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Caring about Dying

Palliative care and support for the terminally ill

a guide for donors and grant-makers

April 2004

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Caring about dying

Palliative care and support for the terminally ill: a guide for donors and grant-makers

Executive summary

"You are all going to die. How would you like to do it?"

Sharon Carstairs, and Minister with Special Responsibility for Palliative Care, Canada

- **This report provides a guide to grant-makers and donors seeking to understand and address the problem of care for the dying in the UK.** It shows how well-placed philanthropy can have a significant impact on quality of life in a person's final days.
- **There are around 600,000 deaths in the UK each year, of which 25% are from cancer.** Patients typically experience pain, uncomfortable symptoms and psychological distress in the last year of life; palliative care has a well established role in alleviating this.
- **80% of us would like to die at home or in a hospice, yet only 24% of deaths take place in these settings.** Most deaths take place in hospitals and nursing homes where palliative care is not well applied.
- **Many factors influence where and how we die;** sadly, arbitrary factors such as the local history of service development are still influential. Black and minority ethnic patients are less likely to access hospice care and those from the most deprived communities are less likely to die at home.
- **Some groups have specific needs:** services for those dying from a condition other than cancer need to be further developed and rolled out. Carers are often desperately in need of a break yet reluctant to take one. Children and adolescents need to be cared for by those with an understanding of their developmental stage, and home is usually the centre of care.
- **The sector costs over £600m a year, over half of which is provided by the voluntary sector.** Increased funding and support for good practice indicate more commitment from the government but the contribution of the voluntary sector remains essential. Government and voluntary sector are in any case co-dependent. Palliative care originated in the voluntary sector, and trail-blazing and innovation remain the sector's strengths.
- **Children's services** are not well-funded by government, with a heavy burden placed on the voluntary sector.
- **Funders have a range of options.** There is a continued need for the £370m pa that individuals, charity trading, corporates and grant-makers contribute to the direct delivery of palliative care. Alternatively, a funder can make a strategic donation, for instance to address weaknesses and inefficiencies in the sector; explore a particular area of unmet need; support the education of key professionals; or fund research, which could influence government funding in the future.
- **The report assesses the outcomes of interventions.** Some outcomes relate to the dying patient and their carers directly. Others relate to the quality of care of the dying in general.
- **The research in this report is based on a survey of the subject together with examination of organisations working on the ground.** A separate series of detailed reports on some of the individual organisations is available to donors and grant-makers.
- **NPC seeks to encourage higher levels of funding for outstanding charities and initiatives.** The final section of this report articulates clear priorities for private funding.

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Introduction

Benjamin Franklin said the only two certainties were death and taxes. Many of us spend a considerable part of our lives fretting about taxes, working to reduce the taxes we owe or damning the taxes we pay. Few of us spend similar time thinking about our death, preferring to think it too far away to be of consequence. For people confronting terminal illness death becomes a stark, even imminent reality and the manner of death an important concern. This report is about how people are cared for in the closing months of their lives, through the provision of palliative care. The report also touches on support for people confronting a diagnosis of potential or actual terminal illness, concentrating on cancer as a particular example, and explores how they can be helped during the journey with their disease.

There is considerable evidence that people have strong views about how they wish to live with disease and ultimately die, but that such views are seldom heeded. Too many people die in a place not of their choosing, and too little consideration is given to non-medical aspects of care. Relatives and loved ones are not adequately provided for.

Government plays a crucial role in the provision of palliative care but the voluntary sector is immensely important and can offer interventions beyond the current reach of government. This report outlines the role government plays and the complementary role of private funding. It highlights areas of voluntary sector provision which are currently under-funded and which private donors can support. Crucially it articulates the benefits ('outcomes') from such provision for the dying and their families. In so doing it makes the case for better, more civilised and more compassionate treatment for people in the closing chapters of their lives.

The purpose of this report

This report aims to provide a guide for donors who are interested in funding palliative care. Its purpose is to provide the detailed contextual information and analysis required to understand the extent of the need, the types of intervention, and the outcomes generated by such interventions. A supplementary report takes this process a step further, by making specific detailed funding recommendations. New projects are constantly being developed and existing ones updated by organisations and individuals, and so recommendations may vary over time. NPC is in a position to help with grant-making to projects.

The donors to whom this report is addressed will range from private individuals to grant-makers with extensive experience in this area. While the report aims to help all in this spectrum, it should be recognised that parts of the report have been written for the benefit of newcomers to the subject. When we refer to "donors" we include grant-makers, private individuals, companies or anyone else wishing to donate funds or provide grants.

The content of this report

The report is based on research carried out through extensive meetings with organisations, researchers, policy-makers, analyses of charity accounts and activities and reading of research materials. Opinions expressed in the report are the authors' own.

The report is divided into sections covering NPC's standard need, intervention and outcome approach. Section 1 describes the aggregate picture of palliative care need in the UK. Section 2 discusses the patient journey and the role of early support after diagnosis. As regards early support we have only been able to address cancer: a future report will consider other conditions. We go on to look at the provision of palliative care, and funding of the sector. Section 3 goes into greater detail on service provision by the government. Section 4 describes the role and contributions of the voluntary sector. When considering palliative care, we consider issues surrounding all patients regardless of condition.

Section 5 addresses the outcomes of particular interventions on several levels: that of the patient, the patient's immediate family, and also the wider impact of efforts to enable greater numbers of patients to benefit from appropriate care. Section 6 explores some of the funding options available to donors.

Appendices cover the workings of the NHS in more detail and also provide a brief overview of the situation in Scotland, which is different from that in England and Wales.

Section 1: The need

This section defines palliative care, and examines the numbers of people needing such care, and their experience of terminal illness. It goes on to explore how preferences for end of life care are not being met in terms of place or quality of care. Particular deficiencies are highlighted.

What is palliative care?

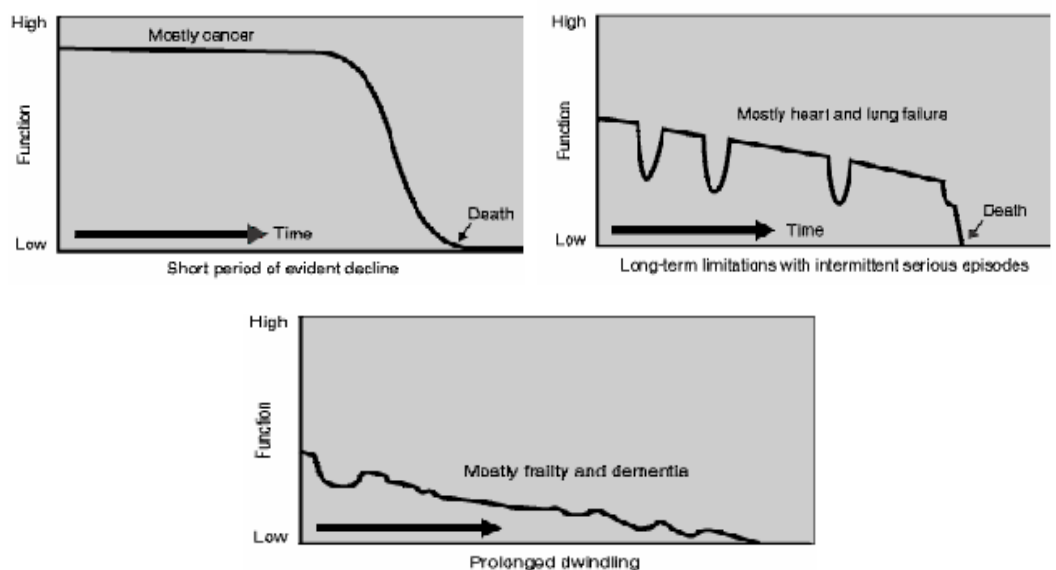
Box 1: The World Health Organisation's definition of palliative care, 2002

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial¹ and spiritual."²

Palliative care affirms life and aims to help patients live as fully and actively as possible until their death.

Palliative care affirms life and aims to help patients live as fully and actively as possible until their death. It aims neither to hasten nor postpone death and regards dying as a normal process. The approach intends to alleviate the "total pain" of the dying person, concentrating not only on relief of physical symptoms, but also on needs for social, psychological and spiritual support. It provides a support system to family and friends as they adapt to their loved one's deteriorating condition and eventual death. Whilst many people associate hospices with care of cancer patients, care for patients dying of other conditions has been a part of some hospices' work since they began. Aspects of palliative care may be applicable at other stages of illness; indeed, there is not always a definitive point where a patient's terminal phase begins. Consequently, there is considerable debate within the medical and caring professions as to what constitutes palliative care, continuing care, or general support for early stage sufferers of a life-threatening or terminal illness.

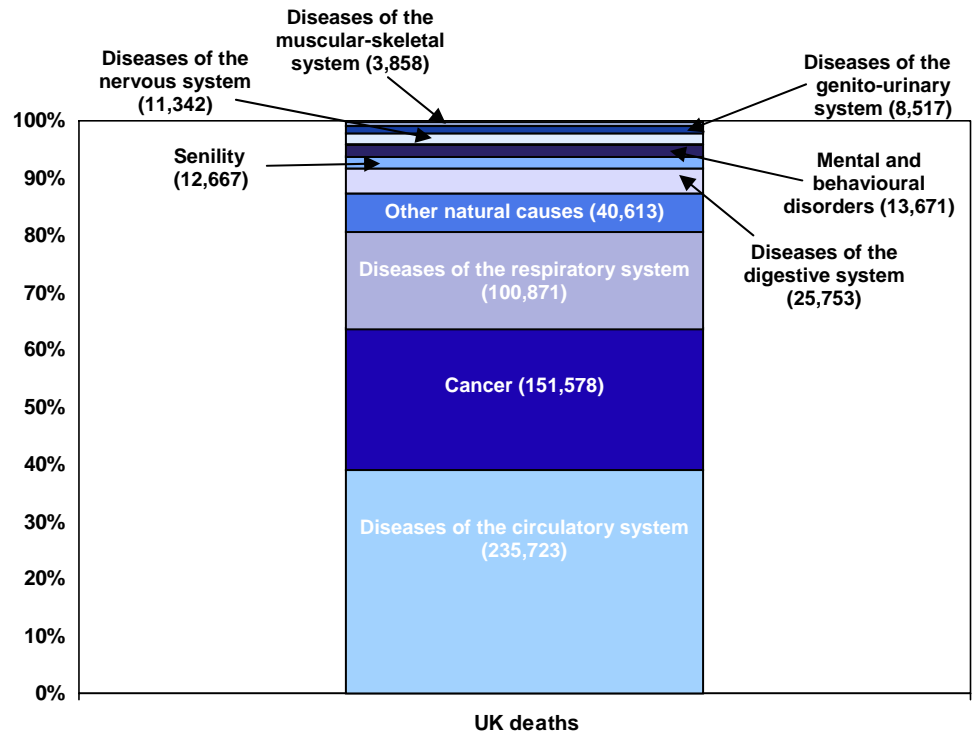
The need for support and services to a patient suffering from terminal illness starts at diagnosis, or even pre-diagnosis as results are anxiously awaited. In the case of cancer, this report will cover the patient's journey from diagnosis through death to the relatives' experiences in bereavement. With other terminal illnesses, our analysis is restricted to the last few weeks of life since the disease trajectories can be very different. In such cases, the dying and their carers often do not know when the end will come, as the diagrams below portraying chronic illness in the elderly illustrate.³ These were developed by Joanne Lynn, Director of The Washington Home Center for Palliative Care Studies in the US. We anticipate a separate report on degenerative conditions in the future.



How many people could benefit from palliative care?

Around 600,000 people die in the UK each year of natural causes.⁴ Of these, 39% die of heart conditions and 25% die of cancer. 63,000 are diagnosed with chronic heart failure each year. Such a prognosis is as bad as cancer and 40% will die within a year, some suddenly, others more slowly. Although neurological disorders only account for around 15,000 deaths according to official statistics, it is thought that there are people with such conditions whose cause of death appears as, say, heart failure on the death certificate.

Chart 1: Natural deaths in the UK, 2001



Source: *Annual Abstract of Statistics 2003, Section 9.5a.*⁵

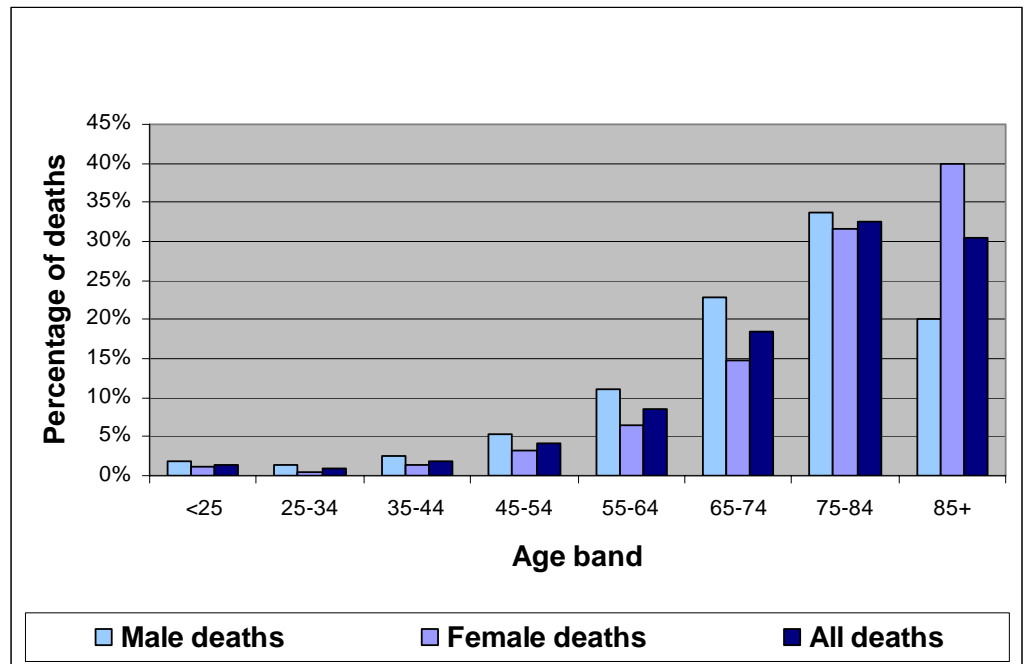
Cancer is not the only cause of death that results in considerable distress in the final months of life for patients and families, yet patients affected by other conditions only account for 5% of hospice in-patients. Whilst most widely associated with cancer, palliative care can also benefit patients dying of other conditions. Palliative and supportive care can be of help in three main groups of conditions:-

- Cancer
- Organ failure (e.g. neurological degeneration, heart failure, chronic obstructive pulmonary disorder, renal failure)
- General frailty, multiple pathology (including e.g. arthritis), dementia and decline.

Numerous studies demonstrate considerable symptom burden, psychological distress and family anxiety amongst those dying from the so-called non-malignant diseases in the second two categories. These patients are sometimes referred to as "the disadvantaged dying",⁶ and, like cancer patients, will not always be in need of specialist palliative care. Care provided by General Practitioners (GPs) and district nurses may be sufficient. However, epidemiological data suggests that the majority of terminally ill patients in need of pain relief have a condition other than cancer, though pain is usually more severe in cancer.⁷

Physical and psychological distress is common in people who are dying.

Chart 2: Age profile of UK deaths, 2001



Source: Annual Abstract of Statistics 2003.

The majority of deaths occur in people aged 65 or above. This is reflected in the need for and take-up of palliative care services. By 2020, 21% of the population will be over 65, up from 16% at present. Social isolation and greater need for nursing care will likely increase in line with expected growth in single person households.

There are 700,000 people in the UK with dementia and one in five people over 80 are sufferers.⁸ In addition to diagnosable problems, old age will ultimately kill patients through general physical deterioration and this can result in distress if the patient is cared for inappropriately.

Inappropriate care occurs frequently in the case of neurological disorders. Often, the only option for young people with Huntington's Disease, Progressive Multiple Sclerosis and in a Persistent Vegetative State is a nursing home. Staff frequently do not fully understand the changeable nature of Multiple Sclerosis, or the communication difficulties that result from Huntington's, leaving patients feeling misunderstood.

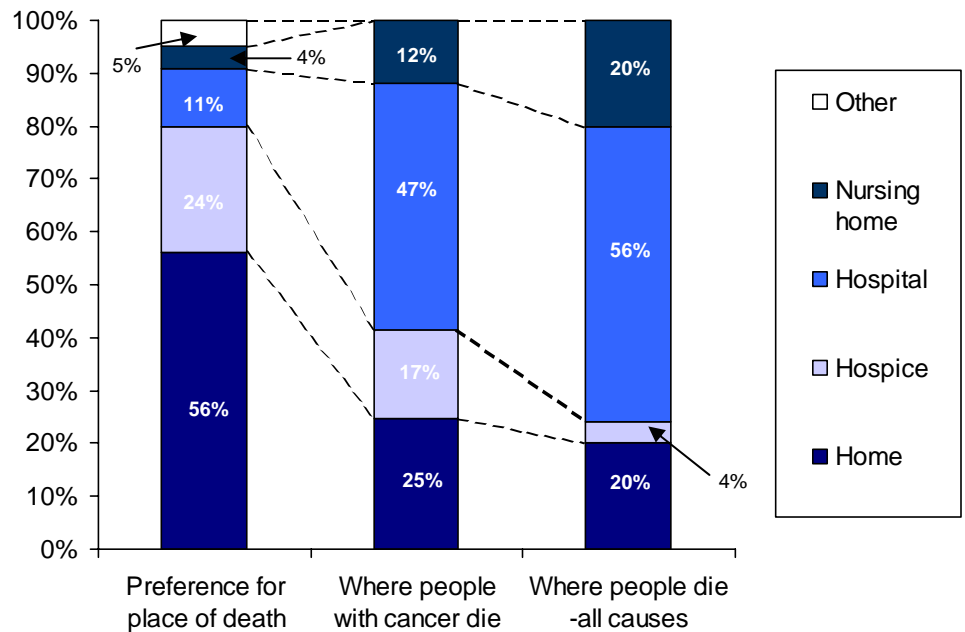
The economic cost of care for the dying is high. It has been estimated that 22% of hospital bed days are used by people in the last year of life.⁹ Not all of these patients can be cared for in a hospice or at home, but transferring care to a palliative care setting has the potential to reduce the pressures on NHS bed spaces and reduce waiting lists. Each day an estimated 3,500 beds are occupied because people lack follow-up care.¹⁰ There is also some evidence that hospice and home care reduces the overall cost of care.¹¹

Preferences for end of life care

When we consider the very last stages of life, we will repeatedly examine three crucial factors which contribute towards a good death: quality of care; choice in the place of death; support for carers.

The majority of deaths - 56% - occur in hospital, though only 11% of the population would wish to die in hospital (another study commissioned by Marie Curie Cancer Care has put it at as little as 4% preferring hospitals).¹² Whilst some hospitals provide very good end of life care, others have neither the resources nor the culture to provide a suitable environment for the dying. 56% of people would prefer to die at home, yet only 20% of deaths take place at home. For those who would prefer not to die at home, particularly if they live alone or in circumstances which would make it difficult, hospices provide a peaceful and accommodating setting. Less than one in twenty people wish to spend their final days in a nursing home, yet one in five deaths take place in this setting.

When we consider the very last stages of life, we will repeatedly examine three crucial factors which contribute towards a "good" death: quality of care; choice in the place of death; and support for carers.

Chart 3: Place of death: preferences vs reality

Source: Higginson, I. (2003) *Priorities and Preferences for End of Life Care in England, Wales and Scotland*. National Council for Hospice and Specialist Palliative Care Services.¹³

The gap between practice and desire in place of death highlights a key failing in the provision of palliative care in the UK. It seems that over half of UK deaths do not take place in the preferred setting. Home deaths seem particularly difficult to achieve because of a break down in home care leading to emergency hospital admission. Scaling up hospice bed provision five-fold to meet preferences is neither practical nor desirable. Hospice care may not be the most appropriate way of delivering palliative care to non-cancer patients, as we shall discuss later. More importantly, choice over place of death reflects anxieties about the other two important factors outlined above that contribute to a good death. There is evidence, discussed further later, that quality of palliative care in some settings, e.g. in some nursing and residential care homes, is poor and that carers are not considered important. If care for the patient was improved across all settings, and support for family, friends and loved ones was appropriate, preferences for place of death might be less marked and more would achieve their preferred place of care. The experience would also be less distressing for those who for good clinical or practical reasons cannot achieve their preferred place of death.

In some areas, there may be a need for more in-patient beds for palliative care: some hospices operate below capacity because of staff shortages, and others report that there is always demand for respite. However, most hospice providers do not report an overwhelming demand for increased bed spaces for terminal care. Hospice beds are increasingly being used for short-term interventions for symptom relief. Rather, there is a strong desire to expand the provision of home-based care and related services. Already hospices care for 100,000-150,000 people in addition to the 24,000 patients dying on the premises.¹⁴ As well as allowing more people to die in their place of choice, this would leave in-patient beds free for those with the most complex needs.

Patient preference for home care drops slightly closer to the time of death, possibly owing to an increased awareness of the difficulties of dying at home and the low level of support outside normal working hours.¹⁵ The patient may prefer the security of having medical expertise near at hand. Fear of failing to care appropriately for their loved one at home is a problem commonly raised by carers of the terminally ill and is often top of the list of their concerns.¹⁶ The anxiety of the carer may rub off onto the patient who may not want to become a burden. Carer panic is a common cause of hospital admissions close to death. With better community support and appropriate services in the home, it is estimated that up to 50% more cancer patients would be able to remain at home.¹⁷

The figures in Chart 3 highlight the disparity between the choice offered those dying of cancer and those dying of other diseases. 95% of hospice patients are cancer patients, implying that only 5,000-7,500 non-cancer patients benefit from hospice services.¹⁸

The majority of people would prefer to be cared for at home; lack of time and resources in the NHS and social services often means this preference is not met.

Experiences of terminal illness

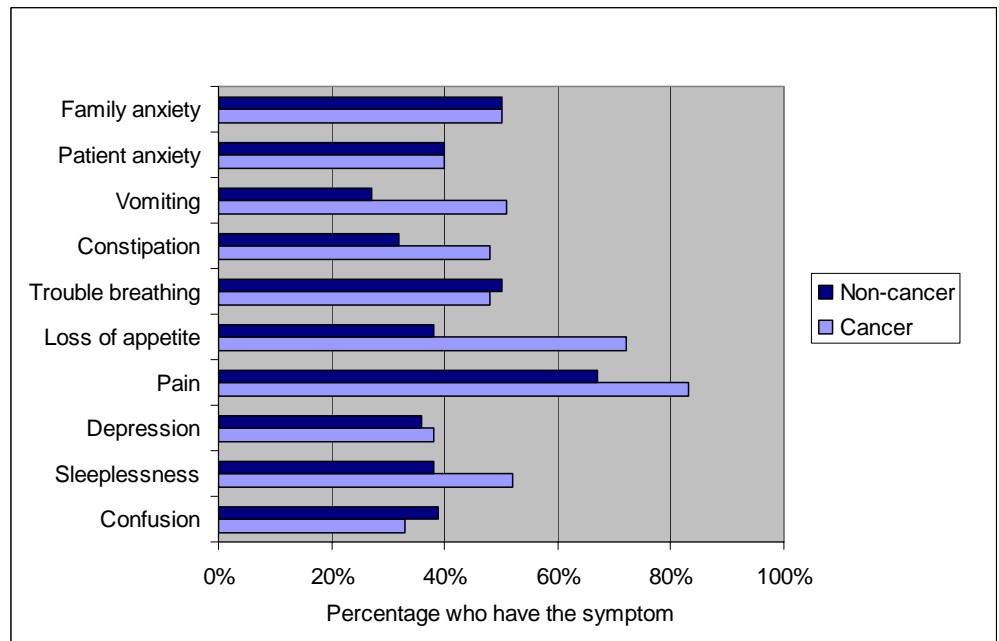
The process of diagnosis leaves some feeling isolated, confused and worried.

Health professionals working with terminally ill patients often find that social and psychological problems date from diagnosis, indicating a need for early support.¹⁹ Some find that doctors do not break bad news with sensitivity, or give them enough time to react and ask questions.²⁰ Lack of a diagnosis can present its own problems. Depending on the complexity of the disease and availability of medical expertise, patients may wait for some time before they have a definitive diagnosis. Estimating risk of dying and life expectancy is not an exact science - doctors are becoming increasingly reluctant to estimate how long a person will live.

The process of diagnosis leaves some feeling isolated, confused and worried. Some become angry, others feel acutely sad. Many find it hard to navigate through the various agencies involved in their care and report a lack of co-ordination. Patients report unmet needs with respect to daily life and managing emotions.²¹ Most people told that their condition no longer responds to curative treatment report feelings of shock and disbelief, giving way to strong and sometimes overwhelming emotions, no matter how long they have known this was a possibility.

The dying person may grieve for the loss of a future and worry about how their loved ones will cope without them. Some feel frightened about the prospect of physical and emotional pain. Relationships are often strained by serious illness and many find it difficult to know how to respond to a dying person, leaving them feeling isolated and alone.²²

Chart 4: Prevalence of problems experienced by patients in the last year of life



Source: Higginson, I. (1997) *Epidemiologically based needs assessment for palliative and terminal care*, Radcliffe Medical Press.

Patients typically experience a range of symptoms and discomfort in the last year of life. These can be alleviated by in-patient palliative care or home care, which both tend to produce better outcomes when compared to conventional hospital or community care.²³ However, there is scope for improving the quality of care by generalists through education and support from specialists in palliative care. Unsurprisingly, symptoms include high levels of anxiety and depression, and these conditions can also benefit from professional intervention.

Whilst some bereaved in an NHS setting report excellent and compassionate care, others report a lack of thoughtfulness and attentiveness. Many relatives and friends complain about a lack of continuity of care, with weak and vulnerable people having to repeat their histories and preferences again and again. This sometimes results in conflicting advice.

A recent study on care of the dying in the NHS²⁴ found that, in many cases, death is not discussed in advance with the patient and their carers. The terminally ill person can lose trust in their medical team if their condition is deteriorating and this is not acknowledged. Sometimes, doctors do not have sufficient expertise to recognise the progression of terminal

Carer anxiety in the last weeks of life is often high. Relationships tend to be under emotional strain.

illnesses and thus cannot accurately “diagnose dying”. In other cases, they are simply afraid to broach the issue with the individual and their carers.

Invasive procedures, investigations and treatments are often pursued at the expense of the comfort of the dying patient. As a result, he or she may die with uncontrolled symptoms and with a lack of dignity, without having had the opportunity to resolve unfinished business and seek spiritual support. Distressing deaths may lead to complex bereavement problems.²⁵

Relatives are often angered or distressed when their loved one dies without a doctor having discussed this possibility with them. Conversely, if relatives are told that the patient is dying they have the opportunity to ask questions, stay with the patient, say their goodbyes, and prepare themselves for the death.

Doctors may be reluctant to let a dying patient know their prognosis. Some patients keep their fears to themselves.

Caring and informal carers

Box 2: The strain of caring

“A lot of doctors don’t understand. They can see you doing the physical bits and pieces, but they don’t see the mental side – that’s the worst side, you know. They can see you doing the washing, the ironing, the hoovering, cooking, all that. But the mental side, nobody sees that. That’s the side I find very hard. I can cope with everything else, but the mental side, and the anguish and frustration and temper that builds up, you’ve nowhere to release that – there’s no outlet for that; it does become – well, it certainly does for me – a problem.”

Sources: Rose, K. in Payne, S. Ellis-Hill, C., 2001, *Chronic and Terminal Illness: New perspectives on carers and caring*, Oxford University Press

The impact of the terminal illness and death of a loved one can be huge. Families also wrestle with powerful and confusing emotions as they adapt to the diagnosis and prognosis. Often a family member takes on the responsibility for the majority of physical and emotional care. As with the patient, carers’ difficulties often begin when a serious medical problem manifests itself.

The impact is perhaps the greatest on the person who takes on the majority of the care. Throughout this report we will refer to ‘carers’, by whom we mean the patient’s spouse or partner, or members of the family, or friends, who are unpaid and undertake the lion’s share of the responsibility for day to day caring for the individual. There are over 5.2 million unpaid carers in England and Wales, including both those looking after terminally ill and those caring for others, of whom over a million provide more than 50 hours of care per week.²⁶ Carers span all age groups and social classes, but are most commonly female, aged between 50 and 70, although 33% of care for people over 65 is provided by people over 70 and 175,000 are under 18.²⁷

Carers can often be under intense physical and emotional strain, particularly in the case of a long or physically debilitating illness. They may be taking on a variety of unfamiliar roles, delivering physical care, acting as patient advocate and taking on responsibilities that previously fell to the sick person. Carer breakdown or lack of confidence is a major cause of hospital admission, yet once the person has died, regret that the loved one died in hospital is common.²⁸

Carers often find it difficult to continue their former roles, be it paid work, childcare or other commitments. Giving up work has substantial financial implications and often two incomes are lost (both patient and carer). Carers may also find that they have no time to themselves, and it is common for carers to fall into ill-health because they neglect their own needs.

Carers may see it as their job to be sympathetic and supportive to the patient and feel guilty and ashamed if they find it hard to maintain this. Some may get support from families and friends but others can feel isolated and overburdened. Carers rate time away from their role as their greatest need but are often ambivalent about taking such time off.²⁹ Some feel they have no identity and only exist in the context of the patient.³⁰

Many do not know what to expect as the illness progresses and are unsure of what to do when their loved one is very sick.³¹ It is unsurprising that the most urgently reported needs are psychological and informational.³² They may worry about leaving the patient alone, particularly as death approaches. However, they are often seen by health professionals as providers of care and not as people with their own needs.³³

Many find their financial situation is affected by loss of employment and lack of access to benefits.

There is evidence that patient distress increases with carer anxiety; and that the potential for a carer to become distressed increases with both patient pain and psychological status.³⁴ This suggests that neither patient nor carer can be considered alone – only when the distress of and strain on both are alleviated is the experience of both improved.

Bereavement

The period directly following the death can be particularly difficult. Bereaved children sometimes lack appropriate support.

The process of bereavement starts before the loved one dies, and the quality of death will frequently affect the experience of bereavement. “Poor” deaths have a worse effect on the bereaved than “good” deaths.³⁵

Carers whose loved one died in hospital interviewed for a recent study reported receiving little basic emotional support from staff. Few were asked how they were coping. Having been extensively involved in the patient’s care outside hospital, many wanted to remain involved during in-patient stays, but few were encouraged to do so.

Carers who lose a loved one in hospital often report feeling stranded once they die. Most report a lack of emotional support from health professionals and little guidance offered about obtaining death certificates and organising funerals. Grief, though painful, is a normal process, from which most people gradually recover. It is sometimes described as having three stages, starting with an initial stage of shock, disbelief and denial, followed by a mourning period, lastly shifting attention to the outside world and re-engaging with enjoyable activities.³⁶ These stages may overlap. Some find it hard to get through a particular stage and psychological support may be of value in such cases.

Children’s experience of bereavement will be influenced by their developmental stage. The ability of the parents to manage and communicate their own grief is thought to be critical for the emotional health of the children in the family.³⁷ Communication prior to the death is also thought to be crucial – many children are not told of the probability that their loved one will die. Some may think their own bad behaviour has led to the death.³⁸ Where there is open communication within families the level of anxiety in children has been found to be lower.³⁹

Deprivation

Within deprived areas, people tend to use health and social services less than their levels of need indicate that they should.

The 1998 Independent Inquiry into Inequalities and Health chaired by Sir Donald Acheson identified that poor health was associated with low levels of income, education, employment and housing.

There are several possible reasons for the observed inequalities. Some suggest that health related behaviours, like cigarette smoking, poor diet and lack of exercise, lead to greater levels of ill-health. Others suggest that there are hazards inherent in society to which the more disadvantaged have no option but be exposed. For instance, hazards relating to poor housing, certain occupations, pollution, unemployment and psychosocial stress have all been associated with poorer health.⁴⁰ However, for those conditions for which certain behaviours are risk factors, for example coronary heart disease, research indicates that these factors cannot account for the large observed differences in mortality. The risk of death from many causes for which there is no evidence of a life-style connection, is still higher in less privileged groups.⁴¹

While there is no simple reason for the observed inequalities, it is clear that those in deprived areas use the health service less than their levels of need would indicate they should. Longer travel time, greater travel cost and low car ownership are all thought to be contributory factors. These individuals experience inequalities in access to a range of primary and specialist services. The confidence and articulacy of the middle classes are thought to be key in obtaining a good service.⁴²

Palliative care may be harder to deliver to the most deprived communities. Research has found that people from the bottom third of local authorities, ranked by deprivation, were 6% less likely to die at home than those living in the top third of local authorities.⁴³ The fact that deprivation makes it less likely that you will die at home (and, correspondingly, more likely that you will die in hospital, a care home or nursing home, where palliative care is often poor) suggests the greater need for care is not mirrored in adequate or accessible services.

Black and minority ethnic patients

The numbers of black and minority ethnic (BME) patients accessing hospices and palliative care services are not proportionate to the size of ethnic minority populations. In 2001, ethnic minority groups accounted for 8% of the UK population, yet only 3% of recorded adult palliative care patients were from ethnic minority groups.⁴⁴ However, one would not expect 8% of hospice patients to come from an ethnic minority, as the UK ethnic minority population is younger than the general population and incidence of life-threatening illnesses increases with age.⁴⁵ There are conflicting opinions on what percentage one should expect but there is consensus that it is considerably above 3%.

There is some disagreement as to whether cancer is as prevalent in black and minority ethnic groups as in the rest of the population. The predominant life-threatening illnesses are thought to be diabetes, hypertension, heart disease and stroke, which are not as well catered for as cancer by palliative care services.

There are other possible reasons that ethnic minorities are under-represented. In some cultures there is a strong preference for dying at home. This might be for religious reasons, or it might be seen as a matter of honour and integrity. Some members of a minority ethnic community might sense a hospice stay or help with home care as a failure. However, this is not true of all BME families. Medical professionals sometimes over-generalise and assume that all minority ethnic groups “care for their own” and thus do not need support.

Additionally, there is thought to be a lack of knowledge among ethnic minority communities about palliative care services. Where communities do know about services, they sometimes lack confidence that the care provided will be sensitive to their culture and beliefs. It could be important to a black or minority ethnic person that:

- their special dietary needs are understood and catered for. Fasting is of profound religious significance in some faiths.
- they die conscious, for religious reasons (thus certain types of pain relief may be inappropriate)
- their extended family and friends have space for prayer or ritual around the time of death and their body is appropriately handled after death.

Language may also be an issue for some first generation immigrants. It could be a frightening prospect to be cared for by people who you can't communicate with. Translation services are not always easily accessible.⁴⁶

Children and adolescents with terminal conditions

14-20,000 children in the UK have terminal conditions, of whom half will be in need of palliative care at any one time.⁴⁷ Such children have distinct care needs.

Despite this number of children requiring palliative care, there has been no systematic mapping or review of existing provision of children's services, unlike adult services which are reviewed by the National Council for Specialist Palliative and Hospice Care Services from time to time. It is generally felt that the needs of many children and their families are unmet, but to what extent is difficult to determine given the absence of reliable data.⁴⁸

Box 3: Parents' and professionals' comments on care for a life-limited child

“No one seems to understand the physical and emotional strain looking after a terminally ill child has on a carer, and strain on the family. Constant obstacles are placed to prevent children getting rights.” *A mother*

“Parents have to be very persistent to get appropriate services, some just give up, others go on crusades, family life suffers, marriages break up, other children in the family suffer.” *A health professional*

Source: *Voices for Change*, (2003), Association for Children with Life-threatening and Terminal Conditions and their families.

The social and cultural needs of black and minority ethnic people are often misunderstood by mainstream services.

Children and adolescents should be cared for in an environment which is sensitive to their needs and developmental stage.

Need > Delivery > NHS services > Voluntary Sector > Outcomes > Conclusion

Children's palliative care is distinct from care for dying adults in a number of ways. 40% of terminally ill children have cancer; the majority die of other rare childhood diseases. The time span of these illnesses is often different to adult illnesses and palliative care may extend over many years. In order to deliver appropriate care, a palliative care in-patient unit must co-operate closely with the children's paediatricians and specialists.

The Kennedy report into high mortality rates from heart operations in Bristol emphasised the need for children to be cared for in a child-centred environment. In order to respond sensitively to sick children's emotional needs, care staff need an understanding of the ways they may react to their condition. Children's understanding and attitude to their illness and to death often change as they develop physically and emotionally. They can become depressed or frustrated during a long period of sickness, distressed if they feel they are being deceived, or rebellious against apparent over-protectiveness. They can feel isolated from their friends by their ill-health. Intellectual impairment is a feature of some childhood degenerative illnesses. Children suffering from these conditions will have particular emotional and behavioural needs and may require specialist help.

Children need to feel at ease in the setting where they are cared for, and should not feel restricted from acting in the way they normally would at home. Space to play and freedom to move around are important. Provision of education is a requirement and staff may need to be employed to cater for this when care is provided in an in-patient setting.

Parents and family members are central to the care of sick children and they should have facilities to stay with the child when they wish. The child's sickness and care may significantly disrupt family life. Well siblings may feel overlooked and may have no one to discuss their fears and emotions with. Parents and siblings may feel very isolated due to the rarity of the child's condition. Research shows that parents and families rate help with care in the home and respite care as equally important components of any intervention.⁴⁹

The needs of adolescents are specific and different from both children and adults.⁵⁰ There are thought to be 6,000 to 10,000 young people aged 13-24 with a terminal illness in need of complex daily care.⁵¹ Teenagers continue to develop physically, emotionally and socially and do not want to be cared for in an environment geared for children. Like their peers, terminally ill adolescents seek greater independence but may at the same time become isolated and dependent as a result of their illness progressing. Depression is not uncommon. Anecdotal evidence shows that bringing young people together for treatment or recreation can help. The transition from adolescence to adulthood is not well understood or catered for.

Geographical inequalities in access to palliative care

Box 4: Inequalities in palliative care

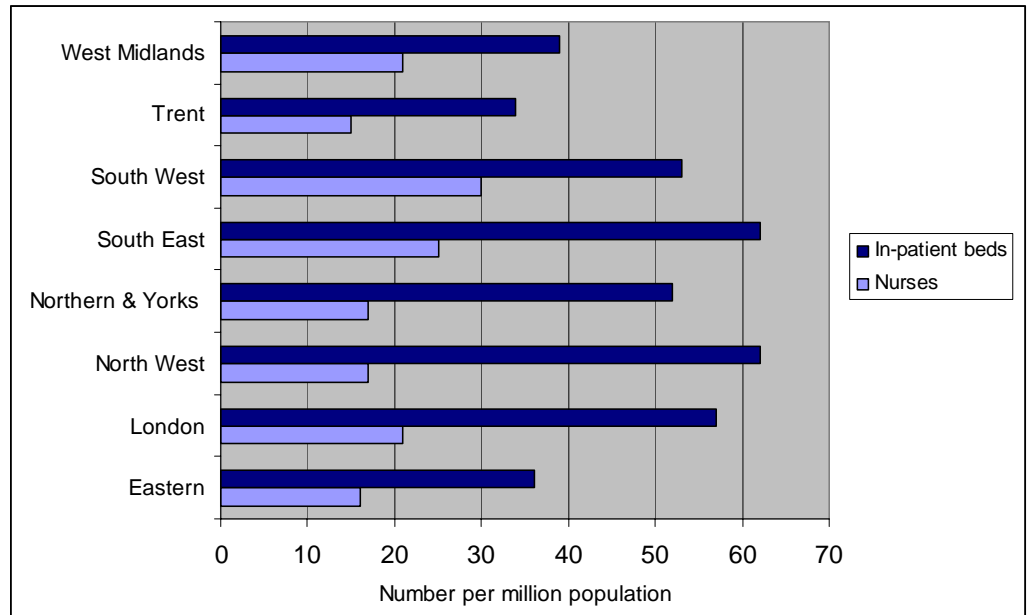
"Access to and availability of specialist palliative care services is variable and inequitable throughout the country."

Source: The National Institute for Clinical Excellence, October 2003. *Improving Supportive and Palliative Care for Adults with Cancer*. Draft for second consultation.

"Some palliative care patients in the community are suffering due to an uncoordinated approach to care provision which has led to inequity of access to generalist and specialist palliative care and gaps in the provision of palliative care."

Source: Dr Keri Thomas, 2001. *Out-of-hours palliative care in the community*. Macmillan Cancer Relief

Inequalities in access to the provision of palliative care are widely recognised, though difficult to quantify and map. Chart 5 gives some indication of inequalities.

Chart 5: Palliative care in-patient beds and home care nurses in the English regions, 1999

Source: *The Palliative Care Survey 1999*, National Council for Hospice and Specialist Palliative Care Services.

There are other indicators of inequalities too. Only 55% of hospitals in England had full multi-disciplinary palliative care teams in 2001.⁵² Similarly, only 50% of families with a terminally ill child have access to a paediatric community nurse.⁵³

A constant level of provision is not necessarily desirable. Different populations have varying palliative care needs, depending on the death rate from cancer and other diseases, age profile of the population and level of social deprivation, amongst other factors. Levels of in-patient beds and of home care nurses should not be considered separately, as both are required but, for example, an increase in resources for community care could lessen the need for in-patient care.⁵⁴

Other disadvantaged groups

NPC has not considered the situation regarding patients who have problems relating to mental health, disabilities, or other conditions leading to particular vulnerability. This is an area of considerable concern, which is likely to feature in future reports. However, it is too large a topic to include here.

Summary

Half of all deaths do not take place in people's location of choice; in some of the most common settings, people often receive inadequate palliative care and little attention is paid to their carers. Improving quality of care and support for carers would probably alter many people's preferences over place of death. The following changes are all necessary:

- More support is needed for people dying at home, and their carers, in order to provide better care and prevent hospital admissions. More palliative care in the community would reflect the majority preference for home deaths.
- Improved palliative care within hospitals is needed, to help both patients and family, where hospital admission is necessary and there is no specialist palliative care unit within the hospital.
- Improved palliative care in nursing and residential care homes is essential, given the large numbers of older people living and dying in these settings.
- Palliative care should be more widely extended to non-cancer patients where appropriate.
- Providers should address the accessibility of their services to individuals from BME communities.

Provision of home and inpatient care should not be considered separately; both are necessary. Acceptable service levels remain a distant vision.

- Care for children and adolescents needs to take place in an environment focused on their particular needs. They should be cared for by professionals with training in paediatric palliative care.

Delivering these changes would ensure better quality of life for the dying and their carers, a goal to which society should aspire. This vision remains distant. Before we explore the role that private funding can play in attaining this, we need to understand the delivery of palliative care, paying particular attention to the distinction between the role of the voluntary sector and the role of government. Such a 'road map' is provided in the next section.

Section 2: Delivery of palliative care

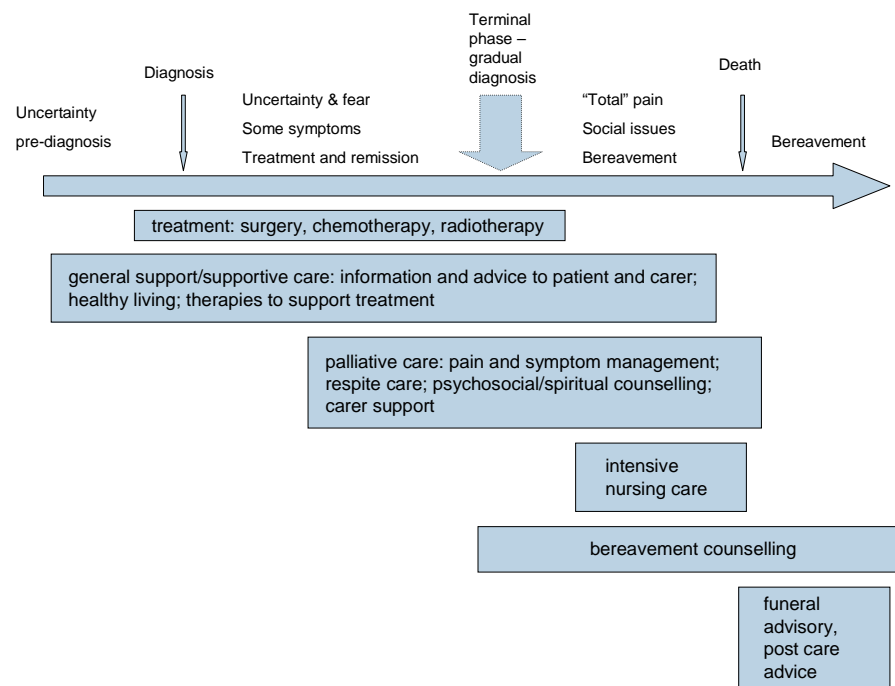
This section outlines the 'journey' from diagnosis of a terminal condition through to death. The broad range of 'interventions' along this journey are described and the division of responsibilities between the statutory and voluntary sectors are discussed. Any division of responsibilities begs the question of why a private funder should be willing to fund palliative care. This question is addressed at the end of the section.

The patient journey

The journey from diagnosis of terminal illness to death is often a complex one involving patient, immediate family and close friends encountering a number of different health and social care professionals, volunteers and others in various locations. The situation may be complicated by the fact that the prognosis cannot always be predicted. Some patients recover completely, some go into remission and lead long and fulfilling lives, others endure a swift and painful deterioration.

The degree of care and support on this journey will change as the disease progresses and will vary enormously depending on the patient's conditions. The needs of a recently diagnosed patient with breast cancer, say, will be very different from those of a patient with advanced pancreatic cancer. Non-cancer diseases such as motor neurone disease have a very different advancement profile from cancer.

Terminal illness journey and interventions – example of cancer



The diagram above describes the ideal provision of support and services during a patient's journey. It is most applicable to cancer patients, although other conditions also involve these elements and services. For some patients however, the reality may be far from this ideal. Many of the interventions overlap, but for ease we place them into the two broad categories:-

- general support/supportive care, information, advocacy;
- palliative care.

Some patients' experiences are far from the ideal illustrated in the diagram.

General support, including information and advocacy

Box 5 working definition of supportive care

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

Source: Thomas, Keri, 2003, *Caring for the dying at home, Companions on the journey* (2003), p. 82 quoting National Council for Hospice and Specialist Palliative Care Services

In the early stages of cancer and some non-malignant diseases, the disease may be life-threatening but not definitively terminal. Even if the diagnosis is terminal, death may be years away, and the patient has plenty of living to do. A patient may need little in the way of intensive nursing or care during this period, except during any debilitating treatment. However, the diagnosis of a serious illness has many implications for patients, and the availability of support and information at this stage is important for a patient's well-being and may even affect how he or she responds to treatment. A patient's response to treatment, particularly cancer treatment, has two dimensions:

- how treatment is affecting the progression of the disease;
- how treatment is otherwise affecting physical and emotional well-being.

A combination of support, information, and palliative care can be effective in addressing the latter.

The demarcation line between general support and palliative care is blurred. Fortunately, providers of services are not dogmatic in distinguishing between someone who is suffering and someone who is specifically “dying”.

A number of services have been developed by the voluntary sector in supporting people with cancer:

- information: publications, leaflets, on-line information;
- complementary therapies such as massage, aromatherapy, acupuncture;
- counselling for patients, families and carers;
- psychosocial therapies such as art, relaxation, spiritual healing;
- telephone help-lines providing detailed information on particular conditions, treatments, and service providers as well as providing emotional support to people living with cancer, their families and carers;
- courses and coaching on how to help oneself to live with cancer through diet, exercise, relaxation techniques etc.;
- physical places to go to for support, information, counselling;
- support groups;
- patient literacy: training and advocacy for patients in order to obtain the best from the services available;
- therapies to combat the physically demanding side-effects of chemotherapy and radiotherapy.

This report does not cover support, information and advocacy services to non-cancer sufferers as this will be covered in a future report on degenerative diseases.

Patients often have a lot of living to do before their death.

Palliative care

During the course of the disease, the emphasis of the support may shift towards more intensive control of symptoms, and the care requirements of patients will become more complex, although general support will still have a role. Palliative care is applicable to any patient, cancer or otherwise, adult or child, suffering from terminal disease. Some practitioners deem palliative care to be the term applied to care in the last year of life. Others would dispute whether it is possible to apply a cut-off in this manner.

Physical symptoms near the end of life are likely to include increased levels of pain, possible nausea or vomiting, failures in their digestive systems (leading to constipation or diarrhoea), difficulties associated with urination (either retention or incontinence), as well as problems with swallowing leading to thirst or dryness of the mouth. There may also be pressure sores and breathlessness. The combination of physical symptoms will vary depending on the condition. These symptoms are distressing, and can lead to agitation and depression. However, such symptoms are controllable and manageable, making a huge difference to patients.

As palliative care involves more than one discipline, a multi-disciplinary approach is desirable. Team members may come from more than one service provider. Public services and the voluntary sector are heavily entwined in the provision of services and the question of "who does what" varies depending on the local health services, the local voluntary sector presence, the condition of the patient, and where the patient is being cared for.

In reality there appear to be more than one type of overlapping care: specialist palliative care, hospice palliative care and general supportive palliative care. The first involves a multi-disciplinary team offering a full range of clinical and other services. Often consultant-led, and requiring detailed clinical input, such as drug management, specialist palliative care has raised the profile of the sector in the medical world and is desirable in some clinical cases. General palliative care on the other hand involves more practical care, although may involve some specialised input, and is helpful for those patients not in an acute condition. Both pay attention to the psychosocial well-being of the patient. Hospice palliative care, described in more detail later, frequently combines elements of both specialist and general palliative care.

Palliative care services include:-

- pain and symptom control (specialist care, intensifying towards the end of life);
- symptom alleviation (general care; complementary therapies, physiotherapy);
- practical nursing care (e.g. bathing or use of a commode);
- psychosocial therapies (e.g. art or writing);
- psychosocial support for patients and families ranging from spiritual guidance, and emotional support, to hairdressing or practical advice on benefits;
- bereavement counselling (this may start before death and continue thereafter, and may be applied to patient as well as carer and family members);
- respite care for carers (this is particularly important during intensive caring phases).

Research

Although research is not directly linked to the patient journey, it is vital in evaluating and determining best practice and the outcomes of support and palliative care. Research into cures for cancer and other diseases is high profile and enjoys substantial budgets from large organisations such as Cancer Research UK and the Medical Research Council. Research into non-curative areas such as palliative care has been historically neglected – only 0.18% of the cancer research budget is spent on palliative care,⁵⁵ despite 56% of patients dying within five years of diagnosis.⁵⁶ A strategic planning group with representatives from the Department of Health and the voluntary sector has been convened by the National Cancer Research Institute (NCRI) to identify problems and develop responses.

Research into good practice is an under funded area. Understanding and disseminating good practice is crucial.

Who provides palliative care?

The voluntary sector provides much of the general support for the early diagnosis of patients through physical centres, on telephone lines, over the internet and through published materials. However the role of the cancer team, including doctors and clinical nurse specialists, is also very important. Depending on the type of service provided, the NHS team and the voluntary sector support provider may liaise closely.

The delivery of palliative care also involves both the public and voluntary sectors as well as the patient's family, and the roles are often entwined. Individuals in the sector, particularly specialists, sometimes hold posts simultaneously in both the NHS and voluntary sector. Consequently new initiatives may be developed jointly, with the voluntary sector providing financial and other support for individuals who have straddled responsibilities in the NHS. This can be strategically advantageous.

Palliative care is delivered from the following locations:

- **In hospital:** in hospital the delivery of palliative care is mainly undertaken by the NHS, though as noted in Section 1, only a little over half of hospitals in England had full multi-disciplinary palliative care teams in 2001.⁵⁷ There is sometimes input from the voluntary sector (local hospice, Marie Curie Cancer Care or Macmillan Cancer Relief) who may provide elements of palliative care teams on hospital wards. But many people who die in hospital may not receive material palliative care.
- **At home:** care at home requires the involvement of various nursing and general care teams:-
 - District Nursing Services (DNS) provided by the local Primary Care Trust (PCT) - District Nurses are not usually specialists in palliative care but undertake much of the practical and clinical care in a general way;
 - Social Services (general care), or the voluntary sector - provide general personal care where required (but this is not always free);
 - Marie Curie Cancer Care, some local hospices or hospice-at-home services, provide more intensive nursing services such as 24/7 care or night sitting for free;
 - Macmillan nurses are available to offer specialist palliative care advice, particularly for cancer patients, but this service is not 24/7. This service is usually paid for by the NHS or local hospice. Some hospices also have specialist palliative care nurses available.
- There is generally collaboration between the services to determine who is providing what. As noted in Section 1, 20% of people die at home, though more people are cared for at home at some stage prior to death. It should be noted that the services provided by Marie Curie Cancer Care and Macmillan Cancer Relief are mainly directed at cancer patients, although some non-cancer patients may benefit. **In a hospice:** there are 208 voluntary sector hospices and 62 NHS hospices; PCTs fund on average 25% of the costs of adult voluntary sector hospices and 5% of children's hospices.⁵⁸ Only 4% of people, approximately 24,000, die in a hospice, although many people dying at home or in hospital may have benefited from hospice services during their terminal stage. Hospices begin their role earlier in the patient journey than many people imagine, offering respite and rehabilitative care during treatment, as well as terminal care. As advances in medical science prolong life, people may dip in and out of hospice services for a number of years.
- **In a nursing home:** most nursing homes are funded privately or by Social Services, and basic medical care would be covered by one nurse in charge and local GPs; 20% of people die in nursing homes or long term residential units (see below). Nursing homes may also be referred to as care homes.
- **In a long term residential unit for people with special needs:** Social Services generally contract out service provision to non-profit organisations. Some charities, such as Sue Ryder Care, offer specialist homes for neurological cases.

Some places are more effective at delivering palliative care than others. The latter two environments (apart from the specialist Sue Ryder Care homes) are not advanced in the delivery of palliative care. Elderly people in care homes can be particularly short-changed in comparison to other settings.⁵⁹

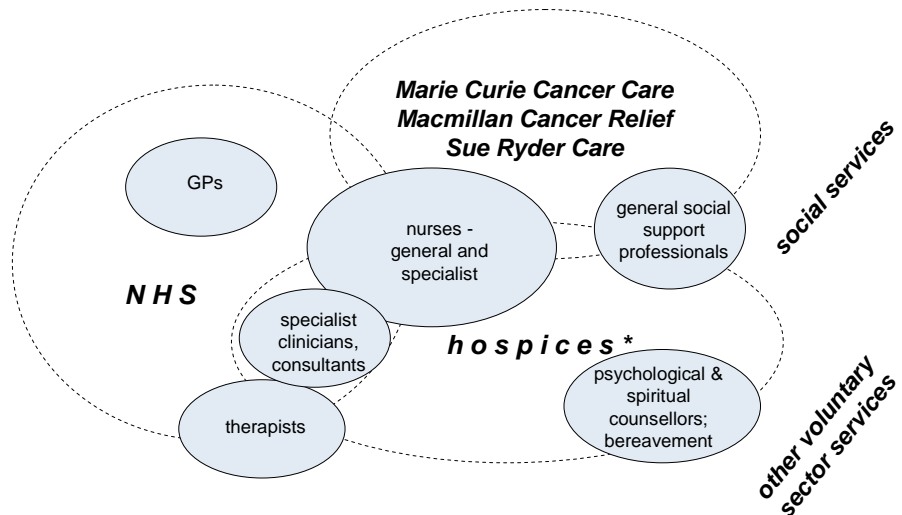
People die in four main locations: hospital, home, hospices and care/residential homes.

A wide range of professional services deliver care in these different settings; both public and voluntary sector have crucial roles.

The diagram below gives a stylised representation of the different groups involved in providing palliative care. This illustrates the range of activities together with the overlapping nature of statutory and voluntary bodies. To understand how services are delivered, it is helpful to explore how they are funded. A fuller explanation of the workings of NHS and Department of Health bodies is available in Appendix I.

Service provision to terminally ill patients, mainly cancer

Patients often encounter a number of different agencies and professionals as they reach the end of their lives.



* Hospices include NHS specialist units

The nexus between government and the voluntary sector – who funds what?

Table 1 shows the estimated principal funding sources of support and palliative care provision for the period up to 2002.⁶⁰ Table 1 excludes support provided by non-cancer organisations as this will form part of future research on degenerative diseases and ageing. NPC estimates that cancer support organisations spend approximately £20-25m pa, but this is excluded from the table.

Table 1 includes palliative care provided directly by the NHS. NPC estimates the cost of providing in-patient beds in the 62 NHS palliative care units and hospices is around £71m pa.⁶¹ Palliative care is also delivered on hospital wards but this is extremely difficult to quantify as a separate clinical service. It is equally difficult to quantify the cost of GPs' and District Nursing Services' contributions to care. The contribution of the social services to the care of those who are terminally ill is also excluded.

Much of the new funding provided by the government, described below, has been excluded from Table 1 as it applies to 2003 onwards.

Table 1: Funding for palliative care pa for the financial year up to 2002, £ms

	Marie Curie Cancer Care	Macmillan Cancer Relief	Sue Ryder Care	Indep't hospices	Home nursing	NHS palliative care units and hospices	Total
Funding from NHS and lottery	15	2	16	94	13	71	211
Voluntary income	52	71	7	175	6		311
Other income*	4	4	4	45	2		59
Total income	71	77	27	314	21	71	581
Total charitable expenditure	46	48	28	226	19	71	438
Fundraising/publicity expenditure	16	22	2	27	1		70
Other spending	5	5	2	19			27
Total expenditure	67	75	32	272	20	71	535

* This includes interest and net trading profits from shops, lotteries etc. Numbers may not add up due to rounding.

Notwithstanding the limitations of the data and the items excluded, Table 1 gives a valuable insight into palliative care. Most particularly, the table shows the importance of voluntary income. Over half of total funding for the sector – some £370m pa – comes from voluntary sector sources and trading.

Why fund palliative care?

Current funding of palliative care by the government and voluntary sector is inadequate. However, we need to address the question of why a private funder should step further into the breach and increase funding.

On the government side there are signs (discussed in more detail later) that interest in the provision of palliative care is increasing, through the provision of additional funds and concern over standards and strategy. Ironically the latter may serve to demonstrate that the government is not providing enough funding to meet its own standards.

There are aspects of palliative care providers' work which the government is unlikely ever to fund but which may nonetheless significantly impact on someone's quality of life. Private funding is crucial for such services to be offered. These are interventions such as adult education classes and art therapy, which are intended to restore the person to the patient. These may return the dignity, self-worth and enjoyment of life to someone who has lost these in the course of their disease.

In general, hospices do not want to receive all their funding from statutory sources. They think that if they did, they would be prevented from tailoring services to bring maximum comfort and pleasure to patients and would be less able to respond flexibly to varying needs.

In addition to this, the voluntary sector can pioneer new approaches that are expected to deliver significant benefits but will never receive government funding in their early stages. For example, whilst there is plenty of evidence of the unmet needs of patients dying from conditions other than cancer, there is not yet a body of evidence that palliative care benefits them. Similarly, charities can pilot posts, such as a hospital based discharge coordinator, which the NHS may not want to fund until the need for it is proven. NHS personnel are capable of producing world-class medical research and developing exciting innovations, but much of this is actually funded by non-statutory sources. The voluntary sector has a proud tradition of encouraging change and introducing innovation. It is important to stress that evaluation of innovations and dissemination of findings are crucial, particularly as evidence-based research is more likely to influence government policy.

Voluntary income plays a crucial role in the delivery of palliative care, providing more than 50% of total income.

A private funder can channel funds to unfashionable or more risky areas in a way which is more difficult for government.

One advantage of private investment in the voluntary sector is that the donor can channel funds to unfashionable or more risky areas in a way which is more difficult for government. Furthermore, a private donor can fund programmes tackling weaknesses in the sector, which could increase the impact and efficiency of future donations. Umbrella bodies are an option in this regard. These have greater lobbying power to influence government bodies and the ability to coordinate new programmes and research strategically. They can invest in development of resources that can benefit all hospices under their umbrella, thus avoiding duplication.

In conclusion, there are many options for the donor. The field of palliative care as a whole needs substantial funding simply to keep going. The majority of hospices rely on private sources for the majority of funding. Donors should not ignore this substantial need to pay for the day-to-day services provided by hospices and other palliative care providers (such as those discussed in Section 4). Such “plain vanilla” funding should not be belittled, particularly as “new” services are often emphasised at the expense of important existing services.

The voluntary sector often provides palliative care alongside or in cooperation with the statutory sector. It is possible to engage in philosophical discussions about what the state should provide and what should be left to private action but this dilemma is not helped by the fact that the statutory boundaries for palliative care provision are blurred: there is as yet no document that sets out the mandatory obligations of the state. Some donors may feel uncomfortable funding services that, it might be argued, should be provided by the NHS. Such donors may recognise that the situation is unacceptable and improved palliative care should be available but are uncomfortable with putting resources into areas that the NHS could fund with increased resources or better resource management. For such donors the choice should not be seen as between Hospice X and Hospice Y but between the range of interventions described below whose outcomes will be analysed in Section 5. Many such interventions offer significant potential leverage, particularly if it is likely that they will be taken up by the statutory sector as part of a strategic plan.

Role of government – new and recent funding

The total spend of the NHS and voluntary sector was last officially calculated in 2000 in the lead-up to the Cancer Plan. NPC's own estimate of government spending, together with lottery funding, in the period to 2002 is £211m pa.⁶² This excludes the contribution of District Nurses and GPs, but includes PCT and lottery funding of independent hospices. It also includes NPC's estimate of the cost of running NHS palliative care units and hospices. Lottery bodies are not strictly speaking government funding, however using the data available it is extremely difficult to distinguish between the different funding sources: they are too frequently conflated.

Since the 2002 data, an extra £50m pa under the Cancer Plan and some funding for training and money from the New Opportunities Fund are being made available. We describe this additional funding below. NPC's own estimates therefore indicate that the palliative care sector is currently *costing* approximately £610-620m pa with an estimated 47% of the sector's income being provided by government and the lottery.⁶³

New Opportunities Fund

The **New Opportunities Fund** was set up in 1998 to distribute lottery money to health, education and environment projects. NOF funds new projects rather than existing work and grants tend to last for three years.

The New Opportunities Fund has allocated a total of £84m in palliative care for adults and children over the last two years. The funding for children, some £48m, was focused on three strands: expansion of community based palliative care teams in order to improve home care; funding for children's hospices; and bereavement services. The £22m funding for adults in England is focused on home care and areas of particular deprivation. The grants are generally for three years. Applications must include 10-15% non-cancer services, helping to address the issue of the “disadvantaged dying.” Services must be “new” or developments of existing services, and subsequently be picked up by the local PCT or some other funder. There are some concerns as to how this will work in practice. There is also funding of £4-5½m for Wales, Scotland and Northern Ireland.

£50 million for Specialist Palliative Care

The government has committed an extra £50m pa for palliative care for cancer patients, beginning in 2003. Funding may go to both voluntary sector and statutory providers of care. The extra funding has been set aside for three years – after that, the intention is that this funding will be built into main allocations. According to the Department of Health, this

Government and lottery funding for palliative care is on the increase but many needs remain unmet.

represents a 38% increase on the amount of government funding, which the Department estimated in 2000 to be £131m, though it is unclear exactly where this figure comes from and NPC estimates of government spending are higher.

Department of Health funding for palliative care is notionally allocated to **Cancer Networks** (described in more detail later) on the basis of criteria developed by the **National Partnership Group** (described in more detail later) which takes into consideration existing levels of provision versus need (populations, age profiles and social deprivation). The extra £50 million funding has been earmarked for service developments and existing services working towards the **National Institute for Clinical Excellence** model outlined below. It is particularly aimed at tackling inequalities in access to palliative care as well as helping to contribute to the costs incurred by voluntary hospices in providing agreed levels of service.

Some have questioned whether this is really new money. Some of the money has gone to continuation costs of projects previously funded by the New Opportunities Fund. The money is intended to fund, among other things, extra posts: 71 District Nurses, 162 Cancer Nurse Specialists and 86 specialist palliative care in-patient beds.

The Department of Health claims that the extra funding has led to more consultants, nursing specialists, and specialist palliative care beds as well as increased provision of community services. Although 71 consultant posts have been funded, it is not clear that these posts have been filled owing to the shortage of specialist consultants available.

£12m for training 2003

In December 2003, the Secretary of State for Health announced an extra £12m over three years for palliative care education. The funds will concentrate on the **Gold Standards Framework (GSF)** and the **Liverpool Care Pathway for the Dying Patient (LCP)** models of best practice developed by partnerships between the NHS and Macmillan Cancer Relief and Marie Curie Cancer Care respectively, and **South Lancashire and Cumbria Cancer Network's Preferred Place of Care** scheme. The GSF and LCP are described in more detail later in the report.

The funds will be available for cancer and non-cancer services alike. Although the government's support for these initiatives is encouraging, £12m for training will not be sufficient to fully roll them out across the country. At the time of going to press, there is little knowledge as to how this funding will be used in practice across the 34 Cancer and Supportive Palliative Care Networks.

Summary

The resourcing of the sector is complex, but the major sources can be broken down as follows:⁶⁴

- Statutory and lottery funding for voluntary sector service providers (hospices, home nursing, Marie Curie Cancer Care, Macmillan Cancer Relief, Sue Ryder Care) amounts to £140m pa in the period to 2002.
- Cost of NHS palliative care units and hospices is estimated at £71m pa.
- The government also provides components of palliative care e.g. District Nurses, GPs, and social services which cannot be quantified.
- Additional funding provided by the government from 2003 onwards amounts to c£54m pa for three years (£50m pa and a third of the £12m allocated to training).
- Additional funding provided by the New Opportunities Fund is £28m pa for three years.
- The voluntary sector and trading provide around £370m pa to the sector.
- The voluntary sector also contributes to services via its volunteers.

The provision of support and palliative care is a joint effort between the voluntary and public sectors. Sections 3 and 4 will describe in greater detail the contribution of each, and how they complement and leverage each other when the relationship is working well.

Section 3: NHS service delivery

This section describes in more detail the provision of palliative care by the NHS. The government provides services through a range of outlets, some direct and some via voluntary sector providers. These include voluntary sector hospices, and NHS hospices and palliative care units. Primary Care Trusts (PCTs) are responsible for District Nursing Services (a vital component of palliative care provision) and also GPs.

NHS services

Funding of voluntary sector hospices

As noted above, adult hospices receive an average of 25% of funding from local PCTs and children's hospices an average of 5%. PCTs fund hospices through "service level agreements". A hospice may provide services to more than one PCT. There is little consistency of approach across England and Wales and there are substantial funding inequalities. Calculations do not take into account the fluctuating nature of need for palliative care services and this can disadvantage hospices, since they have to meet staff costs whether or not all beds are occupied. In addition some patients might be suitable for community care, but drawing up a care package and making sure the relevant agencies are aware of their part in it may take several days. Discharges may be delayed, which could deprive more needy patients of access.

Box 6: Hospices and PCTs

Hartlepool and Leeds: contrasting local NHS commitment

PCTs meet 15-50% of costs in the course of a financial year. Hartlepool and District Hospice has agreed with the local PCT 30% funding for its "patient care" services. In reality this represents around 20% of total costs. This does not cover the cost to Hartlepool of providing basic care overnight for its ten beds or the costs of day care, home care support or the telephone help line. The area has no statutory funding available for 24/7 specialist support, so there is no 24/7 home care service.⁶⁵ In contrast, St Gemma's hospice in Leeds has negotiated 30% funding for all costs, i.e. over 50% of "patient care" costs. In addition a 24/7 District Nurse is available from the PCT, supported by a St Gemma's specialist nurse.

Children: service providers short-changed?

Children's hospices receive 5% of their costs from statutory sources. However, there are isolated cases where there is greater interest from PCTs.

Acorns Hospice in Birmingham has around 10-13% of direct charitable costs loosely related to service levels paid for by the NHS, and receives a further £1m pa from NOF for new services, though for three years only. NPC estimates the NHS is contributing around £75 per bed-night for the children in their care.

There are substantial funding inequalities across the UK.

NHS hospices and palliative care units

The NHS provides 20% of all in-patient palliative care beds itself, either in one of its 62 hospices or on hospital wards.⁶⁶ The quality of care and nurse-patient ratio is comparable to voluntary sector hospices although in some cases the environment may not be as pleasant.⁶⁷ Additional services, such as complementary therapies, bereavement support and art therapies may be provided through voluntary organisations recouping some of their costs from statutory sources. Some NHS palliative care centres focus on short term interventions for respite or pain control rather than on terminal care.

Funding for services for children and adolescents

Charities working on supportive and palliative care often have a greater chance of accessing statutory funding if they can make a case that funding would result in an overall cost saving. This is harder to make in the case of children's hospices, who, because of the in-patient emphasis on respite care, provide no obvious savings for the NHS. The strong history of

voluntary funding for children's hospices may also act as a disincentive for the government to invest more resources in this area.

Hospitals

56% of people die in hospitals. It would be preferable if this number were lower, as there are more peaceful and appropriate settings. But if patients must remain in hospital, standards of care must be improved.

With most deaths taking place in NHS hospitals or equivalent, a large number of patients receiving treatment for a terminal condition ultimately find themselves approaching the end of their lives in a hospital. Other than admission to hospital for clinical treatment (e.g. surgery, chemotherapy or radiotherapy), hospitals will try to avoid offering general care to the patient. It is in a hospital's interest to discharge a patient, where clinically possible, in order to free up bed space for other patients. The discharge process is not always well co-ordinated, leaving patients requiring further palliative care without full care plans when they return home. Bed blocking is commonplace, leaving the patient receiving below-standard palliative care. While a patient may receive some of the clinical elements of palliative care in hospital, it may not provide a full service unless it has a specialist wing or hospice attached. The ability of hospitals to care for the dying varies enormously, yet a very large number of people end their journey in them.

Box 7: Standards of hospital care

Poor hospital care

Doctors came and went throughout the day and night. One doctor refused to let us stay in the room with Mum while he listened to her chest. As a result he came over as arrogant and insensitive. This was our Mother who was clearly dying; we had been with her without a break for 36 hours, nothing he was going to hear with his stethoscope was going to save her; yet he behaved as if his function as pulse and temperature monitor took priority over support and tenderness

The night shift nurses seemed unaware that this noble woman was breathing her last and persisted in taking blood pressure and giving injections. It was a macabre, laughable, misplaced lack of efficiency on a grand scale. We requested that they discontinue these treatments. Mum's waves of survival continued until 8.50am until she died.

Source: Thomas, K. (2001) *Continuing care for the dying at home, Out-of-hours palliative care in the community*, Macmillan Cancer Relief

Good hospital care

I couldn't fault the Hereford [General Hospital] in their care for my father as he lay dying over Christmas. The entire terminal phase - the administration of the process of dying physically and practically and all the concomitant medical alleviations - was overseen and controlled with tact, diplomacy and the highest levels of professional competence. There was even gentle humour, which never wavered despite the constant comings and goings of a large number of family members. A Macmillan nurse seconded to the hospital was in charge of the process, supported by an excellent cast of hospital nurses.

Source: Christian Jennings, family member, Christmas 2002

Many hospitals have partnerships with other palliative care providers and specialists (hospices, Macmillan Cancer Relief, Marie Curie Cancer Care) to assist in the delivery of palliative care. Some hospitals have specialist palliative care units attached. It is the government's intention to improve the palliative care services offered to all patients dying in hospitals regardless of which ward they are on and their condition.⁶⁸

Nursing services

District Nurses have a key role in general care provision, not only at the end of a person's life but also during earlier stages of disease development, checking on treatment and symptoms, offering advice, reporting back to clinicians. The PCTs commission the District Nursing Service, which vary according to PCT: some but not all offer 24/7 coverage. Some are staffed by NHS employees, other PCTs contract out to providers such as Marie Curie Cancer Care. There are 40,000 District Nurses and it could be said that up to a quarter of their time is spent on palliative care.⁶⁹ Under the Cancer Plan £6m is being invested in

palliative care training for district and community nurses during 2000-2004. The Department of Health estimates that this programme will reach one in four District Nurses.⁷⁰

General Practitioner (GP) practices

GP services are included within the remit of PCTs and GPs are more or less active in the management of patients' care throughout the patient journey. Only a minority of the 11,000 GP practices have specialised palliative care skills, although the GSF initiative is trying to address this (see later). Often there are problems with out-of-hours care, as many GPs now use practice collaboratives or GP deputising services without handing over details of dying patients. Putting in place systems to do so is a key part of the Gold Standards Framework.

Box 8: Late admission to a hospice: would community care have been a better option?

Mr Wilson, a 68 year-old with lung cancer, expressed the wish to remain at home until he was "carried out in his coffin". He rapidly deteriorated, with increasing breathlessness, weight loss and anxiety and his wife was becoming exhausted and frightened. One Saturday, he coughed up a large amount of blood. The deputising doctor who visited had no knowledge or information about the family. In view of the severity of the symptoms and high anxiety, he offered admission and reluctantly Mr. Wilson was taken to the local hospice. He died within eight hours of admission. Mrs. Wilson felt the burden of guilt as well as that of grief and asked the hospice staff whether more could have been done to have kept him at home. They also asked themselves that same question.

Source: Thomas, K. (2001) *Continuing care for the dying at home, Out-of-hours palliative care in the community*, Macmillan Cancer Relief.

The NHS generally has to refer patients to voluntary sector care providers: patients are not usually self-referred. It is important to note that NHS and voluntary sector palliative care provision is free at the point of delivery regardless of means.

Out of hours care and other support issues

Since Dr Keri Thomas (see Box 7) published her concerns, "Accrediting Providers of Out of Hours Care, a system for improving patient care and assuring quality", was produced by the Department of Health and Royal College of General Practitioners in 2002 for immediate implementation. Some people say improvements are discernible but concerns remain, particularly as responsibility shifts from GP practices to PCTs.⁷¹ At the time of going to press, Health Minister John Hutton had announced that £30m had been allocated to reward PCTs for improvements in out of hours care.⁷²

The **National Institute for Clinical Excellence (NICE)** guidelines on supportive and palliative care, discussed in more detail later, recommend that at least one member of each team of generalists supporting a patient with advanced cancer should have post-registration training in palliative care. **NICE** is a Special Health Authority in England and Wales which produces evidence-based guidance on best practice. This is intended to inform providers and commissioners of care as well as the public on what they may expect from NHS care.

Role of social services

Palliative care lies at the interface between health and social care. This raises some tricky issues, since health care is free at the point of delivery and social care is means assessed. People with a reasonable level of assets can end up paying substantial amounts for their care. NICE has raised the interface between health and social care as an issue, and wants to encourage more research in this area.

Care in the home

Social Services provide a substantial proportion of home care for the chronically or terminally ill. Social services may sometimes already be involved in providing practical care and help for vulnerable people such as the elderly alone or people with disabilities. Historically many of these services were provided by the District Nursing Service. Social Services are not obliged to employ people with vocational or medical qualifications, and carers may not be able to offer the same level of skill as was previously the case.

The support of GPs and District Nurses is vital for sustainable community care. NHS professionals are sometimes assisted by voluntary sector practitioners.

Palliative care lies at the interface between health and social care. This raises some tricky issues, since health care is free at the point of delivery and social care is means assessed.

Many elderly people need long term care with access to specialists.

Sometimes nursing support from agencies, Marie Curie nurses and hospice nurses is provided.

When a patient is discharged from hospital it is possible that someone from social services will be provided to assist with personal care. However these services are only provided free to those who cannot afford to pay for them otherwise. Furthermore, the quality of service can be variable.

Some users complain about the quality, flexibility and relevance of social services care. Many people need adjustments to their home or special equipment in order to return home but delivery is often slow and sometimes expensive. Most Social Service employed carers have little understanding of non-malignant conditions and find it hard to understand the communication difficulties of a person with Huntington's, say, or the changeable nature of Multiple Sclerosis. They are not contracted to provide help with domestic tasks, which frustrates carers who would like to spend more time with their loved one but are bogged down by other day-to-day tasks. Putting to bed services can be valuable but can be at wholly inappropriate times of day. Box 8 gives an example of an ill-coordinated service.

Box 9: Case study - the effects of lack of co-ordination on care

Tony was 41 with advanced cancer. He lived at home with his wife Sue and two young children. When her mother, who was looking after the children while Sue worked, became ill, she was desperate for child care and Tony was also needing more help. A package of care was arranged by the Social Services Department providing cover throughout the day. After a few days tensions were building at home. Tony resented the constant stream of professionals and carers asking the same questions and invading their privacy. The last straw came when Sue arrived home from work to find a row of visiting cars in the driveway and no space to park outside their own home.

From Dix, O and Glickman, M. 1997 *"Feeling Better"*. Published by the National Council for Hospice and Specialist Palliative Care Services

Since 1996 individuals in some areas who have been assessed as needing services can apply for direct cash payments in lieu of social service provision. The scheme is still expanding and the aim is to give people greater choice and control over their lives. Patients and their carers have the opportunity to choose who they would like to deliver their care – social services, experienced individuals or professionals employed through private sector agencies. However, uptake has been slow.

Care homes⁷³

Social services generally contract out the care of the elderly and disabled to not-for-profit or private care homes, which include nursing homes and residential care homes. The funding of such care is complex, and tends to be meagre at point of service delivery: for instance in Scotland social services pay £400 a week per resident for "normal" care. Most care homes are not charities or part of the voluntary sector and therefore do not "top up" the contribution from social services with voluntary income. £400 per resident per week is unlikely to be adequate: by comparison, hospices may have £200-300 per day at their disposal because of their voluntary income.

18% of people in England and Wales die in care homes (nursing homes and residential homes). Following the government's shift to "care in the community" and the closure of geriatric wards during the 1990s, there has been a huge influx of users into care homes. Many residents have multiple pathological problems (few have cancer) and cognitive impairment and may even suffer from dementia. Many really need 24/7 care but in practice are either placed in nursing homes (where nurses must legally be present) or residential homes (where nurses are not mandatory). Even for the qualified, it is difficult to interpret pain experienced by dementia sufferers through behaviour.

Although it appears that few people would choose to die in a care home in reality this is where large numbers of elderly spend the latter years of their lives once they become unable to live independently. Once in a care home it may not be desirable to move a person to another setting such as an acute ward on a hospital, which can be traumatic for a patient, merely because they are dying. In an ideal world, the option to remain in situ but receive the appropriate level of care would be attractive. This has the added benefit of avoiding unnecessary hospital admissions. Even before a patient's condition becomes acute, palliative care may be appropriate, for instance in alleviating severe arthritic pain.

In reality, although many care homes deliver good care for residents and develop good long term relationships with those in their care, at the terminal phase these advantages are not capitalised upon as well as they might be. The availability of resources and full training for staff is limited when delivering end of life care, and care home managers may not always have the confidence to cope with the dying. Care homes can be clinically isolated, and sufficient support from PCTs, including GPs and district nurses, is not always available. However, specialist GP input and District Nursing Services can help if given the training and resources. Marie Curie Cancer Care aims to be able to offer support to care homes, and hospices are sometimes very active in providing support as well. And with the right support, care homes are ideally placed to benefit from initiatives such as the GSF and LCP. Professor Mike Richards has stated that he wants care homes to benefit from LCP where possible. NPC will be exploring this issue further in a future research project on the elderly.

There is a limited amount being done to address this problem. Dr Keri Thomas is aiming to pilot GSF in eight care homes. There is also a programme of learning about palliative care developed by Macmillan Cancer Relief and supported by the NHS and the Open University that can be used by care home staff. Help the Hospices funds courses for people in care homes, where courses may be found, and also funds hospices to provide appropriate training to neighbouring care homes.

Services for children

40% of deaths in children are from cancer, the rest are from degenerative conditions. There are a number of issues affecting the care of children:

- The pathology of terminal illness in children is often complex. Their diseases may bring problems relating to their mobility and development or cognitive abilities.
- Children need appropriate and intensive levels of emotional, mental and physical stimulation. A healthy child receives support from parents, school and friends. An ill child is no different, except the support required is in many cases greater.
- Conditions often continue for a prolonged period, particularly as treatment and care improves. Children with Duchene's Muscular Dystrophy can now survive until their twenties. The transition through adolescence to adulthood is a particularly difficult phase for many, and few service providers have a specific focus on this area.
- Siblings of an affected child have specific needs and children's hospices have developed good models of tackling these issues.
- Parents and carers need care and support themselves. The emotional and physical demands of looking after a terminally ill child are severe.

Most children's parents are the primary care givers at home. This often means that family income is lower as parents take time away from earning to look after the child. Even if a carer is able to look after the child, respite is frequently desperately needed.

Children with life-limiting conditions may need to attend hospital regularly, and this can result in geographic and logistical problems for families torn between staying with the child being treated or spending time with healthy siblings. As with adults, children with non-cancer conditions are more likely to experience patchy NHS provision. Out of hours care is particularly inconsistent: although 70% of the country has "access" to a children's community nurse, the reality of this access is that it may be a one-person team covering a large area;⁷⁴ 24/7 service may not be available;⁷⁵ the service may not include specialist paediatric palliative care expertise.

In 1999 ten "Diana Teams" were set up by the NHS specialising in the care and support of children in their own homes. These cover ten (out of 126) health districts, and are regarded as a good model of care.⁷⁶ Much of the £48m allocated to children by NOF is being used to develop children's community nursing teams along the Diana model.

In general paediatric palliative care is not well-developed as a clinical area. In 2001 there were only four paediatricians appointed as specialists in palliative care in the UK. Similarly, it is estimated that the number of nurses qualified in paediatric palliative care is less than 100.⁷⁷ Both the Royal College of Paediatrics and the Royal College of Nursing have now established Special Interest Groups in Paediatric Palliative Care to develop the specialism. There are also individuals in the sector, for instance in universities, developing courses.

The emotional needs of sick children are vitally important. Children may be beyond their years in experiencing physical and mental distress.

It appears that the services for children, adolescents and young adults are not well mapped and where mapping has taken place, it has indicated that they are not well catered for.

There is a new National Services Framework for children to be published this year, which specifically mentions life-limiting conditions and palliative care. This will help professionals to argue for more resources and attention in this area.

As children suffering from life-limiting diseases are often disabled, social services may also be involved in their care, with the education sector also playing a role.

Strategic responses and standard setting

Cancer Services

The government is attempting to improve services to cancer patients through a number of initiatives, such as the setting up of Cancer Networks, the development of the Cancer Plan, and the Cancer Services Collaborative. But, though more interested, the UK government is not yet as engaged with end of life issues as, for example, the Canadian government.

Box 10: Dying in Canada

“You are all going to die. How would you like to do it?” Sharon Carstairs, Minister with Special Responsibility for Palliative Care, Canada, address to Cabinet 2000.

Senator Carstairs has been championing the cause of palliative care since her appointment to the Canadian Cabinet in 2000. There have been four major accomplishments since the creation of the Palliative Care Secretariat in 2001.

a) Compassionate care leave

There is mandatory six weeks' compassionate care leave for those caring for the terminally ill. The scheme is flexible: the period does not have to be taken at once, and up to six different family members can share the six week “pot”. Employers have not resisted the scheme, recognising the stress caused by caring for a sick person whilst trying to work is beneficial to neither employee nor employer.

b) Better research

Recognising the need for reliable data and the development of a community of experts, the Canadian Institute of Health Research has been allocated £5.5m pa for end of life research. This represents a marked improvement on the £100,000 pa before the institute was set up.

c) Improvement/training of health professionals

Palliative care is now part of the core curriculum for physicians and doctors.

d) Technology

A “Canadian virtual hospice” has been established and includes online nurse/physician/clinical advice for service providers 24/7, online education and information aimed at patients, carers, and palliative care professionals seeking to share information and expertise.

There are no equivalent initiatives in the UK.

Cancer Networks and Cancer Plan

The 1995 Calman-Hine report on commissioning cancer services recommended the establishment of **Cancer Networks**. These were identified as the organisational model to implement the 2000 Cancer Plan on reduction of waiting times, service improvements and equitable access. There are 34 such Networks in England, roughly the same number as the **Strategic Health Authorities (StHAs)**, each serving one to two million people. The Networks predate the StHAs and consist of clusters of the old Health Authorities, thus they do not correspond exactly. Each Network consists of commissioners (e.g. PCT

representatives), providers (health professionals), local authorities and voluntary sector representatives. There are also three Networks in Scotland, three in Wales and one in Northern Ireland.

The aim is that local resources can be targeted to areas of greatest need and that services are developed and monitored consistently across a network. Each Network has a Palliative Care Group, which develops a strategic plan.

The Calman-Hine Report itself highlighted the need for integration between curative and palliative care teams, with some aspects of the latter coming in earlier in the illness than the terminal phase. It recognised that the nature of the hospice movement had led to units growing up in an ad hoc way, which subsequently led to under-developed links with purchasers of care. The report's vision was that new developments would be based on needs assessments and consultation between voluntary and statutory authorities, so that resources were not duplicated or inefficiencies encouraged. Most new adult services are discussed with PCTs and Networks, but there are still occasional examples of adult or children's hospices being developed as a result of emotional appeals rather than compassionate, yet rational assessment.⁷⁸ The Cancer Plan outlined a commitment to invest £50m pa extra directly in palliative care and £6m pa during 2001-2004 for palliative care training for nurses, as discussed earlier.

Palliative care standards

The **National Care Standards Commission** is an independent public body set up under the **Care Standards Act 2000**, to regulate care services throughout England according to standards developed by the Department of Health. The Care Standards Inspectorate for Wales performs a similar role. Hospices undergo inspections by the Commission and there is some anxiety in the voluntary sector over compliance because of the mandatory costs of implementing requirements. Marie Curie Cancer Care estimates that it will cost it £25m to comply.

The Commission has been in existence for two years but will be replaced after 31st March 2004 by two bodies: a) Commission for Health Audit and Inspection (CHAI) which inter alia will cover hospices and b) Commission for Social Care Inspection (CSCI) which will cover care homes. The two bodies are expected to work together where appropriate.

The government has also commissioned **NICE** to develop evidence-based guidance on supportive and palliative care for adults with cancer. These will be published in March 2004. The guidance applies to the voluntary sector providing palliative care under NHS service agreements. Key recommendations from the latest draft of the guidelines are in Box 10.

No money is attached to the NICE guidance as yet and opinions vary on whether additional funding to implement the recommendations will follow. Approximate costings on adjusting provision to meet recommendations at a local level are included in an economic review attached to the guidance. However, the costs at a national level are more difficult to estimate, due to the huge variations in local need and provision. The likelihood is that implementation will take some time.

Box 11: NICE – key recommendations:⁷⁹

The guidance discusses the importance of good information and communication between patients and the professionals involved in their care throughout the disease process. It envisages a level of supportive care being provided by patients' normal health and social care professionals, with referral onto specialists if necessary and signposting to voluntary sector services. There is an emphasis on patient-centred care (which many see as the very essence of palliative care) and on developing mechanisms for users of palliative care services to express their views and needs to those who deliver care and determine policy. In particular it stresses that :-

- Sufficient palliative care services should be provided to meet the needs of local populations.
- All patients should undergo needs assessments, addressing physical, psychological, social and spiritual needs at key point of their cancer journey. Assessments should be undertaken by or in conjunction with healthcare professionals who have received further education and training in palliative care. Identified needs should be met in a timely fashion, though not all must be met through specialists in supportive or palliative care. They could equally

Government interest in care standards will affect the sector: there will be cost implications but also the opportunity to obtain fairer funding from government.

Patients and carers receive the best quality care when health and social care professionals work together to meet their needs.

well be met by GPs, district nurses and social workers.

- In-patient care should be delivered by a multidisciplinary team, comprising of, at base level, a consultant in palliative care and nurse specialists. The team should have links to social, psychological and spiritual support workers. Such care is referred to as specialist palliative care. In some cases, the guidance recommends explicit partnerships between organisations, for example, providers of palliative care and social service departments.
- Generalists involved in palliative care provision should have greater levels of education and training made available to them. At least one member of each team involved in the care of a patient with advanced cancer should have post-registration training in palliative care.
- They should have good access to specialists, so they can refer complex cases appropriately.
- Each patient should be assigned a key worker to ensure continuity of care. Effective and regular communication between teams involved in patient care is essential. Professionals should be aware of the limits of their expertise so they can refer on to relevant specialists as appropriate. Referral criteria should be based on clear network protocols.
- Home care should be available 24 hours a day to all patients with advanced cancer. Nursing advice should be available to all patients in the community and generalist healthcare workers 24 hours a day.

A number of other initiatives impacting on the sector, including policies drawn up by the devolved parliaments, are described in Appendix I.

Section 4: Voluntary sector pioneering service delivery

This section describes the role of the voluntary sector in palliative care. The voluntary sector supplies a great deal of support early in the patient journey, and mechanisms for this are particularly well developed for cancer patients. As a patient's condition becomes more advanced, patients may access hospices and nursing services, which are mainly delivered by the voluntary sector, in collaboration with the NHS. The sector also has a good track record of developing new services and improving practices and consequently there are exciting strategic initiatives.

Introduction

The voluntary sector is active in the following areas:-

- Contractual service delivery to government for services which government chooses not to deliver itself but will pay for in part or in full;
- Delivery of additional services (in terms of quality and volume) which the government will not provide or pay for, but which are seen as desirable by non-government stakeholders such as service users, service providers, donors and volunteers;
- Development and piloting of new services, which may in future become sufficiently mainstream to be taken on by government;
- Providing a voice for patients and their families, and enabling people affected by cancer to have their own voice to influence change.

Specific activities include the following:-

- **General support** for diagnosed patients. In this report we focus on cancer, not because there are no critical needs for non-cancer patients, but because the topic is so large and the diseases so complex that degenerative diseases will be covered in future reports. Many of the lessons of cancer can be transferred to other non-malignant diseases.
- **Palliative care:** We discuss both cancer and non-cancer here. The voluntary sector is vital in providing hospices and collaborating with the NHS in provision of nursing services. The development of new protocols for application in a variety of settings is an important part of voluntary sector palliative care. This should include helping carers.
- **Children and services for children:** care of children with terminal illnesses and their families is complex.
- **Education:** this burden is shared with government, but in the absence of sufficient courses and government funds for sending practitioners on courses, it frequently falls to the voluntary sector to educate practitioners and professional carers.
- **Research:** research into palliative care is carried out by a mixture of government bodies (medical and/or educational establishments) and the voluntary sector. The newly formed **Cicely Saunders Foundation** for instance is largely funded by the voluntary sector.

General support, information and advocacy for people living with cancer

These services are provided by a wide range of charities. Some are general cancer charities concentrating on a particular service or cluster of services. Others are for sufferers of specific conditions; breast cancer is well served in this regard. Some charities offer "drop-in" support, whilst others are residential. Some examples:-

Macmillan Cancer Relief is very active in supporting people living with cancer as well as undertaking clinical activities. It has set up 50 Macmillan Cancer Care Centres, which offer a wide range of services, including clinical treatment, as well as other therapies and general

The voluntary sector is active in providing palliative care, presenting a collective voice for the terminally ill and their families, and as innovator of new approaches.

support. The set-up costs are funded by local Macmillan appeals, but thereafter the facilities are taken over by the NHS. Macmillan Cancer Relief distributes hardship grants (totalling £5m pa) to nearly 15,000 patients for the purchase of items such as a washing machine or other piece of equipment. It is piloting a National Benefits Advice Line and expects the demand to be very high, once it goes public in mid-2004. Macmillan offers information, training and resources to over 700 cancer support groups and also supports CancerVOICES, an independent network of people affected by cancer who want to have their say in cancer services. This enables people with experience of cancer to participate in strategy groups within the Department of Health, Cancer Networks or other national bodies. Macmillan Cancer Relief also produces helpful publications. **CancerBACUP** runs a help-line which offers telephone, e-mail or letter support to 50,000 cancer patients each year. The help-lines are staffed by qualified specialist nurses, and their advice is supported by a substantial library of clinical publications. This enables many patients to have more informed discussions with their medical practitioners. CancerBACUP also has satellite information centres in some regional hospitals, and is developing a project supporting people from ethnic minorities.

Breast Cancer Care concentrates on people with breast cancer and provides information on cancer services, help-lines, publications, after care, volunteer support and support groups, advice on healthy living and help with prosthetics.

The Haven Trust also concentrates on people with breast cancer and has a centre in London with one planned in Hereford. The centre is "drop-in" and offers counselling, a relaxing environment, support groups, as well as complementary therapies.

As well as funding research, the **Roy Castle Lung Foundation** also provides information, support groups, support services and advocacy. The **Prostate Cancer Charity** provides similar services.

Bristol Cancer Help Centre covers all cancers, and provides residential courses to people with cancer in dealing with the disease. The courses cover diet, complementary therapies and psychosocial techniques. In addition, the centre has help-lines (volunteer manned) and provides appointments for therapies.

Maggie's Centres (currently three in Scotland, more planned in England) are situated close to hospital oncology units and are ideal for patients needing somewhere before or after hospital appointments to relax, talk to fellow cancer patients, find out information, to discuss therapies and symptoms with nursing specialists. **Linda Jackson Centre** in Mount Vernon was an early pilot of such services.

Liverpool Cancer Support Centre is a centre offering support groups, advice, a drop-in facility and complementary therapies. Most of the people running the centre have been affected themselves, and the emphasis is on self-help: patients are helped in self-advocacy skills. They are part of the Macmillan Cancer Relief CancerVOICES initiative.

Funding for such support services varies. The Liverpool Cancer Support Centre is precariously funded from statutory sources. On the other hand, the services provided by Maggie's Centres and the Bristol Cancer Help Centre receive no statutory funding at all with the former relying upon private donations and the latter partially financed by beneficiary contributions.

Table 2 below summarises the type of services provided by the major voluntary sector groups and organisations. The services, together with examples of the work of organisations, are described in more detail later.

There are a number of organisations set up to support people with cancer which offer highly valued services.

Table 2: Voluntary sector organisations and activities

Organisations	Activities			
	In-patient/ day care/ outpatients	Home care/ nursing services	Patient and carer support/ social welfare/ information	Research and professional education ⁸⁰
Hospices – independent and NHS	✓	✓	✓	most
Marie Curie Cancer Care	✓	✓	✓	✓
Macmillan Cancer Relief	✓	✓	✓	✓
Sue Ryder Care	✓	✓	✓	
Help the Hospices	indirectly	indirectly	✓	✓
National Council for Hospice and Specialist Palliative Care Services				✓
ACT			✓	
ACH				✓
Maggie's Centres			✓	
CancerBACUP			✓	
Bristol Cancer Help Centre			✓	✓

Hospices

The modern hospice movement started in 1967 with the founding of St Christopher's Hospice in Sydenham, South East London by Dame Cicely Saunders, who was the first person to understand the vital interaction between doctor, nurse and social environment in caring for the dying in a co-ordinated way. Dame Cicely recognised the issue of "total pain" (including spiritual, emotional and social needs as well as physical), and also the effect on family and friends. Many subsequent developments in palliative care have come out of the hospice movement.

"Hospice" should be regarded as a philosophy of care, rather than a physical place, with many hospices covering more patients at home than physically in the building. The point at which a patient is referred to a hospice varies enormously, and depends upon a range of factors such as provision of other services (e.g. District Nursing Service); relationship between GP/District Nursing Service and local hospice; attitude of the patient and family; patient's condition. A patient may be referred early in order to maximise opportunities for planning, therapies and symptom alleviation, carer respite and psychosocial services. The level of usage of the hospice is likely to intensify as the condition advances, but it is not unusual for a regular hospice user to die at home rather than in the hospice.

Hospices themselves are usually cheerful places. As well as in-patient rooms and wards there will be a day room for in-patients and day patients, often with a drinks trolley available before meals; there may be an art room for art therapy and the walls often display the work of previous patients; complementary therapy rooms often smell of the aromatherapy oils used. A garden is a frequent asset, including an area of remembrance. The emphasis is on living well at the end of life, in a homelike rather than clinical environment. The care is flexible and tailored to individual needs, including the achievement of wishes, prior to death. Dignity is also crucial. Simple services like hairdressing are often provided so that patients can continue to feel well-groomed and dignified even if they are very unwell.

"Hospice" is a philosophy of care: hospices' premises act as centres of excellence, from which a range of services can be deployed within the community as well as on-site.

What services do hospices provide?

Hospices generally provide at least some of the following facilities and services:

In-patient beds

These are bedded units where patients may stay for stabilisation of symptoms, for respite for carers, or to die. Average patient stays are for around 13 days⁸¹ and many patients are discharged after a stay: on average up to half of patients return home. Sometimes the beds are in single rooms, sometimes rooms of two or more people (patients may prefer company to being alone). Often there are facilities for carers to stay either in the room with the patient or separately elsewhere in the building. Not all hospices have in-patient beds, instead concentrating resources on day care facilities and/or home services.

Day care and outpatient facilities

Some of the sicker patients may need facilities during the day for symptom stabilisation or daytime respite for carers. They may not need to stay overnight if they receive appropriate care at home. Other ambulatory and semi-ambulatory patients may attend in order to get treatment of symptoms and other therapies such as reflexology, physiotherapy, massage or aromatherapy. Some are there for psychosocial support or simply to socialise. Patients may have come in order to be bathed comfortably using special equipment provided, or they may be there for the day to give carers a respite during working or shopping hours. Such facilities provide an opportunity to continue a patient's personal growth through creative therapies such as art, music, writing, crafts, or to participate in group work.

Home services

Sometimes referred to as "hospice at home", home services range from providing patients with occasional symptom control to providing intensive 24/7 nursing during the latter stages. The home service may also be providing psychosocial support to both patient and carers, and bereavement services to carers. It may also include a liaison role between GPs, District Nurses and other services. Home care will be discussed in more detail later.

Bereavement and services to carers

Social workers are generally available to advise on anything from benefit eligibility, to future child care issues to writing of wills. Some hospices have dedicated support groups or counselling for carers. Bereavement counselling may also be provided, not only after death but often before, as it is recognised that the process of bereavement starts long before the loved one dies. Better resourced hospices may have a small flat or suite where families can stay during the most intensive periods of decline.

Hospices are increasingly advising families on arrangements after death including funerals. There is frequently a chilled room for the viewing of patients who have died by relatives and friends. It is particularly important that cultural rituals are respected (e.g. who may or may not touch a body or washing procedures).

Spiritual care

Spiritual care is often interpreted as something exclusively for people of faith. Those working in palliative care would apply a broader definition, taking spiritual to refer to the aspects of life which give a sense of meaning to life experiences, re-establishing a sense of connection and hope. Those coming towards the end of their life may find themselves reviewing their life and wanting to reconcile unfinished business. Such needs are often picked up on by nurses, who are seen to be in a key position to respond to these needs but often view spiritual concerns in terms of religion and therefore refer to clergy.⁸² A chapel (multi-faith) or quiet room is usually available.

Clinical involvement and staffing

The bulk of hospice personnel are nursing staff and care assistants. Looking after patients is physically and emotionally demanding. A normal nurse:patient ratio in an in-bed unit would be 1½ nurses per patient.

The degree of medical involvement varies. Prescription of drugs to control pain and other symptoms is complex when the patient is already receiving extensive medication for their conditions. Many hospices favour the involvement of consultants with palliative care qualifications so that the hospice is responsible for the patients' pain and symptom control. Other hospices however will have less involvement from the medical profession and though they administer medication prescribed by hospitals or GPs, would not prescribe medication

Living well is as important as dying comfortably. Many patients come and go as in-patients and out-patients, depending on their needs.

Spiritual care is not aimed merely at people of faith; it addresses the search for meaning that every human being encounters in their life.

themselves. Whether a hospice has a high degree of medical involvement or not may be affected by a number of factors:

- patient profile (some hospices dedicate a greater number of resources to general long term care rather than acute palliative care);
- availability of specialist palliative care staff (sometimes in short supply);
- role and proximity of other health services, e.g. hospital or GP.

Staff try to enable patients to achieve a wide range of desires while they are living. For example, at one hospice a daughter's wedding was held in the day room so that her dying mother could attend. At another, a patient was married to her partner on the premises. Even bungee jumping may be an option, or learning a new subject.

Who provides hospices?

Hospices and related service providers (providing a total of 3,279 beds) fall into the following principal groupings:⁸³

Independent adult hospices	158
Independent children's hospices	34
Marie Curie Cancer Care	10
Sue Ryder Care	6
NHS	<u>62</u>
	270

Hospices may be independent, or be part of a large national group such as Marie Curie Cancer Care or Sue Ryder Care.

The average adult hospice size is 15 beds. An estimated 41,000 new patients are admitted as in-patients each year. In addition, hospices provide bases for an estimated third of the 334 palliative care nursing services available to patients.⁸⁴ Day care provision in hospices amounts to an estimated 32,500 patients pa.⁸⁵

Independent adult hospices

UK independent hospices comprise a huge movement, collectively accounting for total voluntary income of around £220m (see Table 1),⁸⁶ excluding the value of volunteers (estimated at £130m). The NHS pays for £80m of independent hospices services.⁸⁷

Hospices are often local initiatives which have been set up by an energetic (and often bereaved) individual in response to someone's death. The core of support will come from local communities and loyalties can be fierce. The philosophy behind the hospices will sometimes vary, for instance there are some with very strong religious roots. There will be enormous variations in the nature of relationships with the local PCTs. The standard of care is generally excellent, and there are numerous examples of innovation and leadership within the hospices.

Hospices are rarely set up as a result of a "needs based" assessment of local services and requirements. In the past there have been instances of hospices being set up in the wrong place, or on a non-sustainable basis, and this has impacted on the fundraising capability of an existing nearby hospice as well as relations with the PCT which commissions services. However, there are few adult hospices currently in development, and increasingly when they are developed, it occurs with appropriate consultation.

Marie Curie Cancer Care

As part of a national network of ten hospices, Marie Curie Cancer Care is in a position to adopt a coherent strategy towards its hospice development. As an early forerunner in the hospice movement, some of its facilities now seem dated, and consequently they have developed four new facilities since 1990's. However, it has a programme to upgrade its properties and is able to decide location on needs-based criteria. They also have one day care centre.

Marie Curie Cancer Care is primarily a cancer care provider. However, it will take up to 10% non-cancer in-patients, and will share other facilities (such as lymphodema treatment) with non-cancer patients more generously depending on local provision.

Sue Ryder Care

Sue Ryder Care runs six hospices and ten neurological care centres. Care centres are mainly situated in ex-stately homes, donated to the charity by connections of Sue Ryder, the founder and driving force of the organisation until her death in 2000. As a result, hospices are mainly situated in rural areas. Some units provide home care.

Although hospice care is a core area of expertise, Sue Ryder Care is not likely to expand its hospice provision in the near future; instead, any expansion is likely to be in the area of neurological care. There is very little suitable care for those suffering from degenerative neurological conditions such as progressive Multiple Sclerosis and Huntington's disease. Such conditions are highly physically and sometimes mentally debilitating, requiring specialist care. Many sufferers need residential care.

Sue Ryder Care's purpose-built neurological care centre in Aberdeen is a model for the future development of the organisation. Built in partnership with the local council and Scottish patient support organisations and designed in consultation with people with degenerative neurological conditions, the centre provides long-term care to those who would otherwise be in unstable or unsuitable caring situations. Care becomes palliative as the disease reaches its final stages but may continue for several decades. The centre offers residents greater independence, understanding and fulfilment than they would be able to find elsewhere.

Nursing services

With most patients preferring to die at home, nursing services are crucial to the provision of palliative care. Nursing may be required at various stages (e.g. during periods of aggressive treatment or after surgery) but needs will intensify as the patient deteriorates.

As mentioned earlier, most PCTs provide their own nursing services, but provision varies widely across the country. The most visible voluntary sector nursing services are provided by Marie Curie Cancer Care and Macmillan Cancer Relief. It is important that their roles are clearly differentiated (see below). Both organisations are cancer oriented, with only limited remit to care for non-cancer patients. Hospices may also contribute to nursing provision: there are 334 palliative care nursing services, a third of which are run through hospices. An estimated 135,000 patients are seen annually.⁸⁸

Marie Curie Cancer Care

Marie Curie Cancer Care nursing services tend to be 24/7, with approximately 80% of the work taking place at night towards the latter stages of disease progression.⁸⁹ The nurses are often deployed during the patient's acute periods, and when family carers are unable to cope, and tend to be general rather than specialist palliative care nurses. They undertake arduous physical nursing required by seriously ill patients, but do not supplant family carers. As some PCTs also provide 24/7 services, the extent of the care provided by Marie Curie Cancer Care will vary accordingly. To complicate matters further, many PCTs contract Marie Curie nurses to provide services, but reporting to the PCT rather than to Marie Curie Cancer Care. The nurses wear Marie Curie Cancer Care uniforms and comply with Marie Curie Cancer Care standards, but day-to-day management is by the local PCT, and they work alongside NHS nurses. However, the PCT generally only pays 40% of Marie Curie Cancer Care's costs of employing the nurses (arguably the NHS should pay a larger proportion).

95% of PCTs have Marie Curie nurses in their care plans for patients. Marie Curie Cancer Care provides 2,500 nurses and an equivalent of 800,000 nursing hours to patients. Some of the nurses are on contract, but most are "bank" (a common nursing system whereby nurses are called to work *ad hoc* on a mutually convenient basis). Marie Curie Cancer Care is trying to increase the number of nurses on contract because of recruitment uncertainties. Critics would regard Marie Curie Cancer Care as a nursing agency for the NHS. In reality they are trained to a particular standard and with considerable expertise, and they are also advocates for home death and related issues. Marie Curie Cancer Care estimates that where a Marie Curie nurse is present, 94% of patients achieve a home death if desired. Marie Curie Cancer Care would like to aim for 100% 24/7 nursing coverage of dying patients in the UK by a combination of the NHS or themselves. A pilot programme in Norfolk, where current needs are being met 92% of the time, is being developed to see if 100% coverage is possible. The same pilot is also trying to improve the continuity of care for patients who are discharged by the NHS.

There are hidden coverage issues: it may appear that demand for home nursing is being met, but in reality not all patients are being referred. GPs are sometimes a stumbling block,

Nursing services can keep patients out of hospital even as death approaches.

Voluntary sector nursing services must liaise closely with NHS services in order to maximise the benefit to patients.

not readily understanding what Marie Curie nurses do and leaving the District Nursing Service to liaise. A national campaign by Marie Curie Cancer Care to educate GPs has the support of the National Cancer Director, Professor Mike Richards, and the roll out of the Gold Standards Framework (described in more detail later) will help with this gap in referrals.

Macmillan Cancer Relief

Macmillan nurses have a very different role. With a Macmillan nurse, general care may still rest with the family carer. Macmillan nurses attend during the day for short periods (sometimes as little as once a week, or even once a quarter, depending on circumstances), and come to advise on and apply symptom control. They are more clinically specialised than Marie Curie nurses and do not undertake general physical care. They are, however, helpful in providing specialist and psychosocial support, particularly regarding diagnosis. A patient may not yet require 24/7 care, but may need advice instead. Macmillan nurses also provide support services to hospital in-patients.

The funding situation is complicated. Macmillan Cancer Relief will “pump-prime” posts for three years, at which point the post is funded by a third party, either the PCT or the local hospice or a combination of both. However, the title of Macmillan is retained.

Sue Ryder Care also provides home care.

Cancer services are advanced. It should be possible for non-cancer patients to benefit from the experience of the cancer services, albeit modified to suit their conditions.

Box 12: Delivering palliative care to non-cancer patients

Despite there being convincing evidence of symptom burden and psychological distress in those dying from conditions other than cancer, there have not been many studies that show that palliative care can be of benefit to them. It should not be assumed that the cancer care model should be extended to them. Although many aspects of the approach are likely to be of benefit, in-patient care may not be the ideal approach. Some palliative care teams have had concerns about accepting non-cancer referrals, including:

- Accepting other patients will lead to services being overwhelmed. Increased resources may be necessary. The changed disease profile being catered for will lead to a drop in charitable giving.⁹⁰
- It will be difficult to judge life expectancy in non-malignant diseases, which tend to have a less well-defined terminal phase. As there are less well developed community services for non-cancer patients, they may end up bed-blocking.⁹¹
- Many palliative care specialists have a background in cancer and may not have the confidence or expertise to manage other conditions.⁹²

However, a growing number of hospices now cater for a relatively high proportion of patients with conditions other than cancer. Others are developing particular specialisms such as chronic pulmonary obstructive disorder. Many have found that they have not been overwhelmed by referrals, though it could be the case that demand increases once public awareness increases and referrers become more familiar with what palliative care can offer to such patients.

Some believe that the feared bed blocking could be minimised if units are clear about what they are offering patients and any intervention has specified goals and is on a clear timescale.⁹³ In addition, keeping links with the referring clinicians and developing links with nurse specialists may give palliative care professionals more confidence in dealing with patients.⁹⁴

Carer support and social welfare

The welfare of entire families who may have lost more than one income is of concern to organisations such as Macmillan Cancer Relief who have identified carer breakdown as a principal reason for hospital admissions. Besides its hardship grants, Macmillan is piloting a help-line for advice on benefits. It also funds a befriending scheme for carers offering practical and emotional support, and works in partnership with other carer organisations such as Crossroads.

Help the Hospices (described in more detail below) has identified carers as a group in particular need of support. Help the Hospices estimates that 84% of carers suffer psychological distress and can be poor at seeking help for themselves. Help the Hospices wants to develop a programme to encourage hospices to engage more with the needs of carers, whilst simultaneously researching the issue and evaluating services. Many hospices, including St Christopher's, are addressing the needs of this group, and consequently a body of research is starting to emerge.

Strategic initiatives and bodies

The palliative care sector is somewhat fragmented, having been driven by the voluntary sector and by people who either are focused on one particular problem, or on a particular geographic area. There are now increasing efforts to act strategically, to consolidate, to re-group and to explore replicating best practice. Both the government and voluntary sector are concerned with strategy and there are several voluntary sector organisations and bodies which are well-placed to make a strategic impact.

Help the Hospices

Independent hospices have not always been collegiate in outlook. However, the revitalisation of the umbrella group Help the Hospices since the mid-1990's is resulting in greater marshalling of common interests. So far, Help the Hospices has developed a number of services for hospices (on education, training and information) which improve efficiencies and save wheels being reinvented. It also attempts to bring parties together to collaborate across the sector. Activities are currently being developed in the following areas.

National funding partners: Help the Hospices has helped secure corporate partners such as BAE Systems, Sainsbury's, Lloyds TSB and Tesco's to generate nationwide funding for hospices (£3m has been raised to date).

Grants programmes: two major grant-making trusts run their hospice grants programmes through Help the Hospices in order to make application for grants more efficient and equitable. These programmes focus on particular areas of developmental need, such as training and education. Help the Hospices wants to develop further programmes for services to under-served populations, e.g. carers and non-cancer patients. It proposes to encourage hospices to extend existing services (by channelling funding to hospices developing their services), but at the same time to research and evaluate the outcomes of such service provision to determine best models and best practice.

Models of best practice: when new legislation comes into force, Help the Hospices develops models and policies on compliance for hospices so that 200 or so organisations do not have to undertake this independently.

Information and communication: their information centre is available for hospices and users and has internet and telephone access.

Hospice-Connect: this is an IT initiative improving access to electronic patient records by hospices (these are records currently held by NHS and are vital to patient care).

Shared services: a number of hospice administrative functions (IT, finances, human resources, utilities, buildings maintenance) could be shared between hospices to reduce costs. This is an area Help the Hospices wishes to explore in detail.

Income generation: Help the Hospices wants to develop ideas for additional income generation for hospices such as a funeral advisory service which would not only help the vulnerable bereaved to navigate their way through funeral options, but would also generate income through funeral providers paying the hospice a small commission per recommendation. Help the Hospices also wants to extend local lottery activity in the sector, given its success in some parts of the country. Help the Hospices liaises with the **National Council for Hospice and Specialist Palliative Care Services** in order to influence policy and government on the concerns of its constituents.

Macmillan Cancer Relief

Macmillan Cancer Relief retains the branding of its post-holders described above, even after expiry of their funding by Macmillan Cancer Relief. This maintains the profile of the organisation, which helps in fundraising. Beyond the initial three-year pump priming, it offers every post-holder continuing training, education and development.

Help the Hospices can help funders make targeted grants.

Strategic grant-making can have particular benefit in this sector.

Historically, Macmillan Cancer Relief has been active in developing clinical posts, but is now satisfied that the NHS is now taking palliative care seriously, so is increasingly moving into other areas. That said, the bulk of charitable expenditure still is on clinical and nursing services (43%) with 21% on social care. Capital costs, education and information make up much of the remaining costs.

Macmillan GP “facilitators” (themselves doctors) are helping GP practices to acquire the skills and protocols necessary to apply the GSF. Macmillan Cancer Relief supports GP practices by “buying” two sessions per week to allow GPs to acquire the skills and implement the protocols.

The Gold Standards Framework is a tool to help GPs and others provide more coherent care without the need for significant extra resources.

Box 13: Gold Standards Framework: Macmillan Cancer Relief (GSF)

The Primary Health Care Team, which includes GPs, provides the mainstay of care for patients in the community. GPs may also be covering nursing homes and other residential care homes; they may be involved with a patient admitted to a hospice or hospital. Although palliative care is important to GPs and District Nurses who are skilled in general medicine, many have little extra training in it.

The GSF has been developed by Dr Keri Thomas, herself an NHS GP with a special interest in palliative care, with support from Macmillan Cancer Relief. The aim is to improve the provision of palliative care by GPs. As National Clinical Lead for Palliative Care in the Cancer Services Collaborative Dr Thomas has been tasked with rolling out GSF to every practitioner. The GSF provides guidelines for best practice on teamwork with other service providers, continuity of care, planning, symptom control, and support of patients and carers. The key components are:-

- **identification of patients:** e.g. the keeping of coherent registers of patients requiring palliative care;
- **assessment of needs:** including consultation with patients and carers as to their wishes; consultation with members of the local palliative care team as to requirements;
- **planning, continuity, communication:** regular discussions about patients at Primary Health Care Team meetings; summary care plans; hand-over protocols and records to minimise unnecessary crises and hospital admissions; passing of information; minimisation of number of professionals;
- **care of patient:** comfort and spiritual support; symptom control (in consultation with users); follows Liverpool Care Pathway (see below) in the final hours;
- **carer support:** includes carers as an integral part of the team, providing them with vital tools and ensuring they are appropriately supported;
- **sharing of experience** and peer education.

The main goals of GSF are: that the patient is as symptom-free as possible; in his/her preferred place of care with care tailored accordingly; that crises are minimised; carers are informed, confident of support, able to cope; staff are confident and able to communicate and teamwork with specialists from the multi-disciplinary team.

Supported by the Cancer Services Collaborative and NHS Modernisation Agency, GSF is being used by almost 1,000 GP practices. Macmillan Cancer Relief is running a two-year support programme including a toolkit of resources, workshops and an evaluation by Warwick University.

Part of the £12m recently announced by the Department of Health for palliative care (discussed in Section 3) will be applied to the roll out of GSF, along with Liverpool Care Pathway (see below).

Marie Curie Cancer Care

Marie Curie Cancer Care undertakes a number of strategic initiatives, most notably developing the Liverpool Care Pathway for the Dying Patient (see box).

The Liverpool Care Pathway is a protocol for caring for patients in the last 48 hours of life.

Box 14: Liverpool Care Pathway for the Dying Patient (LCP)

Developed by a partnership between the Marie Curie Cancer Care Centre in Liverpool and the Royal Liverpool University Hospital, LCP is a programme which ensures best practice in the management of patients in the last days and hours of their life. It provides detailed guidance to practitioners on topics including :-

- determination and clinical description of final dying stage;
- cessation of non-essential interventions e.g. feeding;
- resuscitation and the decision not to resuscitate;
- diomorphine dosage;
- urinary problems;
- keeping a patient's mouth moist and comfortable;
- techniques in how to respond to patient or family anxieties (including body language and eye contact);
- checklists and procedures to ensure that nothing is missed when monitoring all aspects of patient comfort;
- recording patient responses and conditions (providing data for further evidence-based research on particular interventions).

LCP was awarded Beacon status in the NHS in 2000 and has so far been rolled out to more than 100 centres (hospitals, hospices and primary care outlets) across the UK. Monitoring and evaluation of patient/carer benefits and care standards, and dissemination of lessons and findings, is a key component of the programme.

The intention is for LCP to become mainstream practice and to extend this across the 34 cancer networks, via half of the hospitals and PCTs in each network. Many hospices are already adopting practices similar to the LCP, and nursing homes are being encouraged to follow, with a target that 30% of hospices and nursing homes will adopt LCP by 2006.

The NICE guidelines view the LCP as one of the ways of achieving key recommendations in the guidelines.

Part of the £12m recently announced by the Department of Health for palliative will be allocated to roll out LCP, along with GSF. Non-cancer and cancer patients will benefit in each case.

Marie Curie Cancer Care launched a campaign "Supporting the choice to die at home" on 1st March 2004. This campaign has been launched with the benefit of economic analysis undertaken by Professor David Taylor on the costs of providing community care compared with hospital care. Costs are estimated at £300 per diem in hospital versus £179 per diem over a 14 day episode of terminal care.⁹⁵ The campaign makes the case for the NHS taking up the challenge of investing in appropriate community care, thereby enabling patients to choose their place of death and save the NHS resources in the longer term. Marie Curie Cancer Care aims to lobby the government to double the number of people able to die at home. The NHS would need to spend £100m pa on this, though this could free up £200m pa for hospital services.

Sue Ryder Care

The charity has refocused efforts more strategically since the death of its founder, and has drawn up a 10 year plan to direct modernisation efforts towards palliative and neurological care and away from the elderly and mental health services which may be better catered for by specialised groups. The partnership working and needs-driven approach involved in the development of Sue Ryder Care's neurological centre in Aberdeen is likely to be replicated in any future project.

National Council for Hospice and Specialist Palliative Care Services

The National Council for Hospice and Specialist Palliative Care Services (National Council) is the umbrella and representative organisation for hospice and palliative care services in England, Wales and Northern Ireland. It was set up in the voluntary sector in 1991 to provide a single national voice for palliative care. The National Council promotes the extension and improvement of services and through its membership and regional structure it works in partnership to represent the collective views and interests of hospice organisations and palliative care services to all arms of government and to the media. It does not cover Scotland, but liaises with the Scottish Partnership for Palliative Care. Subscribers to the National Council include the main national charities (Help the Hospices, Macmillan Cancer Relief, Sue Ryder Care, Marie Curie Cancer Care), NHS trusts, PCTs, hospitals, nursing teams, and professional associations. It is working to expand its constituency further to include those involved with the elderly and non-cancer conditions.

The National Council's policy analysis and mapping of needs and service provision have helped to inform government policy. It is currently working on standards of palliative care in nursing homes, pain, including "total pain" (in conjunction with Macmillan Cancer Relief), NICE guidance and standards and user involvement in palliative care.

The National Council's 2003-6 strategy focuses on a number of areas of activity, including:-

- issues arising from the NICE Guidance
- development of needs assessment tools for use by service providers, together with plans for a coherent mapping of needs versus services
- development of palliative care for non-cancer patients
- development of user partnership and involvement
- dissemination of good practice across the UK
- continuing work on cancer with the National Partnership Group and equivalent bodies in Wales and Northern Ireland
- facilitation of national debate around ethical issues.

King's Fund

The King's Fund specialises in research into healthcare provision in London. Although the King's Fund is mainly London focused, the research it undertakes has wider relevance. The King's Fund is piloting a project in conjunction with NHS Direct and St Christopher's Hospice providing a 24-hour help-line to patients, carers and health professionals to provide advice and information on end-of-life services and issues. This is being developed in response to King's Fund own research which found that the quality of care received by patients depended on their entry point into the system: patients on the "wrong path" get poorer care. King's Fund is also funding some areas of King's College's community care research on good models.

Research and education

There is some excellent academic work, practice development and research taking place in various locations. However there are some concerns that dissemination of such work is not as effective as it should be. This is compounded by a shortage of palliative care consultants.

Reflecting these problems, there are various initiatives to increase dissemination of specialist knowledge amongst generalists, whilst acknowledging the importance of a

The National Council is an important strategic player in the sector, acting as a high-level bridge between Department of Health and the voluntary sector.

specialist cadre. As one practitioner put it, you may want a fleet of Rolls Royces, but if you only have Mini Metros it would be wise to ensure that their tyres and carburettors are fully functioning.⁹⁶

Princess Alice Hospice in conjunction with Dr Max Watson, Specialist Registrar in Palliative Medicine, Northern Ireland Training Scheme, has developed a very helpful distance learning certificate course for health professionals in palliative care using video and written materials.

There is a need to educate the full range of health professionals at all levels. This includes GPs who may be willing to undertake additional education, although the need to pay for locum cover is a potential barrier to them actually taking the time. If locum cover were available to GPs for free, it would be easier to ensure their participation. Opportunities for distance learning would also be very helpful, and a proposal to pilot a web-based learning tool for healthcare professionals is being developed in the Birmingham Palliative Care Network in conjunction with **Birmingham University**, Dr Keri Thomas and Dr Max Watson. Carers and patients may also be included in this initiative.

Research on palliative care currently takes place in various locations. Macmillan Cancer Relief and Marie Curie Cancer Care undertake research and pilot their own service provision models; universities and hospitals also carry out research.

The National Cancer Research Institute (NCRI) is currently co-ordinating research efforts in cancer, and has identified palliative care as an area of particular need. They are establishing a Strategic Planning Group to address issues such as the overall research infrastructure, the training environment and multi-disciplinary working. NCRI will be reporting in the summer, identifying priorities and strategy. It may be possible in future to fund initiatives through the NCRI. The Supportive and Palliative Care Strategic Planning Group is chaired by the National Cancer Director and comprises representatives from Cancer Research UK, Medical Research Council, Department of Health, Macmillan Cancer Relief, Marie Curie Cancer Care and the NCRI Consumer Liaison Group.

The **National Council** is seeking funding to establish a policy unit to set out a strategy for the development of palliative care services over the period until 2020, particularly focusing on developing access to palliative care for non-cancer patients, addressing inequity of access, the effect of changes in demography including the impact of ageing and ethnicity, developing user involvement, and promoting palliative care policy that will meet the social and health care needs of the coming generations of patients. It will seek to focus on policy options that enhance patient choice and promote dignity and independence at the end of life, developing evidence based practice throughout. **King's College** in London has a specific palliative care research department housing luminaries such as Professors Irene Higginson and Julia Addington-Hall, although the latter is moving to **University of Southampton** to take up the position of Chair in End of Life Care – no doubt this unit will become active. As always, research into care for cancer patients is more advanced than other conditions. Professor Addington-Hall has complained that there was almost no evidence-based research on good palliative care models for non-cancer patients. **The Dame Cicely Saunders Foundation**, currently in development, is looking to establish an institute of research for palliative care (based at King's College) to provide a research focus for the sector and co-ordinate research efforts. No such institute exists internationally.

University of Sheffield Palliative Care Services Group (SPCSG) is also undertaking research in a range of important areas, emphasising patient and public involvement. The North Trent Cancer Research Network is heavily involved.

The Universities of Wales (in Cardiff) and Swansea also contain active palliative care units. Dr Ruth Davies, who is moving to Swansea, is particularly active in paediatric palliative care nursing. Professor Llorca Finlay is Vice-Dean of the medical school. **University of Bristol** also has an active Department of Palliative Medicine which includes Professor Geoff Hanks.

Much more research into children and adolescent palliative care is required. ACH and ACT (described in greater detail below) are keen to extend research in this area, for instance mapping needs and services.

Overall, NPC's sense is that both research and education in palliative care is somewhat disparate and lacking co-ordination when compared to a sector like, say, cancer or diabetes.

Research and education is key: without the first, there is no evidence of best practice; without the second there is no means of disseminating best practice.

Services for children

The voluntary sector is working hard to develop children's services, but demand exceeds provision.

Section 3 discussed the problems of caring for children suffering from life-limiting conditions. Where services such as children's community nursing teams exist, they generally work in partnership with the voluntary sector, and the main voluntary sector providers of care for children with life-limiting conditions are children's hospices. The role of hospices in providing respite care is vitally important, although sometimes children die in hospices too.

When the first hospice opened in 1982, the medical establishment was sceptical as to the need for such a service. In reality it opened a flood-gate of demand and rapid growth. Latest data from the Association of Children's Hospices shows there are now 28 children's hospices, with eight more at the planning stage, and a further six children's hospice-at-home service providers. It is likely that hospices will play an important role in helping to develop paediatric palliative care methods and protocols, including clinical protocols, boosting the efforts in this area described in Section 3. The running of children's hospices is expensive, because of the intensive care needs of children. The full cost per bed night is in the range £500-700, considerably more than the typical cost of an adult hospice.

Children's hospices offer a range of services including residential respite, day care, hospice-at-home, telephone advice, emergency care during "episodes", complex care at the terminal phase, and also provide liaison, contact and key worker services in helping families navigate available services. They also provide a great deal of pre- and post- bereavement support to families and friends. This support continues for as long as it is required after a child's death. Bereavement support may be provided by other voluntary organisations, for instance **Winston's Wish**.

There are two voluntary sector umbrella bodies for children's services:

The **Association of Children's Hospices** and the **Association for Children with Life-threatening or Terminal Conditions and their Families**.

Association of Children's Hospices (ACH)

ACH is a membership organisation which grew out of meetings in the 1990s between the heads of care of some of the early children's hospices. It was registered as a charity in 1998. ACH is still quite small and still in development (turnover is only £230,000 per annum). ACH's objectives are to raise public and professional awareness; promote and support the work of children's hospices; facilitate education, training, research and further service development. Recently its work has tried to improve corporate fundraising for charities, also to improve communication and liaison between members, supporters and patients. It is also turning its attention to care standards and Quality Assurance.

The major issues facing ACH are:-

- Recruitment and availability of paediatric palliative care specialists (a common refrain in the sector), either clinical or nursing.
- Development of new services in the most effective manner. ACH is concerned that new hospices should be developed on the basis of needs assessments and in collaboration with existing services. ACH is considering developing a charter mark for new hospice proposals to endorse those hospices which have undertaken needs assessments.
- Absence of coherent, up-to-date mapping of children's services. At present it is difficult, except through the anecdotal experience of people on the ground, to determine which areas are worst served.
- Adolescents and young adults are poorly served.

ACH works closely with ACT and Help the Hospices. ACH and ACT have observer status on each other's Trustee Boards and some members of senior personnel are present in both organisations.

Association for Children with Life-threatening or Terminal Conditions and their Families (ACT)

ACT is broader based than ACH, having 330 members including children's hospices, community teams, and other organisations. However, in terms of income they are also small,

The umbrella bodies representing the users and service providers for children are needed to speak up for the sector and improve strategic direction. They are still small however, relative to their adult palliative care equivalents.

with only £200,000 annual income. Their purposes are to advocate on behalf of affected children and families; to campaign for the provision of a co-ordinated network of care and support; to promote models of good care and practice; to support families with a national information service (including a help-line and "signposting" service) and to enhance the knowledge and skills of professional carers by providing specialist literature and education opportunities.

ACT has published a number of important papers on the state of care for children. It will publish a generic care pathway for children with life-limiting conditions in summer 2004.

ACT's main concerns are:-

- Training in palliative care for non-doctors and nurses, e.g. the creation of an NVQ in children's palliative care for care assistants and volunteers.
- To increase information directed appropriately to the children (including adolescents) themselves and families.
- To continue to campaign for the provision of co-ordinated services for children including better respite provision and improved services in the community.
- To represent the needs of adolescents and young adults (echoing ACH's concerns in this regard).
- To facilitate the sharing of knowledge and increase the evidence base of research.

Summary

- Palliative care is a large sector. Annual spending of all organisations is over £600m, more than half of which is funded by voluntary income.
- Government interest is increasing, but increases in funding do not match need and specific pots of additional allocated funds may not be available in the long term.
- There are critical strategic requirements of the sector, such as NICE and the Care Standards Act which will have a marked effect on the sector, including on funding requirements.
- Hospices and nursing services are the backbone of the sector. However, initiatives to include a wider range of health professionals (e.g. GPs) and care settings are going to revolutionise the provision of palliative care to patients.
- The voluntary sector provides many of these services, and has been extremely important in supporting and funding the pioneering activity of individuals working in both the NHS and voluntary sector. Dissemination of best practice is crucial.
- However there is a shortage of professionals in the sector: education of specialists and generalists is required.
- The sector is also under-researched: more evidence-based data would strengthen arguments for increased funding as well as ensure best practice was adopted. Not all of the needs are well documented.

Section 5: Outcomes from interventions

If a donor is to make an effective donation, it is important to explore the outcomes of the range of interventions available. This section explains the effect of support and palliative care interventions on the patient and its family and carers. It also steps back and takes a wider look at how strategic initiatives can impact on the whole sector.

Introduction

The outcomes from the interventions described in Sections 3-4 need to be distinguished from their outputs. For instance, an *output* might be a home care nurse on call at night, while an *outcome* would be a peaceful home death in accordance with the patient's wishes. This section is interested in outcomes. Articulating and measuring outcomes is difficult, and the evidence-based research in the sector is patchy. One of the difficulties is that palliative care has been low on the research agenda and funds have not been available to carry out research and evaluations into programmes. It can also be ethically questionable to deny patients support or care during the course of a trial, so randomised control trials are rarer than in many other disciplines. Instead comparisons have to be made either with the situation before a particular pilot was undertaken (often with incomplete data), or with patients elsewhere without access to such resources.

There are broadly two levels of outcome from interventions:-

- Outcomes from services currently being provided and how they affect individuals. For example, the simple payment of a nurse's salary has tremendous benefits for those in his/her care and the need for that particular nurse will never disappear;
- The strategic impact of new services which might be piloted and subsequently rolled out. For example, in the case of education of GPs about the principles and practice of palliative care an outcome would be a skilled GP. A secondary and more important outcome would be dying patients under his or her care having a better quality of life.

We shall describe the broad outcomes first, in order to re-emphasise the importance of the services already developed by the sector and how the provision of support and good palliative care can affect individuals' lives. We then go on to explore the impact of some strategic initiatives, given levels of unmet need, and how these will enable a greater number of patients to benefit from interventions which should be available to all.

Table 3 shows interventions and the qualitative outcomes from these. We elaborate on this in the following. In some cases, the links between intervention and outcome are clear. For example, it is not unexpected that in-patient palliative care leads to improved quality of life in the final days of someone's life. In others cases, the links are harder to discern but are no less real. For example, there is evidence to suggest that good carer support can make care in the home more sustainable and a home death more likely. The first three columns therefore describe outcomes which directly affect the dying person and their circle; quality of life, place of death and coping skills. The last two columns describe intermediate outcomes, e.g. improving sector efficiencies and education for generalists, which should lead to direct outcomes in the long run.

Some interventions are more likely to lead to a desired outcome than others. At one end of the spectrum, there is plenty of hard evidence that many patients die at home when a home nursing service is available. At the other extreme, it is by no means certain that research might affect government policy, although this can happen and can be significant.

Later we shall examine indicative relative costings of interventions, but first the qualitative outcomes need to be explained.

Assessing outcomes involves asking what effect a grant or donation would have on the dying and their loved ones?

Table 3: Outcomes from interventions

Interventions	Quality of life in final days	Patient dies in place of choice	Possible outcomes			
			Improved coping		Improving sector capacity	Influence on government funding
			patient	carer		
In-patient/home care	✓	✓	✓	✓		
Day care	✓		✓	✓		
Information/welfare/support			✓	✓		
Carer support	✓	✓	✓	✓		
Piloted initiatives e.g. GSF or LCP	✓	✓	✓	✓	✓	
Education for health care professionals	✓	✓			✓	
Research	indirectly		indirectly		✓	✓
Funding umbrella bodies	indirectly	indirectly	indirectly	indirectly	✓	✓

Examples of indirect benefits would be practice dissemination or grant distribution programmes.

How can support help people to cope?

The provision of support and information can have an impact that lasts longer than the duration of a visit to a drop-in centre or phone call to a help-line. Such interventions can improve mood, sense of perspective and leave patients and their families with an increased ability to cope with the impact of their condition.

Despite evidence of unmet need for such services, not everyone chooses to access support services.⁹⁷ It is thought that some wish to maintain their self-reliance and independence and regard seeking help as a sign of weakness. Some organisations make a point of employing male counsellors to help men, and others tackle specific communities, such as Black and Minority Ethnic groups. The aim is that those using the service can speak to someone with a natural empathy for their situation.

The cost of support will depend very much on the details of the intervention. However, NPC's research would suggest £30 per call to a helpline⁹⁸ and £250 per beneficiary supported for a year by a small information support centre would be reasonable.⁹⁹

Psychological and emotional support

Information can be a powerful antidote to fear of the unknown, though preferences regarding the amount of information vary. Most valuable are programmes where somebody is on hand to guide patients and carers to appropriate sources of information and to help with interpretation. Those affected have a chance to talk through the implications with an experienced person with time to offer. Booklets on the emotional impact of a diagnosis or prognosis for someone to digest as and when they are ready, can also be valuable. However, there is broad consensus that there is a wealth of information available, so much so that patients sometimes find it confusing. The Coalition for Cancer Information, with representatives from major charities such as CancerBACUP and the Department of Health, is trying to coordinate new efforts to avoid duplication. Tailored information delivery is an area that needs continued funding but it is often not seen as an exciting area to support.

The shared experience and emotional support provided by meeting other people in a similar situation can reduce isolation. Some programmes make use of volunteers who have been through the initial stages of shock and fear after diagnosis and have developed coping skills to deal with their experiences. Others use psychologists or social workers to facilitate group or individual sessions with those affected by serious illness. Such support can help people work through their difficulties and discover their own ability to cope. Some groups also cater for carers and the bereaved.

The provision of support and information can have an impact that lasts longer than the duration of a visit to a drop-in centre or phone call to a help-line.

Obtaining benefits or a grant from a charity may lift a significant burden of worry from those experiencing financial hardship as a result of their changed circumstances.

A peaceful and dignified death lessens the distress not only of the patient, but of their loved ones too.

Different patient groups with different types or stages of disease have different needs. Research shows that patients can be helped to cope with emotional reactions to terminal illness through group support sessions, gaining access to other patients with cancer who can serve as role models, and through the provision of a dedicated social worker.¹⁰⁰ In some cases, significant improvements have been found in the level of depression and other psychiatric symptoms when appropriate support is provided,¹⁰¹ particularly when interventions are individually tailored.¹⁰² There have been studies on the impact of psychosocial interventions on disease progression but their findings are not convincing.¹⁰³ A study on the effect of the “fighting spirit” on life expectancy has been discredited by the authors themselves,¹⁰⁴ and it is now accepted that “fighting spirit” does not necessarily prolong life. This is a relief to those who might interpret rapid decline as a sign of personal failure. However, even if the effect on disease progression is neutral, the effect on quality of life for patients and family is important.

Physical interventions prior to palliative care

Many patients find therapies such as aromatherapy and reflexology have a beneficial effect on their mood and wellbeing – 69% of 463 cancer patients in one survey had tried at least one complementary therapy. There is little convincing evidence that such treatments affect disease progression or alleviate symptoms, and in any case such treatments are rarely aimed at disease progression. However, acupuncture has been found to be effective in the management of chemotherapy related nausea and in controlling pain from surgery.¹⁰⁵ This lack of evidence should not belittle the positive benefit many derive from these therapies, as demand suggests that many feel better for receiving such attention.

Some groups teach relaxation and stress reduction techniques, for practice not only during a session but also in any situation. This can improve patients’ ability to sleep and reduce the psychological difficulties associated with a diagnosis of terminal illness. Some providers feel it is also beneficial for carers to learn such techniques for their own benefit.

Dramatic claims have been made for certain types of diet in halting and even reversing the spread of cancer, but there is as yet no scientific evidence for this. Some alternative diets can even be harmful, as they lead to weight loss in people who should rather be putting on weight. However, sensible dietary advice can be helpful – many find that cancer or its treatment leads to changes in taste, nausea and other side effects. Tips on foods that may be more appealing or that should be avoided can be of great value to someone struggling to eat. Many find taking control of their diet has substantial psychological implications as it is something they can do in the face of a disease outside of their control. They would point out that it seems counterintuitive that there is much one can do to alter a diet to prevent cancer but concern for diet stops at diagnosis. In the case of other conditions, where diet may be restricted or substantially influence prognosis, advice on how to work around limitations may be of substantial benefit to patient and carer.

Social and financial support

Many people affected by serious illness are not claiming the welfare benefits they are entitled to. People may inquire about specific benefits but there is currently no agency that can assess eligibility for a range of benefits. A person with knowledge of the system can direct people to the benefits they may be able to claim. Obtaining benefits or a grant from a charity may lift a significant burden of worry from those experiencing financial hardship as a result of their changed circumstances.

What are the outcomes from palliative care?

Palliative care covers two broad phases of a patient’s journey: the period leading up to the end stage of a person’s life, and then end stage and death itself. This begs the question, what constitutes a “good” death?

As we have discussed, there are three crucial factors: quality of total care; choice in the place of death; support for the carers. A peaceful and dignified death lessens the distress not only of the patient, but of their loved ones too.

This is where palliative care comes into its own, as it enormously improves the quality of life not only for patients, but also has a crucial impact on those around the person: family, spouses, children and friends. It addresses issues of pain and symptom control which are essential to good care. There are numerous studies to show that in-patient and home based palliative care not only reduces physical distress but also allows more patients who wish to die at home to do so.¹⁰⁶

Hospices need continued funding. A bed night in an in-patient unit costs approximately £325. The average stay is 13 days.

Day care is much valued by patients and may help avoid carer breakdown.

As discussed, providing terminal care is not the only role of palliative care providers. Respite and short-term rehabilitative or pain relief interventions during earlier phases of the patient journey are also important. Aspects of general support, discussed above, are an important component of palliative care.

Generalist versus specialist care

Several studies and systematic reviews have highlighted the benefits of a multi-disciplinary team approach with specialist input. Such care has been found to produce better outcomes than care provided by generalists, which has sometimes been found to offer poor assessment and result in insufficient symptom control.¹⁰⁷ Similar improvements in outcomes have been found for specialist care delivered in in-patient units or at home.

Different models of care meet different needs, so residential care provided by generalists should not be dismissed. This may be suitable for those whose needs fall between specialist palliative care and continuing care, or for those without complex medical needs who are unable to die at home. However, there is currently less evidence on the need for such a model of care. Hospices currently lacking a palliative care consultant, and therefore not qualifying for the “specialist” label, may simply be facing the national shortage of consultants. It is also desirable, where possible, that generalists be given opportunities to develop the maximum level of skill so that specialisms can be transferred to generalists where possible.

Hospice in-patient and day care; specialist residential care

A homely environment and the cheerful, positive buzz to be found in most hospices can make a tremendous difference to both patient and family. The little touches and small enjoyments are often the things carers remember most when their friend or relative dies.

Time is a vital component of good palliative care, necessitating a high and expensive staff-patient ratio including psychosocial and spiritual input. PCTs commissioning palliative care services frequently do not have the financial resources to allocate sufficient sums to this aspect of care provided by hospices (although some PCTs with in-house units may include such services).¹⁰⁸ Therefore the voluntary sector is best placed to provide the added value of such services. The extra attention and time is much appreciated by those who have seen how little time NHS staff on acute wards have to offer.

The care provided by specialist centres, such as the Sue Ryder Care neurological care centres, provides dramatically different outcomes to care offered in care homes, mental health wards or by social services which they would otherwise encounter. Those affected experience a quality of care and level of independence which would be impossible elsewhere. The environment and attention can alleviate the sense of institutionalisation.

The impact of palliative day care is not as well evidenced as yet, although informal feedback from users is very positive. This is probably because of the difficulty of measuring the benefits, which, by the nature of the patient group (who tend to have less extreme physical needs) are primarily social. This social support and stimulation is often of huge benefit to those who live alone, or those who have felt isolated and depressed because of their condition.

Respite for carers is an equally important outcome for regular day care and is often regarded as a life-line for those who would otherwise have little time away from the stresses of caring. This benefit is crucial.¹⁰⁹ Respite helps to avoid carer breakdown, one of the biggest causes of hospital admission or institutionalisation. It reduces stress and morbidity of the carer. And from the provider's perspective it is an efficient allocation of resource as day care costs less than full admission.

Hospices need continued funding. Some have more secure income streams than others, for geographical and historical reasons. Although there is no clear correlation between deprivation and difficulty of fundraising, anecdotally it is clear that some hospices are in areas with finite local resources. The level of funding from PCTs also varies widely, leaving some hospices more reliant on alternative funding. Added to this is local variation in terms of need (resulting from demography, deprivation or ethnicity) and, therefore, demands on services.

Hospice outputs could crudely be priced at £325¹¹⁰ per bed night for in-patient services. Patient stays will vary: as noted earlier, the average stay is 13 days.¹¹¹ Patients may attend several times during their journey. So a voluntary sector donation of £75,000, grossed up to £100,000 to include statutory funding, would provide more than 300 bed nights, i.e. 24 13-day stays. This would benefit both patients and their families.

There are other impacts associated with funding individual hospices, as some develop specialisms, for instance in helping patients with chronic pulmonary obstructive disorder, (St. Catherine's Hospice, Scarborough) which can then be shared with other palliative care providers. Increasingly practices developed in one place can be incorporated into training programmes provided or co-ordinated by central bodies.

Home care

Arguably, place of care is less important than quality of care: a badly supported death where the patient experiences uncontrolled symptoms and is in distress, leaving the carer anxious and guilty, is hardly likely to be less distressing at home than in a hospice or hospital. However, given that home and hospice care produce roughly the same outcomes at the same or less cost,¹¹² there is little excuse for patients not dying at home if that is their wish, unless their condition is medically complex. The familiar surroundings of home can be a huge comfort to the dying, perhaps particularly those who have had bad experience of hospital care. It can aid relatives in their bereavement if they know that everything possible was done to help their loved one die in their place of choice. It should be noted that the wishes of carers and patients do not always coincide. Specialist nurse coordinators linked with 24 hour palliative care support phone lines for patients, carers and generalist professionals have proven valuable in reducing hospital admissions and in increasing the chance that patients die at home.¹¹³ With consultant support they are likely to be able to secure quick referrals to outpatient clinics when care needs to be adapted following a change in conditions.

However, the levels of psychological distress reported in samples of carers of patients accessing palliative home care services demonstrates that such generic care does not meet all of carers' needs.¹¹⁴ Optimum home care depends in a large part on adequate care for carers to sustain them in their role.¹¹⁵

A Marie Curie Cancer Care nursing service or hospice equivalent (hospice at home) results in compelling outcomes for patient choice. If a hospice-at-home service is available, 86% of patients are able to die in their preferred place. If a Marie Curie Cancer Care nursing service is available, 94% of patients are able to die at home. Marie Curie Cancer Care estimates that over a 14-day intensive nursing period, the full cost of home care complementing the care provided by family, but including the cost of additional medical and health professional inputs, would be £179 per night, compared to £300 or more for a hospital stay.¹¹⁶ A consultant nurse service, where the nurse visits to advise on issues such as pain relief requiring specialised help costs approximately £40 per patient per day. Such a service would involve the nurse spending much less time with the patient and additional support from social services and primary care professionals might be required.

Carer support and bereavement

Support for carers can have a significant impact on their bereavement experience. Simple recognition of what they are going through is often much appreciated. Reassurance is commonly needed by carers, who may need to hear that what they are feeling – be it anger, guilt, or depression – is normal and not a source for shame. Admission to an in-patient unit or uptake of home care support is a crucial time for support – if their contribution is valued and they are included in patient care, then their guilt can be somewhat assuaged.

Carer support can have the added benefit of preventing hospital admissions. A common reason for admission is "carer breakdown", where a carer is too exhausted or overwhelmed to continue care at home.¹¹⁷ Respite, befriending schemes, help-lines and support groups all contribute to avoiding this situation. Training the carer to administer drugs and to recognise what to expect as the illness progresses can also help to reduce dependence on hospitals.¹¹⁸

Reaching carers in the community can be particularly problematic. The most effective schemes are those that put thought into accessibility. Carers attending support groups that were evaluated for research purposes reported valuing meeting people in similar situations, having their feelings validated and legitimised by facilitators and other carers, receiving informal and professional advice and taking a break from caring.¹¹⁹ There is some evidence that intervention prior to death could also improve bereavement outcomes and thus need for support and counselling later on.¹²⁰

Facilitation of peer to peer support is necessary to run groups as members are likely to be under considerable strain.¹²¹ A home sitting service using volunteers found that they encountered issues maintaining boundaries and with stress, leading to early burnout.¹²² Volunteer selection and training for any support role is crucial; amongst hospices, this tends to be fairly good, as support for all staff is well integrated into operations. Support groups are

The familiar surroundings of home can be a huge comfort to the dying.

Carers often appreciate recognition of what they are going through and reassurance that their feelings are normal.

If relatives are told clearly that the patient is dying they have the opportunity to ask questions, stay with the patient, say their goodbyes, and prepare themselves for the death.

not appropriate for all carers – for the more vulnerable, one to one interventions may be better.¹²³ Indeed, a study of a one-to-one problem solving skills intervention for carers appeared *only* to be beneficial for a distressed sub-sample of carers.¹²⁴

If relatives are told clearly that the patient is dying they have the opportunity to ask questions, stay with the patient, say their goodbyes, contact relevant people, and prepare themselves for the death.¹²⁵ Support in the last days and hours is crucial as loved ones increasingly anticipate and adjust to their loss. Given the relationship between patient and carer status described in Section 1, with carer burden and distress impacting on patient distress and vice versa, it is important not to consider either patient or carer in isolation: support for one is support for both. That said, one cannot expect to alleviate the difficulties experienced by patients and carers as much as possible without care and support for both.

Box 15: The impact of good carer support

“Jane was terrified at the thought of Richard coming home from the hospice, but felt she had to try to comply with Richard's wishes to be at home. She received excellent support from her GP and District Nurse, who reassured her that they would be on the end of the phone, and if she felt she couldn't cope, more help could be offered. She had a night-sitter once but usually one of her teenage children stayed up through the night with Richard. After he'd died very peacefully at home, she felt so relieved that she'd been able to care for him at home, she wondered how she'd ever felt so terrified. Mainly it was a fear of the unknown and of not being able to cope, but with reassurance, information and practical support and the knowledge that help was available if needed, together they'd been able to fulfil Richard's wishes to remain at home for the last two weeks of his life.”

Source: Thomas, K. (2001) *Out of hours palliative care in the community*. Macmillan Cancer Relief

Bereavement counselling is not needed by the majority of people but can help those who are having unusual difficulty responding to their loss. Nurses are often in a good position to identify those most at risk of bereavement problems, for example those who have experienced a string of bereavements and those with little social support. They can refer appropriately to the services available. Counsellors believe that short term interventions around the time of bereavement may have a role in preventing mental health problems later on.¹²⁶

For those who manage their grief independently, the leaflets on what to expect in the various stages of bereavement may provide some reassurance. Opportunities provided hospices, such as memorial services at Christmas, may provide a welcome opportunity to remember and meet sympathetic hospice staff.

What are the outcomes from palliative care for children?

The effects of sensitive care and communication over the illness and death of a child are broadly similar to the effects when the dying person is an adult, except it is even more important to look at the life and death of the child in the context of the family. **Acorns** children's hospice in Birmingham was set up in response to several families at a specialist school not coping well after their child's death, with some family members committing suicide. They hope that their work helps prevent such tragedies taking place again. Helping one member of the family adapt to the child's deterioration and eventual death will have an impact on all family members – particularly since the reaction of the parents is thought to be crucial for the remaining children.¹²⁷ Supporting and including siblings, either in the normal course of their work or through dedicated programmes, can alleviate children's sense of being left out or ignored and their fear and isolation in being the sibling of a child with a rare and fatal illness.

Box 16: The impact of care in a children's hospice

"Acorns turned it into something graceful, something dignified –and not just his death, his life too." *Parent of a child who died at Acorns Children's Hospice.*

"Charlie is now 8 and has an undiagnosed neurological disorder. He is blind, severely epileptic, has profound physical and learning difficulties. This is extremely demanding both physically and mentally because Charlie is completely dependent on us 24 hours a day. All our friends tell us that we need a break but in order to take that break we must be able to leave Charlie with people who are able to meet all his needs. Helen House is the only place I have felt confident leaving Charlie. Medically he is very complex but they take it all in their stride. It is also the only place where I don't feel Charlie's happiness is compromised by our needing a break – he has a ball! When I go to collect him I am reminded of how I felt at about his age when my mum used to come and pick me up from friends' birthday parties." *Parent of a child making use of Helen House, Oxford.*

Sources: 1) Davies, R. *The Growth of hospices in the UK*. Paediatric Nursing, Vol. 10. 2) Helen House and Douglas House News, Spring 2003.

What is striking about parents' stories of respite provided both in hospice and at home is how often they refer to the service as a lifeline. This suggests those who cannot access respite are left at breaking point. Families receiving support in the community or through a hospice are not under the constant strain entailed by fighting a constant battle for appropriate services. Families say that they value the sense of being supported and the environment and staff welcoming the whole family. They say that hospice care takes away their feelings of being alone and helps them to address the issue of the child's death openly.¹²⁸ As with adults, if loved ones are able to look back on a peaceful death and good experiences leading up to it, they are less likely to encounter problems in bereavement.

The crude cost of providing such care lies between £500-700 per bed-night, depending on facilities, staffing ratios, age and condition of children. This may seem expensive, but if one includes the parents and siblings as other beneficiaries of such services, then the real cost per beneficiary is much lower.

For most children, the centre of care is the home. While parents see respite breaks away from the home as important, they also would like more ongoing support in the home.¹²⁹ There are a number of voluntary sector and health service nursing teams which provide such care, though they can currently only reach a small proportion of affected families. Some children's hospices are also active in community based care. Home care for children is an area that NPC has not explored in detail, though we may do so at a later date.

Outcomes of strategic interventions

The current provision of palliative care by the government and voluntary sector does not reach all those who could benefit from it and this seems inequitable and uncivilised. However, there seems increasing political will in both government and the voluntary sector to address this issue and increase coverage.

Although we deal with the outcomes of research separately, we would regard many of the activities in research and education as themselves strategic.

The voluntary sector has a history of trail-blazing in palliative care. The sector can pioneer new approaches that can over time become adopted by government.

As noted earlier, interventions are not limited to funding Hospice X or Y, but instead might include:-

- Programmes tackling weaknesses in the sector, which could increase the impact and efficiency of future donations.
- Programmes allocating resources to schemes in poorer areas, resulting in improvements in equity for all patients.
- Programmes to pilot specialised areas, such as a particular non-cancer clinical condition, so that other service providers can follow developed practice.

It is striking how often parents refer to respite in hospice and at home as a lifeline.

Strategic interventions could impact on quality of care for the dying in all settings.

Need > Delivery > NHS services > Voluntary Sector > **Outcomes** > Conclusion

- Efforts to tackle social issues and issues relating to carers, thereby improving outcomes for patients and families.
- Initiatives to improve efficiency in the provision of palliative care to children, thereby reducing wastage and increasing services.
- Research into the lack of provision for adolescents and young adults where traditional hospice care is not appropriate to their needs.

Umbrella bodies such as the **National Council, Help the Hospices, ACH** or **ACT** may be appropriate conduits for these interventions. The outcome of the National Council's work mapping service provision versus need was important evidence to the government in presenting the case for increased government funding. The result was the extra £50m committed in 2002. Future work undertaken by the National Council may have similar effects.

Large organisations such as **Macmillan Cancer Relief, Marie Curie Cancer Care** and **Sue Ryder Care** are often key in developing models of care and new services which achieve national recognition. For example, the effect of rolling out initiatives such as the LCP or GSF (outcomes described in detail below) will be:-

- proper procedures for practitioners in the care for the dying;
- training opportunities for practitioners;
- improved awareness of palliative care issues among practitioners such as GPs who have sometimes ignored the problem.

The consequential outcomes of these effects will be:-

- better care for patients whatever the setting;
- fewer unnecessary hospital admissions.

Box 17: Outcomes from the Liverpool Care Pathway and the Gold Standards Framework

We can be specific about the outcomes from rolling out the Liverpool Care Pathway for the Dying Patient and Gold Standards Framework, since these have undergone evaluations.

Liverpool Care Pathway for the Dying Patient (LCP)

The impact of LCP will be enormous if successfully rolled out to as many settings as possible. It will allow patients more peace and dignity in death, avoiding inappropriate resuscitations, interventions, feeding etc., help with control of all symptoms and ensuring maximum comfort. The beauty of LCP is that for any particular setting, once the systems are implemented and the staff trained, there are no additional resource implications to following LCP.

Gold Standards Framework (GSF)

The outcomes of setting up GSF in GP practices are reported as follows:¹³⁰

- an increase in numbers of palliative care patients identified;
- increased noting of preferred place of death and numbers attaining their preferred place of death;
- increased numbers using symptoms assessment tools and end-of-life protocol;
- increased carer information provided;
- slight decrease in some areas in crisis admissions to hospital;

- overall improvement in staff levels of satisfaction.

If rolled out to large numbers of GP practices and other settings, then it is likely that many more people will be reached. Each GP, on average, copes directly with 20 deaths per annum, five of which are from cancer; five from organ failure; seven from old age/dementia; three from acute incidents or accidents. As with LCP, once the systems are set up, it is not costly to maintain. A GP “facilitator” in each PCT (providing a couple of sessions a week) would cost £10,000 per annum. A pilot to try GSF in eight care homes is in the pipeline.

Advocacy also plays a part. The outcome, if successful, of Marie Curie Cancer Care’s campaign to improve community services so that patients have the choice of dying at home may be not only to achieve good patient outcomes, but also to save NHS resources. The full cost of the campaign is not publicly known at this stage, but suppose it was £10m and as a result an extra 37,000 patients died at home, and £200m of resources were saved, then this would represent excellent economic leverage, let alone the less quantifiable benefits to patients.

Outcomes of research and evaluation

- Research and evaluation of new approaches is crucial on a number of levels: Demonstrating efficacy is important in order to get other practitioners to consider implementing new strategies or setting up new programmes. It will also convince funders, including government, of the value of a new initiative.
- Dissemination of results will enormously enhance the impact of a piloted service. Funding a network of hospices or national research body where there are existing information-sharing networks and educational programmes will help dissemination. A network of hospices can devise a research and evaluation programme in which components complement and reinforce each other, avoiding the danger of small programmes reinventing the wheel.
- NICE bases its recommendations on research evidence – thus finding convincing evidence that palliative care intervention benefit patients with conditions other than cancer could have substantial implications for statutory funding. For example, as noted above there is currently little evidence of the effect of palliative day care on patients although there is anecdotal evidence of significant benefits. Others would like to see more research on the interface between health and social care in palliative care delivery and into care for patients with longer term care needs. The NICE guidance has highlighted a need for a greater focus on practice-based research as there is already considerable evidence of the need for intervention.
- Needs assessment is vital in determining service provision, and there seems to be gaps in the mapping of needs. While the need is well known nationally, it is thought that there are large variations on a local level. Clearly, it is important that new palliative care services are developed with an understanding of how local need relates to current provision. Mapping this requires considerable effort. This is being undertaken by the National Council for Hospice and Specialist Palliative Care. In the case of paediatric palliative care, there is a similar or worse lack of information on the reach of existing services and levels of unmet need.

How research initiatives across the nation should be structured for maximum impact is hotly debated, and at this stage it is not at all clear where philanthropic funding would have greatest effect. There appear to be several alternatives:-

- **Dame Cicely Saunders Foundation** is intending to set up a large, dedicated institute at King’s College London covering all aspects of palliative and supportive care.
- The **National Cancer Research Institute** is currently co-ordinating research efforts in cancer, and is now expanding its remit to cover palliative care.
- The **National Council** has identified a need to expand data collection regarding need and services.

Research and evaluation of services could impact upon both practice and funding.

- Continuing support for research initiatives scattered across the UK, most of which would be paid for by educational or medical establishments, but some of which may need private funding. Greater co-ordination would maximise the benefits of such research.
- Ensuring that service delivery is evaluated in order to contribute to the pool of research.

Outcomes of education

Educational initiatives tend to be focused on generalists, as they provide the majority of care for the dying and are the gatekeepers to specialist services. As such, changes in their practice stand to make a significant impact on the quality of life of the dying. Changes to the organisation of services, improvements in symptom control and psychological, social and spiritual support is thought to lead to fewer crises, fewer admissions to hospitals, more rapid discharges, and more patients being enabled to die in their place of choice.¹³¹

This is not to say that education to train specialists is not important. In some areas, for example paediatric palliative care, there is a shortage of adequately trained doctors and nurses. Voluntary funding for specialist courses may be appropriate in some cases.

Most information on educational outcomes is on GSF and LCP. As noted above, for these there is strong evidence that guidelines and practice models can improve professional knowledge and attitudes and produce better outcomes for patients.

The impact of education tends to wear off unless training is in some way interactive.

Training has to be backed up by practice development and support. The impact tends to wear off unless the education is in some way interactive.¹³² An evaluation of the Macmillan Cancer Relief course for nurses working in care homes found that while the individual benefited greatly, the lack of support and development back in the home resulted in few changes to practice.¹³³ Training programmes making use of face to face interaction with patients may also be of help.

The voluntary sector can also have a role in developing new training courses where there is a shortage of available courses. For example, there is a shortage of trained nurses in paediatric palliative care. A number of charities, including ACT, would like to develop more courses in conjunction with existing providers. This would raise the profile of the discipline and could be expected to lead to better standards of care for dying children in hospitals, hospices and in the community.

Given the shortage of specialist palliative care consultants, a realistic alternative such as the web-based tool under discussion in Birmingham University and the Palliative Care Network (Drs Keri Thomas and Max Watson) is needed in order to transmit academic knowledge of clinical palliative care to other professionals in the front line.

Comparison of costs of interventions and their outcomes

Table 4 gives indicative costings of the interventions studied, to give a potential funder an idea of how many lives will be affected by a donation of £100,000. These can be scaled up or down for different sums.

Table 4: Costings associated with outputs and consequent outcomes

	Cost per unit	£100,000 buys	Beneficiaries
In-patient care ¹³⁴	£325 per 24 hrs	24 'episodes' of care (13 days each)	12 patients and families
Home nursing care ¹³⁵	£179-300 per 24 hrs, but varies	333 patient-nights	Similar to above
Day care ¹³⁶	£40 per patient per day	2,500 patient-days	200 patients pa
Information/support e.g. helpline ¹³⁷	£30 per enquiry	1 ½ nurses on fully serviced helpline	3,000 enquiries answered
Carer support	n/k	n/k	n/k
GSF ¹³⁸	£1.3m per 1,000 GP practices	80 GP practices brought into scheme	3,200 patients
LCP	n/k	n/k	n/k
Education for generalists – e.g. proposed learning centre ¹³⁹	£100,000 running cost pa + set-up costs	50-100 generalists pa on courses	If GPs, 500-1,000 patients may benefit
Research – e.g. children's services mapping	£40,000 to map Wales ¹⁴⁰	Wales plus part of England: 1.6m children population	Needs of approx 2,000 children mapped ¹⁴¹
Funding umbrella bodies	Variable	Variable	Variable

The table mainly identifies outputs, but from the discussions in this section it is possible to extrapolate the outcomes. For instance, if 3,000 telephone enquiries are answered, then that could mean up to 3,000 people (but probably fewer as each person may call more than once) has benefited from support, reduced ignorance of a condition, advice. Similarly, the 500-1,000 patients benefiting from a learning centre may experience a significantly reduced number of emergency hospital admissions.

It is important to stress however that although some interventions look inexpensive, such as education for GPs, the intervention in question may not be successful without the existing infrastructure of hospice and home nursing provision. For instance a GP will only be able to apply his/her newly informed recommendations for a patient if he/she has tools available to him such as a 24/7 nursing service or local hospice.

Section 6: Conclusions

Having analysed the outcomes of voluntary sector interventions, we are now in a position to highlight charities and initiatives well-placed to tackle the unmet needs we have identified. Whether a donor or grant-maker is attracted to supporting hospices directly, or to investing in education and research, voluntary funding is essential for providing compassionate care to the dying.

The voluntary sector pays for more than 50% of palliative care. Without voluntary support, the sector would collapse. There are significant gaps in the current provision of services by the government and the voluntary sector which could benefit from funding. In Section 1 we highlighted that people's wishes regarding place and manner of death are often unfulfilled, and that many people die in settings where palliative care is inadequately delivered. We identified non-cancer patients as being particularly poorly served, and also found that black and minority ethnic individuals may not be receiving adequate services. It appears that the services for children, adolescents and young adults are not even mapped, let alone coherently provided for, which is of great concern.

Without voluntary support, the sector would collapse.

Should the government take financial responsibility for delivery of palliative care? NPC believes that while the government should be encouraged to fulfil its statutory obligations, in reality many PCTs have finite funds and palliative care is subject to the reality of resource limitations within the health sector. Moreover, as noted in Section 2, there are no precise statutory obligations in palliative care. Additionally, many voluntary sector bodies guard their independence and flexibility jealously, taking risks, experimenting, and seeking to add value to patient services over and above statutory requirements.

In Sections 2-4 we discussed the delivery of palliative care and the roles of government and the voluntary sector, highlighting that there is close collaboration between the sectors on many levels. As a consequence, new initiatives supported by the voluntary sector, but developed jointly with the NHS, can gain a ready audience within government. The climate for innovation seems positive, and so donors can have a leveraging effect. Ideally, some initiatives developed may be cost neutral for the NHS: if the costs of inappropriate acute care were fully quantified it may be found that it is equivalent to the palliative care services which lead to avoided hospital admissions.

Meanwhile, the existing voluntary sector infrastructure requires long term support, and could also be "worked" harder. Much of the physical infrastructure is out-dated and will need replacement under the Care Standards Act. Human capital needs investment to provide more services: recruitment is often a major barrier to service provision. In practical terms it is rare to find a hospice where practitioners are satisfied that all local needs are being met. Although data discussed in Section 1 suggests that more people would like to die in hospices if given the opportunity, PCT commissioners and some voluntary sector Chief Executives see local in-patient resources as adequate and worry instead about community service provision. The experience of practitioners suggests instead that other services, such as day care and home care services often need development, particularly for under-served populations (non-cancer patients and those who are hard to reach). The voluntary sector is also well-positioned to help carers, and by helping them, to help patients.

Priorities for private funding

New projects are being developed by organisations and individuals all the time, and NPC therefore views the opportunities for donors to be a constant case of "work-in-progress". Currently there are various options for donors:-

Funding of hospices: directly to hospices and indirectly via Help the Hospices.

Independent hospices can either be funded directly, or via the umbrella body Help the Hospices. Direct funding is helpful if a donor has a particular interest in an individual hospice because of:-

- locality e.g. near the donor, or in a deprived and poorly serviced area such as Hartlepool;
- an activity e.g. developing/researching palliative care for a specific non-cancer condition such as efforts in Scarborough on chronic pulmonary obstructive disorder; or work with carers such as St Christopher's in Sydenham, London;

New Philanthropy Capital is aware of a number of interesting funding opportunities in individual hospices. Help the Hospices is well placed to distribute grants looking to achieve particular outcomes.

- issues relating to BME groups;
- physical infrastructure is being appropriately replaced e.g. relocation from a Victorian building to a purpose-built facility in hospital grounds. As noted earlier, a proposal for a new hospice should only be funded if a full needs assessment has been undertaken, in collaboration with the local PCT and other service providers.

NPC is aware of a number of interesting funding opportunities in hospices from conversations with chief executives and visits undertaken while researching this report.

Help the Hospices alternatively can administer grants programmes to a number of hospices on behalf of (and in consultation with) donors in order to achieve the strategic outcomes discussed in Section 5. This is helpful if a donor is keen for particular services or efficiencies to be developed by many hospices, for example:-

- **Services to non-cancer patients.** Help the Hospices has just started a £250,000 pa grants programme which is currently being supported by a corporate focusing on services to non-cancer patients, including patients who are in settings such as non-palliative hospital wards and elderly care wards. This would fund 12-18 extra services, but NPC expects that demand will soon outstrip supply under this programme. Providing additional funding for this programme would be attractive as it would build on an existing infrastructure within Help the Hospices.
- **Development of income streams.** The cost of starting up a potentially profitable lottery scheme for an area such as London is estimated at £25,000. A funeral advisory service, being piloted in Newcastle, may offer the solution to the problem of post-bereavement funeral advice whilst raising funds for the hospice in question. Once piloted, set-up costs for other hospices will be known, but are likely to be modest.
- **Shared service efficiency savings.** Help the Hospices is receiving funding for a feasibility study on shared services to hospices (e.g. IT, back office and administration) which may yield interesting opportunities for donors who have particular interest in the financial leveraging effect that can be created by improving operating efficiencies.
- **Training of professionals.** This is an area in which Help the Hospices is already active.

Help the Hospices receive applications from many hospices and select the most appropriate recipients. Help the Hospices are in a good position to disseminate new learning and practice within the sector.

Strategic national funding

Umbrella bodies are well-placed to tackle weaknesses in a sector, which could increase the impact and efficiency of future donations. These have greater lobbying power to influence government bodies and have greater ability to coordinate new programmes and research strategically. They can invest in development of resources that can benefit all hospices under their umbrella, thus avoiding duplication.

The **National Council** has considerable resource constraints (only seven employees) and is currently developing a Palliative Care Policy Unit able to develop a view of how services should evolve over the next 15-20 years. Items on its agenda will include those outlined in Section 4.

Major operators

As discussed in Section 4, NPC has been impressed by initiatives such as Liverpool Care Pathway and Gold Standards Framework. Supporting organisations such as Marie Curie Cancer Care and Macmillan Cancer Relief which in turn support such pilots enables donors to encourage similar initiatives in future.

These two organisations are focused predominantly on cancer, although with some leeway to focus on non-cancer conditions. Service coverage of the cancer population is not complete, however. There are still issues surrounding BME groups, financial hardship, 24/7 care at home, co-ordination of hospital discharge and compliance with Care Standards Act.

Umbrella bodies are well-placed to tackle weaknesses in a sector, which could increase the impact and efficiency of future donations. National hospice operators such as Sue Ryder Care and Marie Curie Cancer Care already benefit from central coordination.

Sue Ryder's expertise on caring for people with neurological conditions is much in demand.

Marie Curie Cancer Care and Macmillan Cancer Relief have been active in developing models of good practice; in campaigning and in providing services to meet specific needs.

There are numerous centres of excellence for palliative care research; funding is in much demand. Co-ordination and dissemination are essential.

All areas would benefit from further development. There is no reason why initiatives developed in the cancer arena could not in future be applied in non-cancer areas. These organisations are also active in tackling social issues.

As discussed earlier, Marie Curie has just launched a nationwide campaign to enable patients to die at home. It commissioned analysis which demonstrates the economic as well as human benefits of improving community care. £150,000 would help to consolidate its work on this campaign.

Sue Ryder Care, as well as running six hospices, has considerable expertise in providing continuing care for neurological patients. Sadly, its excellent care only reaches a small proportion of those affected by these conditions.

Help the Hospices has its own core funding and charitable requirements and plays an important role in presenting a collective voice for the independent hospices.

Extending initiatives such as the Liverpool Care Pathway and Gold Standards Framework to non-cancer settings

The announcement of the £12m from government to help train needs practitioners in these care protocols creates a conundrum for donors in the short term. We know that the funding is insufficient but it is not clear where the deficiencies lie, as exactly how the £12m will be spent is not yet known. However, in future this will create leverage opportunities for donors, who will find it necessary to deal with several parties:

- the individual(s) who developed the initiative
- the organisation which supported the development
- the part of the NHS likely to receive the roll-out
- the care setting which might benefit from the roll-out.

For example, if GSF is to be applied in care homes (there is a proposal to pilot it in eight) the programme would probably be best developed in conjunction with the NHS, and the care homes short-listed for the roll-out. The body taking responsibility for the roll out, which may be the NHS or a voluntary organisation such as Macmillan Cancer Relief, could be a recipient of *designated* funds for such a programme. This pilot has not been costed, but NPC estimates that an initial investment would be less than £100,000.¹⁴²

End of life alliance

There is discussion about developing a new cross-organisational and national end of life alliance, encompassing a constituency as broad as possible, in order to draw strands together and ensure that all those affected are drawn into the net.

Carers

NPC is likely to undertake further research developing strategies for helping carers. These are likely to involve education and information initiatives, and may bring together the efforts of more than one organisation as several of the major palliative care organisations have proposals in development (eg Help the Hospices using a similar system to their existing grants programmes).

Children and adolescents

NPC is likely to be considering issues relating to children and adolescents in greater detail in the future. However, in the meantime, bodies in the children/adolescent sector, such as ACH and ACT, would benefit from funding to enable them to develop. These bodies are not as mature as Help the Hospices, and need to grow if they are to serve their constituents properly.

Most urgently, help is required to map services and encourage those setting up new services to undertake a full needs assessment first. There are two alternatives: undertake a small pilot mapping project in Wales being planned by the University of Swansea (having had previous experience in Mid-Glamorgan) for around £50,000, or support a more ambitious England and Wales study being developed by ACH and ACT (though no formal proposal is available at this stage). This would be more comprehensive and include training

Education of generalists and specialists is vital for ensuring that the reach of palliative care continues to expand.

Funders have the opportunity to make a significant difference to the quality of life of people in the final chapter of their lives.

Need > Delivery > NHS services > Voluntary Sector > Outcomes > **Conclusion**

needs assessments and development of outcome measures. This would require greater manpower.

The development of services for adolescents by existing children's hospices and service providers would also be helpful.

Education and research

There are various distance learning materials developed for professionals but more could be done to help generalists, carers and patients themselves to apply palliative care. With encouragement from a donor, a proposal could be developed jointly between the PCT in Birmingham, Drs Keri Thomas and Max Watson for either an actual or virtual learning centre for people affected. NPC estimates that the running cost of a pilot may be £100,000 depending on its scope. There may be some demand for capital costs, but these have not been estimated yet.

Education for specialists is also vital. There are several hospices and academic departments addressing the national shortages of clinical and social work expertise.

There is demand for research funding across the country. Co-ordination is important, and if donors want to support a particular area of research, it may be worthwhile investigating who else is doing anything in the area to ensure maximum complementarity of efforts.

General points on funding

Depending on circumstances, NPC favours unrestricted funding for charities. Exceptions to this would be where a charity were to undertake a collaborative programme (e.g. Help the Hospices grant administration; GSF roll-out supported by Macmillan Cancer Relief). Then we would suggest designating the funding.

In palliative care, NPC would encourage any programme, particularly new initiatives or roll-out of initiatives piloted earlier, to include a component for evaluation purposes (and research if appropriate). There is a shortage of evidence-based material on palliative care services and this is hampering the determination of best practice and effective delivery.

The NICE guidance can act as a valuable resource for the donor, as it sets out what the government should be paying for. Before funding an area of work included in the NICE guidance, the donor should ask the charity why this is not receiving statutory funding. The donor should explore whether funding this aspect of the provider's work would discourage government from working towards paying for more care specified by the NICE guidance. It is possible that funding could be used more constructively in providing lobbying resources through a national body, or by funding other aspects of voluntary sector activity.

Conclusion

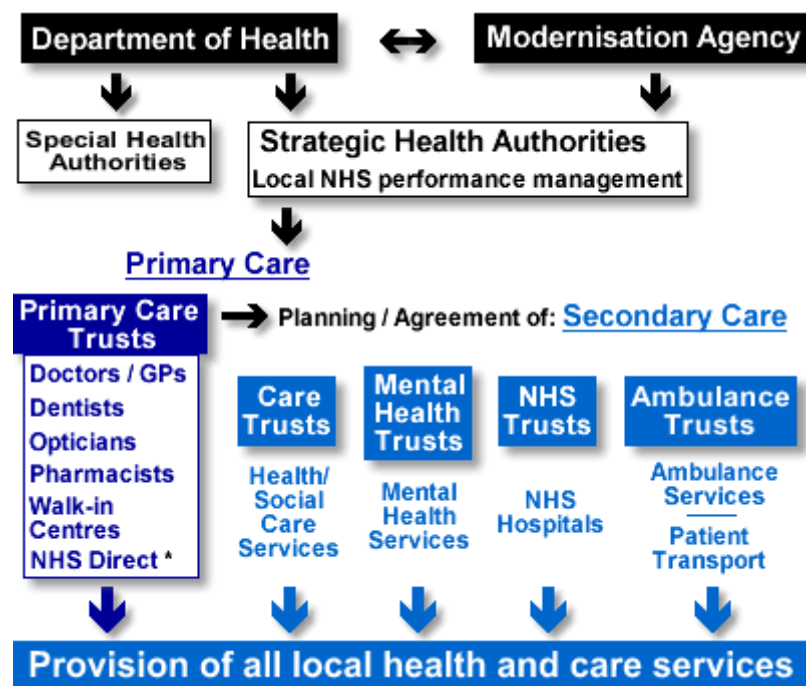
All of us face certain death; sadly, many of the dying encounter doubtful care. Hospices and home care services have proud histories of improving quality of life for the terminally ill and their carers. Voluntary funding, which accounts for more than half of the total funding of the sector, is essential to ensure the continuation of the compassionate care they provide. It costs just £325 per night to care for a dying patient and their loved ones in a hospice or at home.¹⁴³

Donors have the opportunity to make a significant difference to those with specific needs, including children and adolescents, BME communities and patients dying from conditions other than cancer. They can take advantage of the voluntary sector's tradition of innovation and standard setting, funding education programmes that would improve quality of care for all. Or they can tackle the under-funding of palliative care research, focusing on areas which will influence practice and government policy in the future.

Appendix 1: The NHS in England and Wales

For the first four decades of its existence the NHS was run by a monolithic bureaucracy. In 1990 the Conservative government introduced an internal market in which 'purchasers' (Health Authorities and some GPs) were given budgets to buy health care from 'providers' (hospitals and care, mental health and ambulance services). The Labour Party planned to abolish the internal market in 1997 because of the way they judged competition was damaging the character of the NHS, but in fact took a 'third way' approach of retaining the market but adapting the system to encourage more collaboration.

In 2000 the NHS Plan was published, outlining commitments to increase significantly spending on health and at the same time modernise the system (overseen by the **Modernisation Agency**). The most radical component of this so far was the "*Shifting the Balance of Power*" programme in April 2002 which localised decision making by abolishing the 95 Health Authorities and devolving 75% of the NHS budget to the 302 **Primary Care Trusts** (PCTs). These trusts serve populations varying in size from about 60,000 to 340,000.¹⁴⁴ In addition 28 **Strategic Health Authorities** (StHA) were created to help coordination and provide a check on the performance of the PCTs. While most of the "secondary care" purchased by PCTs comes from local **NHS hospital trusts**, they are free to purchase services from whomever they chose, including the private sector or NHS hospitals outside of their geographic area. PCTs are governed by a Board which is advised by a Professional Executive Committee comprising local health professionals, including GPs, nurses, public health specialists, representatives of the professions allied to medicine, and representatives of the social services department.



While local hospitals fall within the remit of the Strategic Health Authorities (StHAs), most of the services are commissioned and purchased by PCTs.

Foundation hospitals are intended as a third way option between the public and private sectors. They will be set up as public benefit corporations and give trust managers more freedom over local decision making (ability to borrow, vary staff pay, not be line managed by DoH, establish private companies), which in theory will stimulate innovation and entrepreneurialism to make health services more efficient, dynamic and responsive to patients. Local people and hospital staff will be able to elect governors who will choose non-executive directors for the trust hospital. Opponents are worried that foundation hospitals will create a two-tier system in which elite hospitals gets more resources at the expense of failing ones, further widening health inequalities. In particular, they fear that foundation hospitals' freedom to pay more will lead to them 'poaching' staff from other local hospitals. Another concern is that by becoming autonomous, hospitals will no longer work together as well.

The **National Institute for Clinical Excellence (NICE)** is a Special Health Authority under the direction of the NHS in England and Wales which produces evidence-based guidance on best practice. This is intended to inform health professionals and commissioners of care as to what they should be striving towards and patients and members of the public on what they may expect from NHS care.

As part of its work, NICE draws up clinical guidelines on the appropriate treatment and care of patients with specific conditions. The guidance on supportive and palliative care is currently undergoing its second consultation phase.

The **Cancer Networks** described in the main text have been set up in most PCTs.

The **Cancer Services Collaborative** is part of the **NHS Modernisation Agency**. They offer practical approaches to delivering the improvement targets laid out in the Cancer Plan. All Cancer Networks participate in its program, which is designed to:

- improve the way in which cancer services are provided;
- reduce unnecessary delays and restrictions on access; and
- improve patient and carer experience.

It has produced guidelines on site-specific cancers, courses of treatment and the patient and carer experience. Each site-specific guidance document refers to palliative care, giving examples of how the Improvement Partnership, which is part of the collaborative, has recommended best practice in the area of information and support, referral criteria and symptom control. Drs John Ellershaw and Keri Thomas, who have involvement with Marie Curie Cancer Care and Macmillan Cancer Relief respectively, are taking the lead on rolling out the Gold Standards Framework and Liverpool Care Pathway on a national basis.

The new funding for palliative care is allocated and monitored by the **National Partnership Group**, a central body comprising palliative care experts from the NHS and voluntary sector, chaired by the National Cancer Director. Each Cancer Network was asked to draw up a plan, agreed between NHS and voluntary sector networks, on how they would make use of additional funding. Once the plan has been signed off by the relevant SHAs, the National Partnership Groups studies the plans to make sure they fit the requirements it drew up.

National Service Frameworks (NSFs) are documents setting out national standards and identifying strategies for their implementation. Some of the documents may be designated National Standards Frameworks. They set targets for progress within an agreed time-scale. On average, one new framework is produced per year. The NSF Coronary Heart Disease Framework acknowledges the contribution of palliative care for patients who do not respond to curative or rehabilitative treatment. There are NSFs on older people, diabetes and cancer, but as yet no document covering palliative care.

The **National Care Standards Commission** is an independent public body set up under the Care Standards Act 2000, to regulate care services throughout England according to standards developed by the Department of Health. The Commission has been in existence for two years but will be replaced after 31st March 2004 by two bodies: a) Commission for Health Audit and Inspection (CHAI) which inter alia will cover hospices and b) Commission for Social Care Inspection (CSCI) which will cover care homes. The two bodies are expected to work together where appropriate.

Hospices recognise the need for regulation but are concerned about the cost implications of the Care Standards Act. Marie Curie Cancer Care estimates that it will cost it £25 million to comply with the act.

Similar bodies carry out inspections in Scotland and Wales.

Other Initiatives and Policies Impacting on Palliative Care

Care Trusts are NHS bodies based on voluntary partnerships between Primary Care Trusts and Local Councils wishing to deliver a joined up, integrated service to their users. They mainly focus on services for the mentally ill and for the elderly. There are currently less than 10 nationwide.

However, many local partnerships between Primary Care Trusts and local councils exist on a less formalised level, for example on intermediate care, where there are thought to be around 25 schemes. An example is a service run by Poole Borough Council and the local

Primary Care Trust providing community support to the elderly. They employ generic care workers to provide both health and social services advice, including benefits and physiotherapy. The scheme's manager claims that they helped 750 people return home last year and prevented 250 hospital admissions. Some partnerships are specifically focused on palliative care, such as a Southwark partnership whereby the sickest palliative care patients are prioritised and the precise funding arrangements are negotiated later.

The **Agenda for Change** is a Department of Health proposal on modernising the NHS pay system, currently being trialled. If successful, the policy will be implemented in October 2004. Jobs are to be re-graded into new bands, based on the knowledge and skills required, the responsibilities of the post and the physical and emotional demands of the job. The average level of pay will go up by 15% over three years. The voluntary sector will need to meet this increase in order to compete for skilled staff.

The Community Care (Delayed Discharges) Act 2003. This Act received Royal Assent in April 2003, though some of its provisions were not mandatory until November 2003. The Act introduces financial incentives for local authorities to provide the necessary community care services for a patient to be transferred from an NHS setting. This act does not apply to palliative care patients but will apply to any patient at an earlier stage of their disease process.

NHS bodies are required to notify the local authority of individuals likely to need community care services upon discharge. The relevant NHS and social services staff then should work together on a needs assessment. The local authority then has a number of days to put together a discharge plan. If they do not need this, or if the relevant services are not available and thus discharge is still delayed, then the local authority has to make a payment to the relevant NHS body.

The Department of Health has recently announced its intention to appoint a bed blocking czar, with the title National Director of Local Government and Social Care. He or she will spearhead and oversee attempts to tackle the problem of older people being forced to stay in hospital when they are medically fit to leave.

There is currently a House of Commons Health Select Committee inquiry into palliative care.

Appendix 2: The situation in Scotland

The National Institute for Clinical Excellence guidance does not apply in Scotland, though there is a move towards funding 50% of hospices' agreed costs. Some have intentionally developed their services in agreement with the agreement of their local Primary Care Trusts and thus are likely to receive 50% of direct charitable expenditure from statutory sources, others will receive less.

Joint Futures is a Scottish initiative aimed at drawing together health and social services provision across the board. This follows from the agenda set by the 1998 action plan Modernising Community Care, which sought:

- Quicker and better decision making, through delegated decision making and financial responsibility.
- More flexible and better quality home care services, including a shift in the balance of care towards these services.
- Local partnership working including strategic planning, joint budgets, joint services and joint systems.

The Joint Futures Group has recommended and set targets for:

- More intensive care at home;
- Multi-professional rapid response teams in every area;
- Free home care for the first four weeks after discharge from hospital and for those needing longer term support; and
- More short breaks for carers

Health boards, NHS trusts, Social Services and Housing Boards have drawn up and implemented local partnership agreements for resource sharing and joint management. A key plank in the delivery of the points above is the single shared assessment, carried out by one care professional, with input from others if required. The assessment takes in health, social care and housing needs and has been in place since October 2002.

Managed Clinical Networks are disease-specific professional networks, with the aim of coordinating care, sharing expertise, promoting best practice and auditing new approaches. The Scottish Partnership for Palliative Care is network devoted to care of the dying. In addition, representatives from palliative care sit on each site-specific cancer managed clinical network.

Appendix 3: Voluntary sector delivery

As research for this report, NPC visited more than 20 organisations and also had conversations with and obtained information on a number of others. The following lists some of the organisations in this field. However **this list is not comprehensive** and inclusion or exclusion in the text below does not necessarily mean a recommendation or rejection. Not all the projects below were visited by NPC analysts. Expenditure figures in the table are 2002 annual figures unless otherwise stated.

General support

Organisation	Description of work	Expenditure (2002, £k)
Liverpool Cancer Support Centre	Support centre with "self-advocacy" approach	44
Maggie's Centres	Support centres in Edinburgh, Glasgow and Dundee, with centres planned UK-wide.	1,168
CancerBACUP	Information, publications, helpline and support for all cancers	
Breast Cancer Care	Information, publications, helpline and aftercare support	2,400
Haven Trust	Support centres for breast cancer patients in London and Hereford	956
Bristol Cancer Help Centre	Centre offering courses for cancer sufferers including complementary therapies and emotional/spiritual support	1,254
Cruse Bereavement	National bereavement organisation provides information, a helpline and counselling.	2,673
Cancer Black Care	Cancer support centres based London, Manchester and Birmingham, targeted at BMEs.	430

National palliative care charities

Organisation	Description	Expenditure (2002, £k)
Marie Curie Cancer Care	Run 10 adult hospices and nursing services across the UK. Developed the Liverpool Care Pathway for the dying patient.	46,014
Macmillan Cancer Relief	Pump-prime palliative care nurses and other healthcare professionals. Make welfare grants to patients. Fund peer-to-peer palliative care training for GPs. Developed the Gold Standards Framework.	84,474
Sue Ryder Care	Run 6 adult hospices and 10 neurological care centres. Some hospices also provide a home care service.	45,924
Help the Hospices	Umbrella body for the independent hospices. Educational and information sharing role. Have programmes related to specific areas of need to distribute funds from Grant making Trusts.	3,608

Organisation	Description	Expenditure (2002, £k)
National Council for Hospice and Specialist Palliative Care Services	Research focused, moving towards a think-tank role.	n/k

Adult independent hospices and children's hospices

There are over 250 hospices in the UK. NPC visited, communicated with or researched a handful (10 in total) for sampling purposes. We are not listing those visited here as it would be inappropriate to single them out. Hospices offering specialist services have been mentioned in the text.

Research and education in palliative care

Organisation	Description	Expenditure (2002, £k)
Department of Palliative Care and Policy, King's College, London	A major and well regarded academic department.	n/a
Dame Cicely Saunders Foundation	Proposed multidisciplinary research centre. To be the first research institute for care of the dying in the world.	n/a
King's Fund	Supports research, education and policy development in health, particularly in and around London.	n/a

Children's services

Organisation	Description	Expenditure (2002, £k)
Association for Children with life-threatening or Terminal conditions and their families (ACT)	Umbrella body with children's hospices, community nursing teams and condition-specific groups as members. Publish guidance in children's palliative care and campaign for professionals and voice the viewsneeds of children with life-limiting conditions and their families on what service provision should be. Runand provide a helpline for affected families.Helpline Service.	158
Association of Children's Hospices	Umbrella body for the children's hospices. Key concerns are the planning of future children's hospices, lack of appropriate trained staff and training and lack of a knowledge about all services available to life-limited children.	246
CLIC (Cancer and Leukaemia in Childhood)	Support and information, home from home accommodation, adolescent activities, care, social/financial support for respite, research	6,149
Sick Children's Trust	Home from home accommodation for families	578
Sargent Cancer Care for Children	Supports children with cancer and their families.	8,603

Glossary

24/7: round the clock, seven days a week, all year round

ACH: Association of Children's Hospices

ACT: Association for Children with Life-Threatening or Terminal Conditions and their Families

BME: Black and minority ethnic

DoH: Department of Health

DN: District Nurse

DNS: District Nursing Services

GP: General Practitioner

GSF: Gold Standards Framework

LCP: Liverpool Care Pathway for the Dying Patient, sometimes referred to as Liverpool Care Pathway

MCCC: Marie Curie Cancer Care

NICE: National Institute for Clinical Excellence (see appendix 1)

NICE guidance: is the guidance in second consultation draft (October 2003) "Improving supportive and palliative care for adults with cancer". It comes in three parts, a manual, research evidence and economic review.

NHS: National Health Services

Non-malignant diseases: non-cancerous conditions

NOF: New Opportunities Fund, a lottery body

PCT: Primary Care Trust (see appendix 1)

Psychosocial care: care which may use formal psychological methodology and enhances well-being, confidence and social functioning. Such an approach would be focused on the individual needs about the situation they are encountering and would emphasise both affirming the individual's feelings and discussing ways to cope.

Specialist palliative care: care delivered by a multi disciplinary team, including consultants in palliative care

StHA: Strategic Health Authority (see appendix 1)

Umbrella Body: A not-for profit organisation that co-ordinates a sub-group of voluntary sector organisations. Activities might include co-ordinating education, commissioning research and running national charitable activities, such as a helpline.

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Further reading

Care of the dying – A pathway to excellence edited by John Ellershaw and Susie Wilkinson; Oxford University Press, 2003
End of life in care homes – A palliative care approach edited by Jeanne Samson Katz and Sheila Peace; Oxford University Press, 2003
Facing death – Palliative care for older people in care homes edited by Jo Hockley and David Clark; Open University Press, 2002
Caring for the dying at home – Companions on the journey by Keri Thomas; Radcliffe Medical Press, 2003

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- ¹ Psychosocial support means care which may use formal psychological methods and enhances well-being, confidence and social functioning. Such an approach would be focused on the individual needs about the situation they are encountering and would emphasise both affirming the individual's feelings and discussing ways to cope.
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- ³ Lynn, Joanne, 2003, Healthcare at the end of life, RAND publications; <http://www.nihcm.org/ExpertV5.pdf> visited March 2004.
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- ²⁰ Conversations with Sylvia Berry of Liverpool Cancer Support Centre and with Rowena Jackson of Help the Hospices.
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- ⁵⁹ Facing Death: palliative care for older people in care homes: Jo Hockley, David Clark 2002 p 1, End of life in care homes: a palliative care approach: Jeanne Samson Katz, Sheila Peace, 2003 p 1.
- ⁶⁰ The voluntary sector information is based on data from Caritas, which in turn is based on the latest financial records available (in some cases for the year ending in 2001) from the top 10,000 charities. Therefore some charities have been excluded either due to size or incomplete data. Their year ends vary. The figures for independent hospices have been adjusted using data from Help the Hospices. The figures exclude the hidden value of volunteering.
- ⁶¹ This figure is calculated as follows. There are 3,029 adult hospice beds, including those in hospital palliative care units. Of these, 596 are NHS beds (data from Hospice Information, January 2002). That equates to approximately 217,500 bed-nights pa. Each bed-night is estimated to cost £325 (as per Marie Curie Cancer Care estimate: Promoting the Choice to Die at Home).
- ⁶² NPC's own calculations: sum of the first row of Table 1.
- ⁶³ This is calculated as follows. The total expenditure on palliative care at present is £617m (£535m expenditure on hospices up until 2002 + £50m extra for specialist palliative care + £28m from NOF + £4m training = £617m.) Government provides £211m+50m+28m+4m = £287m. $(287/617) * 100 = 47$.
- ⁶⁴ There is a small surplus between overall income (£660-665m) and expenditure (£617m) but at 7-8% on income this is quite healthy.
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- ⁷¹ Responsibility for arranging out-of-ours care is to pass from GP practices to PCTs under new proposals to be introduced during 2004. <http://society.guardian.co.uk/primarycare/story/0,8150,1098684,00.html> visited 1st March 2004.
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- ⁷³ Remarks based on a) conversation 19th November 2003 with Jo Hockley, specialist palliative care nurse at St Columba's Hospice Edinburgh, currently undertaking five-year research programme regarding palliative care in nursing homes and b) Katz, J.S and Peace, S. (2003), *End of life in care homes, a palliative care approach*.
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- ⁷⁶ ACT, telephone conversation with Lizzie Chambers, November 2003.
- ⁷⁷ Dr Ruth Davies, senior lecturer in children's nursing, University of Wales, conversation 30th January 2004.
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- ⁷⁹ *Improving Supportive and Palliative Care for Adults with Cancer- Manual (second consultation.)* National Institute for Clinical Excellence Website, November 2003.
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- ⁸³ Help the Hospices: David Burland 17th November 2003.
- ⁸⁴ Hospice Information: palliative care provision statistics 2000-2001.
- ⁸⁵ Hospice Information: palliative care provision statistics 2000-2001.
- ⁸⁶ Table 1 information calculated using information from Caritas. Help the Hospices has also conducted its own estimate of hospice income which puts the voluntary contribution to independent hospices at £240m.
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¹³⁴ Based on Marie Curie Cancer Care's 2003 bed-night costings from "Promoting the Choice to Die at Home". Two 11 day episodes of care are assumed per patient. This is based on NPC's discussions with hospice managers and clinical staff. We assume that each patient has two episodes of care in any one year.

¹³⁵ Based on Marie Curie Cancer Care's 2003 bed-night costings from "Promoting the Choice to Die at Home". Two 11 day episodes of care are assumed per patient. This is based on NPC's discussions with hospice managers and clinical staff.

¹³⁶ Calculated from St Christopher's Hospice 2003 accounts. Day centre costs £300,000 pa to run. NPC estimates 20 patients attend per day. Calculations assume economies of scale associated with running a large unit such as this.

¹³⁷ Calculated using CancerBACUP's 2003 accounts: costs allocated to cancer support service £1.7m pa, employing 25 nurses on helpline, servicing estimated 58,000 enquiries pa.

¹³⁸ Macmillan Cancer Relief: roll out of GSF in Scotland. Assume each GP practice encounters 101015 palliative care patients pa. (Estimate by Dr Keri Thomas).(20 deaths pa, less three acute and two others); 2.7 GPs per practice (30,000 GPs, 11,000 practices).

¹³⁹ Max Watson/Keri Thomas proposal for Palliative Care Learning Centre December 2003. Number of course attendees estimated by NPC based on Max Watson's earlier experience. No of beneficiaries, if course users GPs, estimated at 10 patients per GP as above.

¹⁴⁰ Dr. Ruth Davies, University of Wales College of Medicine, Cardiff.

¹⁴¹ Office of National Statistics 2001: 0-15 yrs olds in Wales grossed up to by 2/15ths to reach 0-17 yr olds = 665,000. If £40,000 covers 665,000 children, then £100,000 would cover approx 1.6m children. 11.7m children in England and Wales. ACT estimates 14-20,000 children with life-limiting conditions. This implies 1,200 children with conditions per million children.

Davies, R. et al: Welsh Paed J 2000; 12: 18-20; Mortality statistics for children with life-limiting diseases are 1:10,000 aged 1-17 years. This underestimates the total number of children affected.

¹⁴² Medical co-ordinator part time + full-time nurse + administrator + evaluation by University + printed materials + medical consumables e.g. syringe drivers.

¹⁴³ NPC's fully costed estimate, not necessarily based on average over 14 days as per Marie Curie Cancer Care's estimate of home care.

¹⁴⁴ King's Fund, *Future Directions for Primary Care Trusts*, May 2003.

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