Cancer (n = 2063) %	Heart disease (n = 683) %	Stroke (n = 229) %
Place of death:			
home	29	29	9
hospital	50	55	67
hospice	14	0	0
residential/nursing home	7	12	24
other place	0	4	0

4 Palliative care needs of patients living with life-threatening non-malignant diseases

Initially hospices focused on patients in the terminal phase of their disease. Although palliative care is still often seen as being synonymous with terminal cancer care, it has broadened its scope in some areas to encompass cancer patients at an earlier stage of their illness, and a recent model of palliative care has suggested that 'many patients need it (palliative care) early in the course of their disease, sometimes from the time of diagnosis'.³⁵ This has been challenged by some palliative care providers, concerned that the needs of the dying may once again be overlooked.^{36,37} This debate is of particular importance when considering the appropriate role of palliative care in the care of patients with non-malignant disease, as the terminal phase of these diseases is likely to be shorter, if recognisable at all. What evidence is there that patients living with life-threatening non-malignant disease who have not reached a stage where they are clearly 'actively' dying have unmet needs in the traditional domains of specialist palliative care expertise, including symptom control and psychological support for patients and families?

The Regional Study of Care for the Dying, the largest UK study of people in the last year of life, has compared the experiences of people who died from cancer, heart disease and stroke, from the perspective of bereaved relatives.^{5,13,25,28} Many patients in the latter groups would not have had a recognisable terminal phase to their illness. The results showed that pain is more common in cancer patients in the last year of life, but that heart disease patients were as likely to have had pain in the last week of life. Two thirds of respondents for cancer patients, half of respondents for patients of heart disease and two fifths of those for patients who died after a stroke reported that the patient had very distressing pain in the last year of life. Pain control by GPs was rated as being equally poor in all three groups, but was reported to have been worse for stroke patients in hospital than for the other two groups. Although nausea and vomiting, difficulty in swallowing and constipation were more common in cancer, dyspnoea was more prevalent in heart disease than in cancer. Low mood and anxiety were common in all three groups.

A recent needs assessment of people living in the community with advanced COPD similarly

demonstrated that the quality of life in these patients is often very poor.²⁷ They were a very sick group of people experiencing great restriction in lifestyle and severe symptoms. Care was focused on acute episodes with the neglect of other aspects of patient care in the community. Relatives and other informal carers had little help, for example in the form of planned respite care, and received little bereavement support.

In addition, there is a considerable body of literature within medical sociology which has investigated the experiences of patients and families living with chronic diseases, both those which are life-threatening and those with a more stable course, and a growing literature on quality of life issues in these patients.³³ This literature demonstrates the need for better information for patients and families, for more psychological support, for better community services, more attention to the needs of informal carers and for suitable long-stay facilities for the young long-term sick.

There is therefore evidence that existing health and social services are not fully meeting the needs of patients living with life-threatening diseases and their families, for physical, psychosocial or spiritual care.

This does not, however, necessarily demonstrate a need for specialist palliative care for these patients. Specialist palliative care is not unique in its stated emphasis on the quality of life and holistic care. The language of general practice, geriatric medicine and of nursing also emphasises the need to see patients as more than physical bodies and to recognise their holistic needs. Although evidence suggests a gap between rhetoric and reality, there are of course examples of excellent care for patients with chronic diseases from services and practitioners outside palliative care who provide well coordinated, multi-professional care.

Patients living with life-threatening non-malignant diseases undoubtedly have needs for symptom control, psychosocial support and appropriate practical help. The question for specialist palliative care is what specifically is its role (if any) in meeting the needs of these patients. This is discussed below.

5 Why extend specialist palliative care to patients with non-malignant diseases?

The principal argument underlying the drive by government and commissioners to expand specialist palliative care to include patients with life-threatening non-malignant disease is that of equity: if people with conditions other than cancer have similar needs to cancer patients who currently receive palliative care it is inequitable to exclude them from palliative care services. The evidence summarised above clearly demonstrates that in the final phases of their disease some patients with non-malignant diseases do have similar levels of need to cancer patients. Health commissioners purchasing services for their local population based on need rather than on established patterns of provision are unlikely to want palliative care to be focused entirely on cancer patients.

To date GP total purchasing projects have had little effect on specialist palliative care services, with the majority of these projects blocking back to the health authority any funds currently used to support voluntary hospice services. Changes in

primary care responsibility for commissioning introduced in the recent White Papers on the NHS are similarly unlikely to lead to a U-turn in the current drive for equity in palliative care provision; a number of surveys have shown that GPs would welcome access to and advice from specialist palliative care services for patients with non-malignant disease.^{39,40}

Much funding for hospices and specialist palliative care services, however, comes from non-NHS sources. Although the NHS contribution is likely to be an important lever for change, some voluntary independent hospice services may be able to ignore pressure from health commissioners and the UK Departments of Health to extend care to patients with non-malignant diseases provided voluntary giving is sustained, and may decide to do so. The equity issue is not, however, a powerful argument simply because of the link between it and NHS funding for palliative care. It can also be seen as an ethical argument against the status quo.

6 Arguments against opening up specialist palliative care services to patients with non-malignant diseases

1 Existing services will be overwhelmed with referrals

A common argument against the extension of palliative care services fully to non-cancer patients is that existing services will become 'flooded' by large additional numbers of referrals, and will be unable to meet demand.⁴¹ Estimates based on symptom prevalence data of the number of patients with non-malignant diseases who may need specialist palliative care range from half to one times the number of cancer patients needing care (not all of whom currently get it).³⁴ This is understandably a daunting prospect for services.

However, the experience of hospital palliative care teams who made submissions to the working party suggest that, although there was widespread concern and recognition of the possibility, 'flooding' may not be an inevitable result of widening eligibility criteria to patients with non-malignant diseases. Some respondents commented on the disappointingly low number of referrals to hospital and domiciliary palliative care teams from other clinicians despite widespread advertising. This was attributed to a lack of understanding or appreciation as to what specialist palliative care has to offer such patients, the stigma attached to the teams' name due to its association with cancer, and the reluctance of some clinicians to seek palliative care advice until the patient was moribund. (Several informants reported that these were in fact similar to the obstacles originally encountered when trying to offer services to oncologists.)

Services which provide care for non-cancer patients emphasised the importance of being clear about what they could and could not offer, being able to decline to be involved when they felt they had nothing specific to offer, and not offering open-ended involvement. With these safeguards, being overwhelmed by referrals has not been the problem many services had feared.

However, many teams have begun advertising their services beyond cancer fairly recently, and the 'market' for specialist palliative care for non-cancer patients has yet to be developed. It is therefore possible that future referrals will increase to the point that services are overwhelmed.

2 The disease trajectory is difficult to determine; estimates of time to death are too inaccurate

Although doctors and nurses are less accurate in predicting life expectancy in cancer patients than sometimes thought, it is generally accepted that it is more difficult to judge the likely time to death with patients with non-malignant disease. For instance, the SUPPORT study generated multi-variable estimates of survival for hospitalised patients and found that lung cancer patients on the day before death had less than a 20% predicted chance of living for two months, compared with the 60% chance of doing so in patients with congestive heart failure.⁴² This leads to fears that inpatient beds and day places will be blocked by patients with non-malignant disease who are accepted by the services when gravely ill, but who subsequently recover and return to their previous state of 'chronic' rather than 'acute' dying. This is clearly linked to anxieties about services being overwhelmed and is understandably a real concern, particularly for smaller hospices and in-patient units.

A counter argument is that prognosis should not be an issue if services are clear about what they are offering to the patient and do not admit patients (or accept them in home or day care) without clearly specified goals and a timescale negotiated with patients and families. Inpatient care for cancer patients is moving in this direction, with only half of admissions in 1994/1995 ending in death.⁴ However, community health and social services are often less developed for non-cancer patients and there is a lack of suitable long-term nursing care, especially for younger chronically ill patients. Difficulty in estimating life expectancy, with a consequent danger of beds being occupied for long periods by patients with non-malignant disease, may be a major deterrent to some inpatient units (particularly smaller ones) considering changing their referral policies to fully embrace the needs of patients with non-malignant diseases.

3 Do specialists in palliative care have the necessary skills?

A third argument against the expansion of specialist palliative care fully to non-cancer patients is that specialists in palliative care do not have the necessary skills and expertise to provide high-quality medical, nursing and social care for these patients. Undoubtedly, many specialists – whether doctors, nurses, social workers or professionals allied to medicine – have a background in oncology and have a greater depth of knowledge in cancer pathology and treatment. Most of the specialists in palliative care currently providing care for patients with non-malignant diseases consulted by the working party voiced anxiety about this. They stated that they and their colleagues did sometimes feel out of their depth, for example, in relation to the complex medication requirements for chronic congestive heart failure or for AIDS.

Doctors emphasised the importance of keeping in close contact with the clinicians who had initially referred the patient, recognising the depth of their specialist expertise, and of consulting them and pharmacists and referring back where appropriate. This appeared less easy for nurses, but several respondents had developed good links with, for instance, cardiology ward sisters or appropriate clinical nurse specialists (eg Parkinson's disease specialist nurses). Social workers reported being less familiar with services available for non-cancer patients. The importance of working closely with colleagues with experience in these fields was emphasised.

There is no doubt that specialists in palliative medicine have expertise in the control of cancer pain, and this may well be relevant to some patients with pain from non-malignant disease. However, palliative care will not be able to provide the full selection of management strategies ranging from invasive and implantation techniques to cognitive-behavioural pain management programmes.

There is a general agreement that lack of knowledge is less of a problem once the patient is actively dying, as the final pathways and associated psychosocial issues are very similar across diseases. There is also agreement that expertise in opioid use and other aspects of

symptom control,⁴³ in team work, in psychosocial support and in negotiating ethically difficult situations are generally transferable. Clearly the lack of expertise outside cancer is a potential problem and has implications both for appropriate models of care for these patients and for the educational and training needs of hospice and specialist palliative care providers. These are considered below.

4 Resources

Charitable giving accounts for much of the funding of hospices and specialist palliative care services in the UK. There is concern that changing admission criteria to include patients with non-malignant disease may result in a drop in public support due to the dilution of cancer's emotive appeal, societal prejudice against older people, and the stigma attached to illnesses perceived to be self-induced, such as HIV/AIDS. Although such concerns have been raised since the mid-1980s, when some hospices first accepted AIDS patients, there is no evidence of the effect of change of admission criteria on charitable giving. The Sue Ryder Foundation, which has always had an explicit policy of including patients with non-malignant diseases in its palliative care homes, has not found this a barrier to fundraising. The possibility that fundraising may be affected cannot therefore be ruled out, but neither can it be substantiated. It is, perhaps, a particular risk if opening services to patients with non-malignant diseases leads to fewer cancer patients receiving specialist palliative care. Education of the general public in the suffering of some patients with non-malignant disease may be needed to stimulate compassion and to sustain giving.

If existing services are to expand to include non-cancer patients, increased funding – whether from charitable sources or from the NHS – will be needed to prevent care for people with non-malignant diseases being provided at the expense of cancer patients, which would clearly be unacceptable to providers and possibly members of the public who financially support voluntary hospices. The quality of existing provision needs to be sustained. Many of the services which provided evidence to the working party stated that they were already experiencing financial constraints and were unable to expand service provision to

fully meet existing demand. Although it may be possible to provide services for patients with non-malignant diseases in particular need by better focusing of existing services, the question of where funding will come from to address fully the needs of these patients is understandably a major barrier to expansion for many services, both NHS and voluntary.

A further barrier is the role played by cancer charities in pump-priming new specialist palliative care services (Macmillan Cancer Relief) and in funding services on a continuing basis (Marie Curie). Marie Curie Cancer Care centres are now able to admit some non-cancer patients following a change in policy in 1996. Macmillan Cancer Relief reports that 'Macmillan would always expect that the majority of people receiving the benefits of a Macmillan service would be those affected by cancer. However, Macmillan Cancer Relief recognises that people other than cancer patients may benefit from palliative and specialist palliative care and has therefore never excluded non-cancer patients from any of the services and post-holders it has funded, although the actual provider of that service, either NHS or voluntary organisations, may have had to introduce local restrictions for resource reasons'. Macmillan Cancer Relief has clearly played an important role in pump-priming palliative care services, and growth in services for patients with non-malignant disease is likely to be slow unless the government provides funds specifically for this purpose and non-cancer charities play a similar role to that played by Macmillan Cancer Relief in the development of

cancer palliative care services. However, several disease-specific charities strongly endorsed the need of their client groups for palliative care, some from quite early in the disease, although their own resource problem inhibited them from providing such a service.

5 Will cancer patients be neglected?

Popular support for hospices has been fuelled by the contrast between memories of poorly handled cancer deaths, during which patients suffered unrelieved symptoms with little support, and personal experiences and popular images of peaceful hospice deaths. Understandably, many professionals, volunteers and supporters have a strong personal commitment to alleviating the suffering of terminally ill cancer patients and are anxious about the possibility that dying cancer patients will again be neglected if the focus moves to the majority of patients with non-malignant disease. Some cancer patients still receive inadequate care despite the huge advances of the past 30 years⁵ and hospice care has not therefore completely fulfilled the goals that it originally set itself. Efforts to improve palliative care for cancer patients throughout the health services must continue. However, some patients with non-malignant diseases also experience considerable unrelieved distress. The challenge is therefore to ensure that all patients who need palliative care benefit, without diluting the available resources and expertise.

This is, no doubt, an incomplete list of reasons why many hospice and specialist palliative care providers currently primarily providing care for cancer patients are cautious about extending their care to other patients. All are legitimate concerns, although some people reporting to the working party suggested that they have not found them to be major problems. In the next section we examine critically some common components of specialist palliative care provision which may be of particular benefit to patients with non-malignant disease.

7 Components of specialist palliative care provision for patients with non-malignant diseases

Promoting the palliative care approach (see page 8) is one possible model for meeting the palliative care needs of patients with non-malignant disease. It concentrates on supporting existing services for these patients in an attempt to overcome structural, organisational or funding barriers to providing holistic high-quality care, and by supporting and empowering others in the palliative care approach via education, thus heightening their sensitivity to the needs of these patients.

Increasingly, palliative care is covered in undergraduate or pre-registration training for doctors, nurses and other health professionals. Social work training is also likely to include coverage of issues around death and dying. In order for non-cancer patients to benefit from the palliative care approach, efforts to increase coverage of palliative care in pre-registration training needs to continue. There is also a growing and uncoordinated range of postgraduate courses available in palliative care and these are not accessed solely by those specialising in this field (or planning to do so). These include uni-professional courses as well as multi-professional courses, such as those traditionally run by many hospices, and a number of university-based courses, both at first degree and Masters levels.

Many people with chronic life-threatening diseases live and die in nursing homes. There are a number of initiatives providing education and training for nursing home staff, including schemes run by individual hospices and the Registered Nursing Home Association's pilot Palliative Care Education project, funded jointly by Macmillan Cancer Relief and the Wolfson Foundation. In addition, the Open University is currently developing training materials for use in nursing homes, based upon research on the needs of nurses and care assistants in this setting and on the impact of training on their skills and attitudes. Palliative care is now included in the list of categories for which nursing homes can be registered in Scotland. The Scottish Partnership Agency has recently collaborated with the NHS Management Executive in Scotland to develop standards for Palliative Care in Registered Nursing Homes which will be published by the Scottish Office.⁴⁴

GPs play a central role in palliative care, as most people who die spend most of their last year in the community. Studies over the past 30 years

have shown that although some GPs provide excellent palliative care, others do not.^{5,14,33} A major challenge in ensuring that the palliative care approach benefits all patients in the community is to educate and train all GPs, not just those already interested in palliative care and motivated to learn more. Courses and conferences with post-graduate education (PGE) recognition are one way of doing this. There is a well developed post-graduate educational and training network facilitated by regional education and training representatives for the Association for Palliative Medicine in Great Britain and Ireland. The Macmillan GP Facilitator scheme, whereby GPs with an interest in palliative care work alongside colleagues to improve their palliative care skills, is another possible way of improving palliative care in primary care. Community hospitals – medical coverage for which is provided by GPs – play an important role in caring for terminally ill patients in many rural areas of the UK and it is important that patients dying in community hospitals receive good palliative care. Community hospitals in Scotland are seeking to improve their current palliative care provision in collaboration with local specialist palliative care services; the SPA is currently developing guidance on this.⁴⁵

There are also opportunities that can be taken in the context of continuing medical education (CME) to enhance the skills of consultants. The need to develop the palliative care skills of consultant colleagues is a challenge that the increasing number of academic departments of palliative medicine/care or well established educational departments in specialist palliative care units needs to address.

Continued efforts to educate trainee doctors, nurses, physiotherapists, occupational therapists, social workers and pharmacists – as well as those already in practice – in the palliative care approach are essential steps to improving the quality of palliative care for all. Further research is needed into effective ways of educating professionals in the principles of palliative care and into ways of implementing the palliative approach in busy units. However, there is no evidence as yet for the effectiveness of education and promotion of the palliative care approach alone in improving palliative care standards. Indeed, the palliative care approach cannot easily 'stand alone' without the backup and expertise of specialist palliative

care. In addition, up to one in five of patients with non-malignant disease who die have symptom-control problems comparable to those of cancer patients who receive specialist palliative care.⁴⁶ There has, therefore, to be doubt as to whether education in the palliative care approach alone can fully meet the needs of these patients. It is also unlikely to reduce pressure from commissioners – or, indeed, patients and families – for equity.

However, in the light of the barriers summarised above, there is understandable reluctance to extend existing services in their current form with perhaps open-ended commitments and full multi-professional input to the full range of patients who die from non-malignant disease, especially in the absence of dedicated funding. Are there alternative components of current specialist palliative care which might be appropriate if funding is forthcoming?

2 Consultancy services

These are services already provided by many hospital palliative care teams, where colleagues offer advice on the care of a patient, often in joint clinics, usually for a specific problem or problems (eg lymphoedema) with no expectation of an ongoing commitment to the patient and their family.⁴³ Responsibility for the patient remains with the referrer. Examples of where consultations may be sought include: specific symptom control problems; giving colleagues support in the use of opioids; one-off counselling support; help in negotiating the withdrawal of active treatment; or helping the existing teams reach – or agree – a decision about treatment or future plans for the patient. Usually only one member of the multi-professional palliative care team is involved. Although patients may have benefited from the involvement of the full multi-professional palliative care team, many already have a multitude of professionals involved in their care and may not have welcomed the ongoing involvement of more services associated with hospice care which the public often equates with death. In addition, consultancy services enable existing specialist palliative care expertise to be used more broadly than would be the case if all patients were offered full multi-professional care.

The range of referrals received seems to depend on the background of the members of the palliative care team and on the availability of other services.

For example, a hospital palliative care team led by a physician trained initially in respiratory medicine receives referrals predominantly from that speciality. In this and other cases referrals build up gradually, initially coming from clinicians already known personally, or through previous professional experience, to members of the palliative care team.

Consultancy services need not, however, be hospital-based. For instance, in 1995 one London hospice developed a consultancy service, which has been valued by those who have used it. Again the pattern of referral reflects the skills of the members of the palliative care team dedicated to this service: the full-time worker on the project was a social worker and, despite initial expectations that most referrals would be for medical or nursing advice, most were in fact for psychosocial support. A maximum of five sessions per patient was offered, and few problems were encountered when ending this involvement with the patient.

The further development of consultancy services will allow a wider range of non-cancer, and indeed cancer, patients to benefit from the expertise of specialist palliative care than at present. This development will also contribute to the process of educating other professionals in the principles of palliative care especially if, as in several examples already in operation, the palliative care team declines to see a patient unless junior members of the referring hospital team are in attendance. Where it is possible to arrange joint visits with GPs or with district nurses, a similar educational effect is likely.

3 Short-term involvement

Some patients will have needs that cannot be adequately met by a one-off or short series of consultations with one member of the multi-professional team. Their needs require a multi-professional input similar to that offered to patients with cancer, involving a domiciliary palliative care team or possibly a hospice admission for respite or symptom control. The experiences of providers offering these services to patients with non-malignant disease highlights the importance of having clear intervention goals and an expected timescale for the involvement. It is also important to have clear plans of discharge back into the care of hospital or GP once problems appropriate for specialist palliative care intervention have been

resolved. Although this should all be negotiated with patients and families at the beginning of the teams' involvement, it is recognised that in practice resources may make this difficult or impossible.

Opinion on the ease of withdrawal once the initial problems have been resolved is mixed. Some consultants reported no difficulty in arranging for discharge from home care teams or hospice after, say, two weeks, while social workers in the same services reported that in many situations this is a major problem. Discharge problems arise from the relative paucity of community health and social services provision, current financial constraints and, in particular, difficulties in some areas in funding and organising good-quality nursing home care for patients unable to return home. This is a particular problem for younger people, and at all ages can cause conflict with patients and families as hospice care is free while nursing home care is not, unless patients fulfil criteria for continuing NHS care. The eligibility criteria for this can vary between local health and social services as well as between geographical areas. Nursing home care may be excellent but it may be less acceptable to patients and families. Some specialist palliative care services have developed a good relationship with local nursing homes to facilitate the discharge of cancer patients no longer requiring specialist input; similar links could be developed for patients with non-malignant disease. An additional approach has been piloted in one voluntary hospice in the north of England which has obtained funding from the health authority to put extra nursing help into nursing homes when a resident is dying, providing the home has its full nursing quota.

Other innovative schemes would be needed in order to ensure that non-cancer patients admitted to specialist palliative care services for the resolution of specific problems have access to good-quality appropriate care on discharge. Some hospices may feel that providing such care on a long-term basis is an appropriate direction to move in. However, it is important to recognise that the continuing care of patients – whether with a cancer or non-cancer diagnosis – cannot be the sole responsibility of specialist palliative care.

4 Comprehensive specialist palliative care

It will be appropriate to offer the full range of specialist care services on an ongoing basis to some patients where patient and family problems become particularly complex and are within the remit and expertise of specialist palliative care, and when patients are close to death.

There is some dissension about the appropriateness of providing full specialist palliative care for motor neurone disease patients, with some specialists reporting that in their opinion these patients should receive respite care or ongoing care in nursing homes, as in their experience, they need little ongoing medical intervention. Others, however, feel that this disease is associated with such severe suffering and people with it need such expert nursing that it should remain within the remit of hospices and specialist palliative care. Similar discussions are likely within hospices and specialist palliative care about the appropriateness or otherwise of providing care for other groups of non-cancer patients.

However, if services are to avoid being overwhelmed, with beds being blocked by the long-term sick, clear referral criteria are needed. In particular, teams should be clear that the patient and informal carers have needs likely to benefit from the expertise of hospices and specialist palliative care in symptom control, psychosocial support, family care, skilled nursing and open communication. It is the responsibility of every hospice and specialist palliative care team to define and make known locally precisely what they can offer.

In the absence of research into the effectiveness of specialist palliative care for non-cancer patients, it is particularly important that care for these patients is audited to see whether – and which of – these patients show the same benefit from specialist palliative care as cancer patients.

As possible models of care for patients with non-malignant disease become clearer it will also be important that full multi-centre evaluations of care are developed.

5 Development of disease-specific clinical nurse specialist posts

A further option is to encourage the development of services specifically for defined groups of patients with non-malignant disease. There are already clinical nurse specialists who specialise in, for example, respiratory disease, rheumatoid arthritis and Parkinson's disease. These nurses are often funded by the pharmaceutical industry and, in addition to their role in drug trials, play an important role in patient and family support and have specific additional expertise in the management of the disease. An increase in funding for these posts, together with educational programmes to enable these valuable specialist nurses to adopt confidently the palliative care approach in addition to their existing skills, and the development of professional links with specialist palliative care teams may be one way to improve the palliative care received by patients with non-malignant disease.

The equivalent in the community may be the development of more link nurse posts: community nurses with extra training in palliative care, who provide a link between their community nurse colleagues, and clinical nurse specialists in palliative care. The development of disease-specific clinical nurse specialist in palliative care posts is also a possibility, provided that they are part of

specialist palliative care teams. A major advantage of this would be that nurses would be able to develop disease-specific expertise, but the potential for further fragmentation needs to be considered.

6 Partnerships with disease-specific service providers

A final option is to work in partnership with statutory or charitable providers of services for patients with non-malignant disease to encourage the consideration of the palliative care needs of patients receiving their care, to further the adoption of the palliative care approach, and to consider appropriate links with specialist palliative care services. One national charity for patients with a chronic neurological condition is actively considering the appointment and evaluation of a palliative care adviser. The brief would include consideration of whether and how the palliative care approach can be implemented by services provided for this patient group, and the monitoring of outcomes for patients and families. Other charities concerned with the needs of patients with a variety of chronic conditions have expressed concern to the working party at the inequitable provision of specialist palliative care services: if successful, this may provide them with a way forward.

This paper has analysed a range of issues concerned with meeting the palliative care needs of people with non-malignant diseases and their carers. The Executive Summary and Recommendations arising from this analysis are set out on pages 9, 10 and 11.

Having outlined the issues to be addressed Council and the SPA will monitor the extent to which these recommendations are put into effect over the coming two years.

Box 3 – Key implications of extending services to patients with non-malignant disease, by type of specialist palliative care setting

	Domiciliary palliative care team	Hospital palliative care team	Day care	Inpatient unit
Lack of skills/ knowledge in non-malignant disease	Can be a problem. Need to establish/maintain good links with referring GPs and hospital teams	Can be a problem. Should be relatively easy to access advice, provided good links maintained with referring hospital firms	Can be a problem. Need to establish/maintain good links with referring GPs and hospital teams	Can be a problem. Need to establish/maintain good links with referring GPs and hospital teams
Difficulty in estimating prognosis	Can be a problem. Clear goals need to be established and discharge plans made when referral accepted	Not usually a problem	Can be a problem. Clear goals and discharge policy need to be established and discharge plans made when referral accepted	Can be a problem. Clear goals need to be established and discharge plans made when referral accepted
Lack of suitable long-term nursing care of patients with non-malignant disease	Can be a problem. Clear goals need to be established and discharge plans made when referral accepted	Can be a problem for the hospital, but not necessarily for the team as they do not take over patient care	Not usually a problem	A definite problem, possibly hindering discharge and 'blocking beds'
Appropriateness (or otherwise) of mixing terminally ill cancer patients and patients with non-malignant disease	Not a problem as patients seen/advised on individually	Not a problem as patients seen/advised on individually	Can be a problem, little known about impact on cancer or non-cancer patients	Can be a problem, little known about impact on cancer or non-cancer patients
Existing heavy workload	Can be a problem. Expansion to encompass non-cancer patients will require extra funding and/or stricter referral criteria, possibly at expense of cancer patients. Cost of expansion less than for day care or hospice inpatient care	Can be a problem. Expansion to encompass non-cancer patients will require extra funding and/or stricter referral criteria, possibly at expense of cancer patients. Cost of expansion less than for day care or hospice inpatient care	Can be a problem	Can be a problem for some, although not all hospices operating at high bed occupancy ⁴
Lack of evidence of benefit for patients with non-malignant disease, and their families	Definite lack of evidence. Further research and audit needed	Definite lack of evidence. Further research and audit needed	Definite lack of evidence. Further research and audit needed	Definite lack of evidence. Further research and audit needed

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Appendix

Organisations consulted

Alzheimers Disease Society
British Diabetic Association
British Geriatric Society
British Heart Foundation
British Medical Association
British Society for Gastroentrology
British Society of Rheumatology
CONCAH – Continuing Care at Home
National Board for Nursing Midwifery and Health Visiting for Scotland
Neurofibromatosis Association
Royal College of Physicians and Surgeons of Glasgow
Royal College of Obstetricians & Gynaecologists
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of Nursing
Royal College of Physicians
Royal College of Surgeons of Edinburgh
Royal Pharmaceutical Society of Great Britain
Scottish Association of Health Councils
Scottish Council for Postgraduate Medical and Dental Education
The Multiple Sclerosis Society
The Pain Society

The many individuals, hospital support teams and nurses teaching palliative care who responded to requests for information and the organisations and associations represented on the National Council for Hospice and Specialist Palliative Care Services

Council's Publications

Occasional Papers (ISSN 1351-9441)

3. ***Key Ethical Issues in Palliative Care: Evidence to the House of Lords Select Committee on Medical Ethics***
July 1993: 17 pages Price: £2.00
5. ***Research in Palliative Care: the pursuit of reliable knowledge***
April 1994: 22 pages (ISBN 1 898915 01 6) Price: £3.00
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**NATIONAL COUNCIL FOR HOSPICE AND
SPECIALIST PALLIATIVE CARE SERVICES**

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e-mail: enquiries@hospice-spc-council.org.uk

**The National Council brings together all those
working in this field. Its role is:**

To represent the views and interests of hospice organisations and palliative care services to ministers, civil servants, MPs, the media and statutory and other agencies.

To provide advice to hospice organisations and palliative care services in their relations with health authorities, local authorities and other agencies on matters of national interest and concern.

To provide a forum for hospices, palliative care teams and those working within them to share knowledge, information and experience.

To undertake or encourage measures to improve facilities, resources and skills within palliative care, whilst preserving the contribution of existing organisations and avoiding duplication.

To develop professional standards and audit in association with others with an interest in this work.

To develop policies to promote better co-operation and co-ordination between the voluntary and NHS sectors and to avoid unwarranted expansion.

To monitor and evaluate community care policies and services for those with terminal disease.

To plan for the collection and publication of standardised statistical information (in consultation with the Hospice Information Service and other agencies working in this area).

To encourage improved professional education and research in all aspects of palliative care, working closely with universities and colleges, the medical and nursing Royal Colleges and international agencies.

To publish regular information about the work of Council, those it represents and the individuals and agencies with which it liaises.

**SCOTTISH PARTNERSHIP AGENCY FOR
PALLIATIVE AND CANCER CARE**

1A CAMBRIDGE STREET
EDINBURGH EH1 2DY
TEL: 0131 229 0538 FAX: 0131 228 2967

**The Scottish Partnership Agency brings
together 91 voluntary and statutory bodies
concerned with palliative and cancer care
services in Scotland.**

Through this partnership the Agency promotes the development of palliative and cancer care provision, aiming to ensure that high quality care is available for patients and families throughout Scotland.

The Scottish Partnership Agency aims to

- establish and maintain effective links for communication among bodies involved with the provision of palliative and cancer care services in Scotland
- facilitate the participation of voluntary sector groups and organisations in developing palliative and cancer care services in Scotland
- facilitate planning, co-ordination and consultation between the Partnership Agency's constituent members and the central departments of Government and related bodies
- encourage education and research to improve the quality of palliative and cancer care
- promote and encourage the development of monitoring and audit of palliative and cancer care in Scotland


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Scottish Partnership Agency for Palliative and
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Department of Health

ACT (Association for Children with life-
threatening or Terminal conditions and their
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Executive Director

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Statutory and voluntary bodies involved in
palliative and cancer care are members of
the Scottish Partnership Agency (SPA) –
voluntary hospices, charities and support
organisations concerned with cancer and
motor neurone disease, professional
associations in palliative care, health boards
and NHS trusts. They meet in four Regional
Groups, a Specialist Palliative Care Group
and a Special Interests Group.

Through these groups they elect the Council
of Management of the SPA. The Council
comprises 12 elected members, 2 Assessors
from the Scottish Office and an Observer
from the National Council.