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# PSYCHOSOCIAL SUPPORT FOR DYING PEOPLE

What can primary care trusts do?



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CATHY SHIPMAN, ROS LEVENSON AND STEPHEN GILLAM

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## Acknowledgements

This discussion paper has been produced following a two-year research project in London examining support for people who are dying. That project, led by Peter Jupp with Mary Bradbury, Kenneth Howse and Leonie Kelleher, looked in some detail at what constitutes a ‘good death’ and what kind of support dying people need in their final weeks and months of life. It also examined existing provision of palliative and psychosocial care in London. Among the major themes in that work was the importance of practical support, as well as traditionally defined care, and the key role of primary care both as a provider and as a commissioner of services for those who are dying.

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## Summary

People with life-threatening illnesses can have physical and psychosocial needs that are not currently being met. Many people, for example, would prefer to die in the comfort and security of their own home, but only about a quarter are able to do so. Services for dying people are often overlooked, access to specialist care is inequitable, and a lack of funding and staffing can limit the amount of support provided. If the National Health Service is to live up to its promise of a 'cradle-to-grave' service for all, it needs to standardise service provision and provide more equitable access to services for dying people, using the new-found commissioning powers of primary care trusts (PCTs).

This discussion paper examines palliative care provision in the community, and identifies key sources of existing good practice that PCTs can draw upon to ensure equitable access to appropriate services for people who are dying.

### **The current situation**

Palliative care is the care of people with life-threatening diseases and of those who care about them. When it takes the form of emotional, spiritual, social and practical help, this is known as psychosocial support. This form of support can help alleviate anxiety and depression to ensure that people who are dying enjoy the best possible quality of life in the time that remains to them.

Psychosocial support is an important part of palliative care that can be overlooked. While there is a broad range of specialist palliative care services available to people dying of diseases such as cancer and AIDS,



people suffering from progressive non-malignant diseases such as heart disease, stroke and dementia are less likely to be offered the support they need and may experience more difficulties in gaining access to it.

Most psychosocial care is provided by family and friends and other support networks within the community. GPs and District and community nurses (DNs) provide most palliative care to patients at home but lack of resources, time and staff can limit their provision of psychosocial support.

For people dying within the community, there is a need to improve co-ordination and liaison between services to respond quickly to their changing needs for psychosocial support such as befriending and companionship or help in planning funerals. Sensitivity to issues of culture, ethnicity and sexuality is also key. There are a number of voluntary organisations that offer PCTs models of good practice in these areas.

## Opportunities for change

PCTs have considerable power to enable change through their responsibilities for health service provision and commissioning. They are in a prime position to work with other organisations across the statutory, specialist and voluntary sectors to make real changes in psychosocial support to dying people and to access the resources they need.

- Through **clinical governance activities**, PCTs can ensure that education and training is made available to support primary care professionals and enhance their role in the provision of psychosocial support.

- PCTs can enhance the role of **District and community nurses** in palliative care provision, partly through working with the new education, training and support programmes funded by the Department of Health through Cancer Networks.
- **New resources are becoming available** to support the development of psychosocial care. The National Institute for Clinical Excellence (NICE) is commissioning guidelines for supportive and palliative care. In addition, Supportive and Palliative Care and Cancer Networks provide vital links to enable equity in access to services.
- To improve services, **PCTs can transfer good practice examples** from a variety of specialist providers into the community. These providers range from hospices and specialist palliative care services to the NHS Beacon Programme and various large charitable organisations.
- **Collaborative working with social services, and primary and community services**, is key to expanding the provision of palliative care. PCTs can draw on current plans for primary and community development (for example, sharing counselling services between practices), and the development of services within intermediate and primary care.
- **The voluntary sector** has much to offer in terms of examples of good practice including services that provide befriending and help in planning for the end of life.
- Finally, **clear and equitable management** of funding and resources is key to ensuring equity of access to palliative care services either within the primary or specialist sectors. However, greater financial commitment to palliative care from the Government is necessary to ensure this.

## Aims

The aim of this discussion paper is to inform the work of primary care trusts (PCTs) in commissioning and providing psychosocial support services by providing examples of good practice and highlighting the opportunities that now exist to improve services. The paper is particularly concerned with the needs of Londoners.

The following issues are discussed:

- What is meant by psychosocial support and what services may be needed that can be provided in a primary care setting?
- What are PCTs' responsibilities in relation to palliative care and the provision of psychosocial support?
- What resources already exist in the community?
- What are the gaps in the current provision of psychosocial support services?
- What new opportunities are there for PCTs to meet their responsibilities in this area?

## Introduction

In April 2002, all remaining primary care groups (PCGs) became primary care trusts (PCTs) with greater responsibility for ‘securing the provision of high quality health services’ for their local population.<sup>1</sup> The range of their responsibilities is wide, but a key area of health provision is palliative care, which aims to help dying people achieve the best possible quality of life in the time leading up to their death.

### **Palliative care**

Palliative care is the care of people with life-threatening diseases and of those important to them. This includes both physical and psychosocial care, both of which are important from the time of prognosis to the last months and weeks of life (terminal care). Palliative care can be practised by all health care professionals and has been distinguished from specialist palliative care, which is provided by specialists to a minority of patients with more complex and severe symptoms. It also differs from palliative interventions provided for patients by specialists who are not in palliative care.<sup>2</sup>

### **Gaps in psychosocial support**

Psychosocial support is the element of palliative care that refers to the emotional, spiritual, social and practical needs of people who are dying. Most people dying within the community are cared for by primary health care teams, which provide most palliative care, including psychosocial support. Most people do not have access to the range of psychosocial services provided through hospice and specialist palliative care. These are usually only available to certain patients (those suffering from progressive cancer, AIDS or some neurological diseases) and their carers. For those who are not covered by a full complement of specialist

palliative care services, the absence of psychosocial support is a particular concern.

Family and friends are often expected to provide much of this support, but not all this kind of help can – or should – be provided in this way. The heavy burden of caring and the lack of resources for people dying within the community can lead to unnecessary admissions to hospitals or hospices. This can prevent some people who would prefer to die at home from being able to do so.

## **Opportunities for change**

With the shift of the commissioning role to primary care, PCTs now have the potential to address this lack of support. Opportunities also exist to draw on joint working with social services departments. If primary care organisations are to fulfil their responsibilities and make a real difference to local health services, there are compelling reasons why improvements to services for dying people should be given greater priority. The development of palliative care has largely been within the specialist domain and strategic development has not taken account of the important role of primary care. PCTs, however, face competing demands from other central and local priorities.

## **Developing existing models of care**

Primary care organisations have many resources to draw upon in improving services for dying people. Supporting and developing the roles of GPs and District and community nurses (DNs) in palliative care is important. Models of hospice psychosocial provision could be transferred to primary care settings and greater contact made with other voluntary services and groups providing psychosocial support. A great deal of innovative work is being done within the community (see pp. 19–27), although mainly for cancer patients. However, a lack of funding and resources limits the number of people that can be helped.

## Defining psychosocial support

If someone is in great pain or distress, their capacity to deal with other matters is severely limited. The importance of services that alleviate or minimise these physical symptoms cannot be overstated. However, the belief that these problems are only part of the pain suffered by people who are dying is built into the definition of palliative care. Health care professionals recognise that people may be trying to sort out their lives and deal with practical and emotional issues while coping with the symptoms of illness and the physical intimations of approaching death.

Effective relief of physical distress is vital, but meeting a person's psychosocial needs is also an important factor in ensuring that people achieve the best possible quality of life in the time that remains to them. This should, therefore, be a major consideration for those who commission and provide services for people who are dying.

### **Problems with definition**

One of the problems in defining psychosocial support is that every individual is different. What one person sees as supportive, another may see as intrusive, inappropriate or oppressive. It is also difficult to assess whether a particular kind of support helped the person who was dying: although people can be involved in discussions about the support services they are offered, limitations are inevitable. For example, low expectations of support, combined with poor experiences of health and social care services in the past, limit what some people think might reasonably be available.

An additional problem is that the service user cannot be asked to make a retrospective assessment about what was helpful to them as they

neared death. However, it is possible to ask carers and family members to reflect back on the services and support that were offered, and a great deal of work has been done in this area.<sup>3</sup>

Although there are a number of problems in defining the term, for the purposes of this discussion paper, 'psychosocial support' is described as:

*Any formal or informal support or services for people who are dying that try to address the dying person's needs, as seen by the dying person himself/herself, other than needs for clinical care.*

Finally, while we recognise the additional importance of supporting carers and those closest to the individual, in this discussion paper we are focusing specifically on the needs of those who are dying. These needs may vary from person to person, and may change for the dying person as they near death.

## **Components of psychosocial support**

Psychosocial support and services may include any or all of the following:

- emotional support, including social activities, companionship and befriending
- personal care, help with bathing or providing massage and other complementary therapies
- assistance in securing financial support
- help inside and outside the home; for example, cleaning and shopping

- supplying practical aids such as wheelchairs and other equipment
- offering counselling and psychological support to help people come to terms with dying
- religious/spiritual support, whatever a person's beliefs
- practical support in preparing for death, including saying farewell, making end-of-life decisions and arranging funerals.

This kind of care or support may be provided either informally (by family and friends or other social networks to which the dying person belongs, such as a religious organisation) or formally (by the provider of statutory health and social care services). Many of these formal services also offer support to the family or carers in their own home.

### **Evidence of the need for psychosocial support**

People who are dying suffer in many ways through knowing (or not knowing) what is happening to them.<sup>4</sup> Sometimes there is a need for help from psychologists or psychiatrists or for support from social workers, chaplains or counsellors. A study in London in 1991 found that about half of people dying from cancer were depressed and 30 per cent were anxious,<sup>5</sup> and these problems can persist. A study in Cambridgeshire in 1997<sup>6</sup> showed that more than half of DNs and a quarter of GPs interviewed found their patients' depression and anxiety difficult to control. Patients suffering from other diseases also suffer significant depression<sup>7</sup> and persistent low moods.<sup>8</sup> One 24-hour telephone advice line to a hospice<sup>9</sup> found that while 29 per cent of patients called because of new or worsening symptoms and 21 per cent called for advice on medication, 28 per cent called because of anxiety.



## Patients' needs

The health, social, practical and emotional needs experienced by cancer patients and carers are complex. They face anxiety and fear.<sup>10</sup> Their needs for emotional support can occur from the time of diagnosis onwards, so palliative care should be provided from the outset, rather than from the time that physical symptoms require control.<sup>11</sup> In addition, carers can experience similar levels of distress to patients.

## Home care services

Home care services are important. They support patients and carers and provide respite care. Many people prefer to die at home, so the provision of additional nursing care within the home is crucial in enabling people to remain there.<sup>12</sup> Hospital admission is only appropriate for complex problems, but it has been estimated that almost a quarter of hospital bed days are used by patients in their last year of life.<sup>13</sup> Patients also want help with practical activities, such as transport, getting out and about, personal care and housework.<sup>14</sup>

## Responsibilities of primary care trusts to dying people

Primary care trusts (PCTs) are responsible for providing and commissioning palliative care services to meet the needs of their local population. They are also required to work with strategic health authorities and with the supportive and palliative care networks (and, in some places, cancer networks) that are developing, to commission specialist palliative care services. These networks were identified within the NHS Cancer Plan<sup>15</sup> to support and improve the co-ordination of care. PCTs are, therefore, in a prime position to enhance palliative care provision within primary care and in terms of specialist services.

### Plans for palliative care provision

Since their inception, the responsibilities of PCTs have been wide-ranging, driven by central Government initiatives such as National Service Frameworks (the Government's blueprints for raising standards of care in these areas, known as NSFs). PCTs now provide or commission most health services. However, while palliative care is mentioned in the NSFs for coronary heart disease and older people, the focus is narrow.

The NHS Cancer Plan announced several measures to improve cancer service delivery and palliative care. These included:

- developing lead cancer posts within each PCT
- providing funding for education and training in palliative care for DNs

- making future funds available through the New Opportunities Fund, to improve community palliative care.

When the Government's National Cancer Plan was published in autumn 2000, Macmillan Cancer Relief commissioned a survey of PCGs and PCTs. The results highlighted the fact that palliative care was low on their list of priorities.<sup>16</sup> The survey found that:

- Less than half of PCGs and PCTs had designated palliative care leads, although 65 per cent said that they were involved to a greater or lesser extent in developing plans for palliative care services, and 71 per cent reported some degree of involvement in commissioning.
- Most PCGs and PCTs were working collaboratively, although mention was made of the difficulty of working with providers (specialist palliative care services and hospices) because of the number of different services in some areas.
- The type of work being undertaken included developing or implementing palliative care strategies, establishing links with local hospices, reviewing palliative care services in the community, exploring proposals for Macmillan GP Facilitators or Nurses, and developing a hospice at home scheme. Plans for future work included developing primary care strategies and extending access to specialist palliative care services.
- PCGs and PCTs highlighted the need for examples of good practice, standards and quality indicators for palliative care provision, and clinical guidelines. They also required more information about specialist services and local services and staff.

At the time of the survey, there had been little opportunity for many PCGs or PCTs to develop palliative care commissioning or to influence the provision of psychosocial support in their localities. Now, with greater commissioning power, PCTs are in a stronger position to move further ahead with local strategies and plans – and there is some evidence that they are taking up this opportunity.

## Providing psychosocial support within the community

Most people die in hospital, but much of their final year of life is spent at home under the care of the primary care team.<sup>17</sup> Many patients particularly value the psychosocial support provided by GPs, DNs and Macmillan nurses.<sup>18</sup>

### Primary and community care

There is a wide range of care available in the primary and community care settings. It is provided by GPs, DNs, hospices and specialist palliative care services (such as community palliative care teams and Macmillan nurses) and additional sources of support, such as social services, the voluntary sector and religious organisations.

#### The role of the GP

The majority of palliative care is provided within the primary care setting, although this is a relatively small part of a GP's workload. An average GP's list of 1800 patients will include 20 per year who are dying (five from cancer and 15 from non-malignant disease), of whom eight will die under his or her care.<sup>19</sup>

GPs are responsible for prescribing, providing symptom control and for onward referral to other services, including specialist palliative care, social services and those provided by the voluntary sector. Most referrals are to DNs, who provide hands-on nursing care at home. Referrals to hospices and specialist services are mainly for cancer patients. GPs also offer emotional and psychological support, such as discussing concerns that patients may have over diagnosis and prognosis.

Providing information about diagnosis, prognosis, financial support, and local self-help groups is also an important part of the GP's role. While there is evidence of increasing involvement in supporting patients over diagnosis and prognosis, there is also room for improvement in providing them with financial and other information.<sup>20</sup>

### Constraints on GPs

Studies with carers have found that patients' level of satisfaction about the care they receive can be related to the frequency of GP visits.<sup>21</sup> Many GPs feel that they spend insufficient time with palliative care patients because of growing practice commitments.

Developments within general practice have led to less continuity of care. There has been a reduction in single-handed practitioners, leading to a growth in the number of larger practices where care of patients may be shared. The development of shared-list systems can lead to a situation where patients lack contact with a GP who has known them and their family for a long time. The growth of GP co-operatives has reduced continuity in care outside of normal working hours where GPs were formerly providing their own on-call service to patients and now no longer do so.

### The role of District and community nurses

Most patients dying at home have some contact with a member of the DN Team, who is seen as the most frequent and regular provider of care.<sup>22</sup> DNs provide most 'hands-on' palliative care in the home. They will visit a patient with increasing frequency towards the end of life, and up to a third of their workload can include palliative care.<sup>23</sup> An estimated 1 in 12 patients on DN case loads have been estimated to need palliative care, and work with these patients forms an even greater proportion of care during night shifts.<sup>24</sup>

Through spending time with patients, DNs provide a supportive role which has increasingly included emotional and psychological components.<sup>25</sup> DNs are also responsible for providing patients with additional resources, such as special mattresses and other equipment that they may need within the home.

### Constraints on the District and community nurse service

DNs providing hands-on nursing care can spend considerably longer with patients and carers than GPs, but they often feel they need more time for their visits.<sup>26</sup> The proportion of DNs to patients, particularly those aged over 65 years, has decreased over time, despite an increase in numbers of people within this age range.<sup>27</sup> One result of this can be that DN visits sometimes seem rushed.<sup>28</sup>

Care for dying patients offers an opportunity to use a greater range of skills. It is intensive work that can allow senior nurses hands-on rather than managerial involvement. This is an area in which nurses often feel their skills, support and expertise are appreciated by patients, families and GPs alike.<sup>29</sup> However, their increasing involvement in providing psychosocial support can lead to considerable stress when workloads are heavy and time is limited, particularly when patients and families have difficulty accepting the prognosis.<sup>30</sup>

### Hospices and specialist palliative care services

Hospices and specialist palliative care services provide symptom control to patients either at home or within the unit. Many also provide short-term respite care to give carers a break and terminal care for patients at the very end of life. However, relatively few patients actually die in hospices or palliative care units (5 per cent of all deaths in London, including up to 21 per cent of all cancer deaths).<sup>31</sup> Psychosocial support can be provided by nursing and medical personnel, including

Macmillan or specialist palliative care nurses, doctors, clinical psychologists, psychiatrists, social workers and chaplains.

Various types of support can be provided either individually or in groups, as an inpatient or outpatient or within day care.<sup>32</sup> Counselling and psychotherapy can provide emotional support and help patients resolve issues that are troubling them and gain meaning from their experiences. Other therapies such as relaxation techniques and hypnosis can help with anxiety and distress. Educational therapies can enhance patients' coping skills and can increase patients' sense of control by providing information. Support groups enable sharing of experiences and can provide mutual support. While most hospices have access to a chaplain and social worker, less than half may have access to counsellors. Support from psychologists and psychiatrists is even more limited.<sup>33</sup> Social and emotional support can be gained from befriending or visiting schemes usually provided by volunteers or by day care schemes.

Hospices and specialist palliative care services also provide advice and support to GPs and DNs in the community, although access may be limited to patients with cancer.

Examples of services available for patients at home are outlined below.

### Community palliative care teams

Support for patients dying at home is available from community palliative care teams, which are accessed through referral from GPs. There are more than 300 such community teams across the UK, and 28 home care teams across London. These vary in composition from a Macmillan or specialist palliative care nurse to a multidisciplinary team of specialist palliative care professionals, led by a consultant. The extent of support provided varies. Some operate during the working week while others provide a 24-hour service.



### Day care units

Day care units in particular offer social support to palliative care patients. There are 16 day-care units across London, but London offers the lowest number of places available *per capita* compared with other regions. Most units surveyed in the North and South Thames regions had doctors, nurses, chaplains, aromatherapists and hairdressers, but less had occupational therapists, social workers, chiropodists, dietitians and music or art therapists.<sup>34</sup> The most frequent activities offered in day units were the review and monitoring of patients' symptoms, bathing, hairdressing, physiotherapy and aromatherapy.

### Hospice voluntary services

Hospices and specialist services provide considerable psychosocial support to patients and carers at home through volunteer services. In 1995, 106 volunteer services were identified in the UK and Ireland that were linked to hospices and provided home visits to terminally ill patients.<sup>35</sup> The main support these volunteers provide is companionship and time to listen, but practical help including personal care is also offered. Thirty-five volunteer services offered counselling.

### Macmillan nurses

Macmillan Cancer Relief provides the first three years of funding for more than 2000 nurses, based in hospitals and the community. All Macmillan nurses are registered nurses with a minimum of five years' experience, including at least two in cancer or palliative care. Macmillan nurses aim to help patients and their families from the moment cancer is first diagnosed. They can give advice about treatments and they spend time with patients and their families, helping them cope with the many emotional and practical problems they may face. For some, the Macmillan or specialist palliative care nurse is seen as the most important provider of advice and psychological support to patients.<sup>36</sup>

### Marie Curie nurses

Marie Curie Cancer Care provides a nationwide network of nurses offering care at home to people seriously ill with cancer. Their remit includes providing practical and emotional support to patients and their families. Marie Curie nurses are an important part of palliative care and their presence enables people to die at home. While Macmillan nurses provide advice and support to patients and carers and primary health care teams, Marie Curie nurses provide 24-hour hands-on nursing care in the home, offering much-needed support and respite, usually in the final weeks of life. Referrals to Marie Curie nurses come from DNs, with 95 per cent being patients with cancer.<sup>37</sup>

Other specialist nurses are sometimes involved in providing care and support, including those who specialise in stoma care, respiratory diseases, cardiac diseases or neurology.

### Additional sources of support

Although services intended specifically for people who are dying tend to cluster round specialist palliative care services, a range of agencies provides some kind of care or support to people living in the community.

### Social services

The core providers in this area, apart from the health services, are social services departments:

- They have the statutory responsibility for making sure that packages of home care (help with domestic and personal care) are available to people who need them.
- Their occupational therapists make assessments for aids and adaptations in the home.

- They provide respite care for people who are being looked after by family or friends.
- They also provide a social work service, which can help with family problems including bereavement.

### The voluntary sector

In addition to the statutory services, there are a number of voluntary agencies – apart from hospices – that have been set up specifically to provide people who are dying and their families with help and support. They do this usually by way of befriending schemes, helplines or bereavement support. Some projects will provide help for people suffering from certain diseases, and cancer is certainly the largest area for such provision. However, there are many different organisations, some of which are described on p. 49. These groups reflect a number of issues that are important for providing good psychosocial palliative care, for example:

- co-ordination and liaison
- befriending and companionship
- planning for the end of life
- sensitivity to issues of culture, ethnicity and sexuality
- other activities.

These activities are dealt with one by one below.

#### *Co-ordination and liaison*

The complexity of the needs of some people who are dying, and the need to respond quickly and flexibly to their changing requirements for

psychosocial support, sometimes pose a significant challenge for service providers. The Motor Neurone Disease Association (MNDA) has a particularly well-organised approach to helping people living with Motor Neurone Disease (MND). Regional care advisors throughout England, Wales and Northern Ireland aim to act as advocates for people living with MND and help them to get the most appropriate professional support.

### *Befriending and companionship*

Dying can be a lonely experience. Some people will have outlived their family and contemporaries, others will have close family and friends, but may feel the need for additional emotional support. The Befriending Network supports people with life-threatening diseases by pairing them with volunteers who provide emotional and practical support within the home.

### *Planning for the end of life*

For some people who are nearing the end of their life, influencing or deciding on their eventual funeral may seem unwelcome, irrelevant or simply unnecessary. For others, planning their funeral is an aspect of preparing for death and an acceptance of it. People may need support of a very particular nature in order to make informed choices about funerals and a project is currently training people from residential and nursing homes and two hospices to provide this advice and support.

### *Sensitivity to issues of culture, ethnicity and sexuality*

While all the examples above have equal opportunities policies designed to promote accessibility to all, specific needs that arise from culture, ethnicity, belief or sexuality may be met more appropriately for certain people by dedicated organisations. Having a choice is what matters. Cancer Black Care is an example of a growing organisation that works with black and minority ethnic people with cancer. In contrast, GaysCan is a very small organisation, essentially run by one person,

offering support to gay men living with cancer and to their partners, families and friends.

### *Other activities*

There are also agencies with a wider role that also provide support and help to people who are dying (see p. 49 for contact details). For example:

- Crossroads Carers' schemes provide sitting services and respite care, and carer centres that offer counselling, support and advocacy services to informal carers.
- The Assisted Living Foundation and the British Red Cross help people who are disabled with aids and adaptations for their homes.
- Some local Age Concern groups offer regular visits to older people who would otherwise have few social contacts.
- Local branches of support groups for specific diseases (such as the Alzheimer's Society, the Multiple Sclerosis Society and the Motor Neurone Disease Association) can often provide information and practical help, as well as support for carers.

Developing a directory of all such voluntary organisations that can support people who are dying would be of great value to those within the community.

### Religious and spiritual support

Many people nearing the end of life require some support of a religious or spiritual nature. Within the major Christian denominations, it is generally part of the local parish priest's job to ensure that such services are provided if required, often with the help of volunteers. Synagogues, temples and mosques often have a group that supports the community leader in visiting sick and dying people.

## Gaps in provision

Most (but not all) people would prefer to die in the comfort and security of their own home, but only about a quarter are able to do so. The reasons for admission to hospital vary and can depend on the ability to control both physical and psychological symptoms in the home as well as socio-economic factors.<sup>38</sup> However, access to effective support services is influential.

Lack of home care services to support patient and carers and provide respite care has been implicated in unnecessary admissions to hospital.<sup>39</sup> Such admission is only appropriate for complex problems but it has been estimated that almost a quarter of hospital bed days are used by patients in the last year of life.<sup>40</sup>

Access to psychosocial support is inequitable. People suffering from non-malignant disease are less likely to have the support offered through hospice and specialist palliative care and are less likely to die at home.

There is, therefore, a clear need for improved, accessible services within the community to ensure the NHS can deliver effective care to more people at the end of their lives.

Palliative care offered by GPs and DNs can be limited by pressure of time and competing commitments as well as staff shortages. Specific issues contributing to this situation are addressed in the remainder of this section.

## **Palliative care in non-malignant disease**

Palliative care has been largely defined by practitioners in relation to cancer<sup>41</sup> although there is a growing movement to identify the needs of patients with non-malignant disease.<sup>42</sup> Similar needs for symptom control have been identified for patients towards the end of life who are suffering from diseases such as progressive heart disease, stroke, dementia, kidney failure, motor neurone disease and chronic obstructive pulmonary disease.<sup>43</sup>

It is, however, more difficult to identify a palliative phase in non-malignant disease such as heart failure or stroke than it is in people dying from cancer. It is only when such a phase is identified that the potential for introducing more palliative psychosocial support arises and GPs and DNs may spend more time than usual with the patient and their family.

## **Lack of continuity**

Outside normal working hours, the need for psychosocial support can be great. Out-of-hours care provided by GPs changed significantly in 1995. New arrangements included the establishment of GP co-operatives that share shift work. These have highlighted particular difficulties that people with special needs can have when trying to get help out of hours.<sup>44</sup> Developing systems for handover of information about palliative care patients to out-of-hours organisations is an important aspect of continuity of care.<sup>45</sup> GP co-operatives are addressing the need to have protocols for providing patient information and facilities to enable palliative care drugs to be accessed out of hours. However, there is still room for improvement.<sup>46</sup>

Lack of DN services out of hours is a further concern for both providers and users of services. The Audit Commission reported in 1999 that 32 per cent of community trusts had no service after midnight.<sup>47</sup> This

may lead to patients who could have been supported at home being admitted to either nursing home or residential care.

## **Separation of nursing care and personal care**

Through spending time with palliative care patients, nurses can provide psychological support and assess ongoing needs for symptom control.<sup>48</sup> However, the amount of time spent with patients has been limited by the separation of personal care from nursing care. Personal care is now generally provided by home carers with little nursing or palliative care experience. Medical or nursing bathing is only available for patients with acute health care needs and with difficulty getting in and out of the bath, or who are in the terminal phase of their illness. Recommendations for greater investment of resources and support in the social care sector have been made to address this issue.<sup>49</sup>

## **Need for education and support**

As palliative care remains a small proportion of GPs' work, it can be difficult to maintain and develop knowledge and expertise. Educational initiatives can help GPs acquire palliative care skills, but communication skills and bereavement care have received less attention.<sup>50</sup> These include the Macmillan Cancer Relief GP Facilitator Programme in Cancer and Palliative Care, which enables GPs with an interest and some expertise in palliative care to support the work of local colleagues. However, GPs have indicated less preference for educational opportunities in such areas as breaking bad news, counselling and communication skills than for physical symptom control, particularly for non-cancer patients.<sup>51</sup>

Education for DNs has been patchy to date but is currently receiving funding through the NHS Cancer Plan.<sup>52</sup> Cancer networks across England have been given funding to develop and extend a range of palliative care educational programmes for DNs in the principles and practice of palliative care.



## Assessing need

Assessing need for psychosocial palliative care is complex and includes emotional and psychological problems and needs for spiritual care. Patients may need practical help including transport, personal care and with housework. They also may require equipment such as wheelchairs or commodes at home (although for many this help arrives too late and they are too ill or may even have died before they can use it).

Assessment of need can be made difficult because some patients and carers can be reluctant to ask for help either because of a desire to maintain independence and dignity or because they perceive resources to be limited. Overcoming these barriers is necessary for effectively providing practical support, both in terms of increasing awareness of what support is available and in terms of sensitive assessment.

### Personal care

Some local authorities respond very well to requests for assessments and services for people who are terminally ill, while others appear less able to do so. It is common for people to deteriorate beyond the point at which they can remain at home before their personal care needs are assessed or met. What is lacking is a widely accepted, nationwide procedure for fast-tracking support for people who are dying to ensure that their needs are prioritised.

### Appliances and adaptations

Similar circumstances apply to occupational therapy services, which continue to suffer from staff shortages across many parts of the UK. Delays in obtaining aids and adaptations, such as wheelchairs and commodes, are frustrating for everyone, but for people who are dying, delays may make the difference between their being able to die at home or having to remain in hospital until death.

## Closing the gaps – opportunities for primary care trusts

PCTs have considerable power to enable change through their responsibilities for health service provision and commissioning. They are in a prime position to work with other organisations across the statutory, specialist and voluntary sectors to make real changes in psychosocial support to dying people.

### **Reaching a consensus on provision**

A supportive care strategy is currently being developed under the leadership of the National Cancer Director. This will provide standards for the provision and monitoring of supportive and palliative care. As part of this strategy, the National Institute for Clinical Excellence (NICE) is commissioning guidelines with the aim of providing ‘evidence-based recommendations on how best to ensure patients receive high-quality information, communication, symptom control, psychological support, social and spiritual support’.<sup>53</sup> This guidance will help PCTs provide and commission services in the community, in hospitals and in hospices, both for patients and carers.

The National Council for Hospice and Specialist Palliative Care Services has led a consultation on the nature of what constitutes supportive and palliative care. This may feed into the ongoing work of NICE. This work will provide a framework within which to consider needs and provision for psychosocial support. However, this work will only have an impact on the current inequalities in access to services if it focuses on the breadth of primary and community palliative care, as well as specialist provision. To date, strategic development of palliative care has usually focused on specialist palliative care.

## Developing new models

New models of service provision could be developed to improve psychosocial support services. The Gold Standards Framework Project (supported by Macmillan Cancer Relief and the Cancer Services Collaborative) is currently being developed across a number of practices within England. The scheme provides a framework for supporting and improving palliative care at practice level. It focuses on:

- teamwork
- continuity of care
- advanced planning
- symptom control
- patient, carer and staff support.

Other potential developments include GPs with a special interest in palliative care and specialist primary and community palliative care teams (made up of GPs, DNs, social workers and counsellors) that could work on a referral basis across a PCT, offering examples of best practice, providing clinical and psychosocial expertise and co-ordinating work with local specialist services and hospices.

Intermediate care developments are in the planning stage for many PCTs. These provide an opportunity to better support palliative care patients through supportive discharge, GP-led beds in community hospitals and greater respite support. Rapid assessment and response teams are a priority area for many PCTs. These teams provide support to patients and carers at home during a crisis, and in some instances have been expanded to cover palliative care for cancer and non-cancer

patients. Hospital and hospice at-home services also provide support outside the institutional setting.

### **Pooling resources**

A survey of PCGs and PCTs in the winter of 2000 found that almost two-thirds shared counsellors and physiotherapists and 44 per cent shared specialist nurses between practices. Less than 20 per cent, however, reported sharing specialist GPs, complementary therapists or nurse practitioners, although many planned to do so.<sup>54</sup> Clearly there is potential for palliative care patients in the community to benefit from a pooling of resources.

### **Inter-agency work**

Joint commissioning arrangements with local authority social service departments relating to mental health and older people's services present opportunities to support palliative care patients. Joint working could enable clearer definitions of packages of care (involving GPs, nurses, social services and providers of intermediate care) to be developed for people dying from both malignant and non-malignant disease in PCT localities.

Recent central initiatives have also strengthened potential links between PCT and local authorities by focusing on patient pathways between health and social care services.<sup>55</sup> This involves exploring pathways of care between GP, hospital and other appointments to avoid delays to the patient and ensure the most appropriate care is provided for each individual patient.

Working with the voluntary sector will enable better packages of care to be developed with hospices and specialist palliative care services and through the non-hospice voluntary sector.

## **Clinical networks**

PCTs can influence palliative care provision by participating in cancer and supportive and palliative care networks, both in terms of specialist and primary care provision. Clinical networks are formal networks of health care organisations that can co-ordinate, resource and deliver services. Supportive and palliative care networks are intended to enable the development and introduction of standards and commissioning of palliative care services across large patient populations. This should help to standardise service provision and enable equity of access.

The networks are large, working across PCTs and the boundaries of current health authorities. However, their focus so far has been on access to specialist services and it has been difficult to achieve primary care representation on supportive and palliative care networks. In some areas, palliative care co-ordination and needs assessment is taking place through cancer networks.

It will be some time before the provision and commissioning of palliative care services across primary and specialist boundaries becomes co-ordinated. However, the need to co-operate with cancer networks is a key feature of recent central guidance.<sup>56</sup> Chief executives of PCTs, for example, are expected to take part in the boards of cancer networks, agreeing on work that the networks will undertake on their behalf.

## **Identifying models of good practice**

Specialist palliative care services and hospices provide many examples of good practice in psychosocial support. Greater access to such services would be of benefit to many people dying within the community. Models of good practice could be transferred into community settings, perhaps basing such a service at a practice or health centre.

Within Primary Care, the Macmillan GP Facilitator Programme in Cancer and Palliative Care funds GPs with an interest and some expertise in palliative care to work with colleagues in their locality to improve palliative care provision. They work in varying ways, depending on the issues and needs of different areas. This includes undertaking practice visits, putting on educational events (often with specialist service providers) and becoming involved in palliative care strategy and service development.

The NHS Beacon Programme, led by the Modernisation Agency, identifies innovative services. A number of these provide good examples of a range of palliative care developments:

- Camden and Islington Community NHS Trust (now within Camden and Islington PCTs) works across primary, secondary and tertiary services, with developments in non-cancer care, new approaches to care and operational management and IT.
- Countess Mountbatten House (Southampton University Hospitals NHS Trust) provides examples of education and training in palliative care and specialist palliative care in the community in collaboration with primary care teams, patients and families.
- Marie Curie Centre, Liverpool (Royal Liverpool University Hospitals Trust) facilitates multi-professional documentation and communication, integrating national guidelines into practice.
- Northgate and Prudhoe NHS Trust supports the palliative care needs of people with learning disabilities.
- South Derbyshire Specialist Palliative Care Services provides integrated services for patients and carers across health and social care.

- The Palliative Care Education Group for Gloucestershire has developed an integrated model of multi-disciplinary education in palliative care.
- Warwickshire Integrated Service Directorate for Palliative Care (North Warwickshire NHS Trust) is a managed clinical network that commissions and provides care equitably and cost effectively, through partnership between independent, NHS trusts, PCTs and health authorities.

Examples of good practice in out-of-hours palliative care can be found in a report by Macmillan Cancer Relief.<sup>57</sup> As detailed earlier in this discussion paper, projects operating in the voluntary sector are a valuable resource to inform service planning and provision.

## **Funding and resources**

Underpinning all these opportunities, however, is the need to address issues of funding and resources. These two issues are key to progress in this area. Specialist palliative care services are largely charitably funded and much Government palliative care funding is channelled through cancer service development. The NHS Cancer Plan identified £50m to be allocated to palliative care development, to reduce inequities in access to services.<sup>58</sup> While the plan did state that this funding should not be confined to cancer alone, it is unlikely to reach many patients dying from non-malignant disease if routed through specialist channels.

Access to funding is further complicated by the demands made on PCTs to balance budgets. Much of the money coming down through the Cancer Plan has been hypothecated but can be spent on priorities that are perceived to be more urgent. Priorities dictated through NSFs may limit local discretion in palliative care service development and in some areas the money may not be getting through.

Funding is also of critical concern for many non-hospice voluntary groups, which provide a range of services within the community. PCTs are well placed to fund these groups and improve access to their help and expertise.

New Opportunities Funding (NOF) has recently become available to improve home-based palliative care for people with cancer and other life-threatening or limiting conditions. £22m has been allocated to improve home-based palliative care to adults and £48m to support children's palliative care services. The funding for adult home care services is focused on 100 designated PCT areas of greatest need, with the aim of extending provision where little exists, increasing availability outside normal working hours and extending provision to people suffering from life-limiting conditions other than cancer.<sup>59</sup>

Registered charities, limited companies and statutory bodies within these designated PCT areas may apply. The applications must, however, be endorsed by PCTs, and this provides considerable opportunity to expand and co-ordinate service provision more widely within the community.

However, to ensure that some of the palliative care needs of people dying from diseases other than cancer can be met, considerably more funding will be required to enable the expansion of primary and specialist services.

### **New responsibilities for nurses**

The strengthened role of the lead nurse for PCTs provides the potential for enhancing support to primary and community palliative care.<sup>60</sup> DNS are central to the provision of palliative care at home and the lead nurse is in a strong position to advocate on their behalf.



With the growing demands made on general practice, greater support for District and community nursing may be the way forward in improving palliative care at home. Key to this is ensuring the adequacy of the workforce in relation to the palliative care demands of the area. Assessment of DN provision and community palliative care needs will enable gaps to be identified and addressed, particularly in District nursing night services. This can be achieved through the responsibility of PCTs for planning integrated out-of-hours services.

PCTs are also in a strong position to shape plans for education and support of DNs currently being developed through cancer networks.

## Conclusions

In the past, greater emphasis has been placed by health care professionals on helping dying people cope with the physical aspects of their illness than with their psychosocial needs. Tremendous progress has been made in physical symptom control for people suffering from life-limiting diseases, but less progress has been made in provision for psychosocial problems, particularly for patients who do not access specialist palliative care.

People's support needs vary considerably, but there is evidence that often their needs are not being met. Support is largely provided by family and support networks, by GPs and DNs within primary care, and mainly to cancer patients by Macmillan and community specialist nurses and other members of specialist palliative care services. Those people who are dying of a disease other than cancer and who have limited family or support networks are particularly in need.

Within many communities, there are often additional sources of support that are underused. This is partly because little is known about them. Developing a local directory of voluntary organisations may increase awareness of these potential sources of psychosocial support.

PCTs are in a strong position to provide for the psychosocial needs of dying people within their localities through their responsibility for commissioning and service provision. They are in a prime position to support partnership working with social services and to enable greater collaboration between primary and community services and voluntary and community groups. They can commission enhanced specialist palliative care services and consider transferring examples of good psychosocial practice into primary care.

PCTs should work with both supportive and palliative care and cancer networks to ensure more equitable access to specialist palliative care support. They should represent the primary care voice and ensure that assessment of needs extends into the primary and community sectors.

PCTs should look again at current plans for developing primary and community care to take greater account of the psychosocial needs of the dying. Sharing services between practices provides opportunities to extend access to counselling, for example. Review of out-of-hours services should include a review of palliative care issues (such as access to specialist and patient information) for better patient support and access to drugs. Developing intermediate services (such as rapid response teams) may well offer improved support to people at home. Current sources of funding could enable provision to be expanded in those areas deemed to be of greater need.

PCTs should strengthen and support District and community nursing services in particular to enable greater help to be available to all dying people. Ensuring that adequate night services are available to support patients at home is of particular importance.

There are examples of good practice to draw upon from the voluntary sector, primary care and specialist palliative care. In areas of particular need, there is also the potential of drawing on New Opportunities Funding.

Need for greater psychosocial support has been found in a number of studies looking at the experience of patients as they approach the end of life. Anxiety and depression as well as social, practical and personal needs can persist. In particular, greater support is needed by those people dying within the community without access to hospice and specialist palliative care services where there is a full complement of professional help. Most palliative care is provided within primary care,

and more resources are needed to support primary care professionals to provide this important part of their role.

This discussion paper has identified many ways in which PCTs can draw on existing organisational links both within the NHS and within the community. These opportunities may enable real differences to be made to the lives of dying people. However, PCTs will need a greater allocation of financial resources to make a major impact.

## Appendix 1: Models of good practice

This appendix provides details of specific projects operating in the voluntary sector offering psychosocial support to dying people within the community. The examples shown are not comprehensive but provide examples of best practice to inform service provision and commissioning. At the King's Fund, the authors welcome further information about other organisations or projects.

### The Motor Neurone Disease Association's regional care advisers

The Motor Neurone Disease Association employs 20 regional care advisers for England, Wales and Northern Ireland, all of whom have either a health or social care background. The advisers aim to become involved proactively with people living with MND as soon after their diagnosis as possible, acting as their advocates and enabling them to access the appropriate professional involvement at the correct time.

Due to the unpredictability of the type and rate of progression of the disease, it is frequently difficult to predict what help will be needed, and when. Usually the key to best practice is communication and co-ordination. Identifying a key worker makes this task easier and the involvement of a multidisciplinary team, particularly one with a special interest in MND, often makes it possible to obtain the best package of therapy and care. Team members can discuss future and potential needs of the person living with MND and their family.

This model of care highlights a number of issues. How far is it possible to apply the MNDA's model of care and support to larger numbers of people? How can the effective communication and co-ordination practised by the MNDA be applied to groups of people with different

disease trajectories? Clearly, the challenges posed to service providers are somewhat different in those circumstances, but some of the principles of good practice remain similar. They can – and should – be applied more widely. They include:

- clear protocols to enable the fast and flexible provision of services
- clarity about key workers and their functions
- the availability of advocacy for people who may need support in accessing services.

*For further details, call 01604 250505 or e-mail:  
care@mndassociation.org*

### The Befriending Network

The Befriending Network is a charity funded by a variety of sources including the King's Fund Grants Unit, the National Lotteries Charities Board, the Macmillan Cancer Relief Trust and several other charitable trusts. It aims to improve the quality of life of people with life-threatening illnesses without limitation of race, gender, class or beliefs, by pairing them with volunteers offering emotional and practical support in the home. At present, the scheme operates mainly in north London, west London and Oxfordshire, but the network hopes to extend itself to establish a project in every London borough and, in time, to set up a network of independent befriending schemes throughout the UK.

The organisation works on the premise that people are all different and each of us may have a different notion of a good death. The nature of the befriending relationship will vary accordingly. While some people openly acknowledge that they are dying, this is not always a major topic

of conversation. If people wish to talk about it, they can be assured that the befriender is able to handle issues that are raised.

One person who had a regular befriender highlighted the value of the relationship:

*What I value is a new friend coming at this strange new stage of my life, without bringing any baggage from the past. I don't have to protect her as I find myself protecting other old friends. I can unload on to her without any qualms and make use of her to bounce ideas off.*

People also report that they value being able to talk about concerns for their families or coping with pain to someone who does not feel obliged to respond in clinical terms.

*For further details, call 020 7689 2448*

### The National Funerals College's Independent Funeral Advisers

The idea of independent funeral advisers originated in The Dead Citizens Charter,<sup>61</sup> a document drawn up by the National Funeral College, a small educational charity that aims to promote better funeral practice. The charter envisaged that advisers would provide impartial information to the dying person and/or those close to them, enabling them to make informed decisions appropriate to their circumstances.

The King's Fund grant-aided a project to test the feasibility of making an adviser available in institutions where people die.<sup>62</sup> Training for this project took place over a two-day period with follow-up support, and included such topics as:

- communication, including raising difficult subjects
- ideas about what makes for ‘good funerals’ and ‘bad funerals’
- costs of funerals
- funeral options, including green, woodland and ‘DIY’ arrangements.

By July 2001, the project director had trained 28 people from a number of residential homes, a nursing home and two hospices where the services of funeral advisers were called upon and appreciated.

A recent report from the Office of Fair Trading<sup>63</sup> supported the appointment of independent, trained funeral advisers in institutions where deaths occur, such as hospitals, hospices, nursing and residential homes.

*For further details, e-mail Rose Heatley at [rheatley@blueyonder.co.uk](mailto:rheatley@blueyonder.co.uk)*

## Cancer Black Care

Traditionally, some black communities have tended to sort out their own problems within their families and communities, but experiences in this country have shown that support networks have not always been available to enable this. Some families have become unable to talk about certain issues and to resolve them entirely within the family, and they may need support in order to enable them to deal with issues at the end of their lives.

Cancer Black Care was founded in October 1995 and is based in east London. Two further centres are planned. The organisation aims to address the cultural and emotional needs of black and minority ethnic



communities affected by cancer, as well as their carers, families and friends.

Services offered include:

- counselling (one-to-one or telephone support)
- a monthly support group
- help with practical issues, such as obtaining benefits and filling in forms
- an information service provided by two information officers, one of whom is a nurse.

It is important to understand specific cultural beliefs and values in relation to illness and death. For example, in some African communities, cancer is seen as a curse or as a result of some misdemeanour in conduct, so issues need to be discussed in a sensitive manner that is aware of cultural context.

While black communities have a variety of faiths and religious affiliations (or none), on the whole, religion often plays a large part in the lives of their members. Churches can be very supportive, but occasionally the belief that prayer will solve problems and cure illnesses can obstruct people's need to sort out problems as part of the process of letting go.

Black people have traditionally made little use of hospices. Frequently, hospices are seen within the black community as being so associated with death that they are thought to hasten death and to be equated with giving up. Some people do not know what hospices actually offer and

may not be familiar with terms such as ‘palliative care’. The organisation is carrying out work in partnership with a hospice to address these concerns.

*For further details, call 020 7249 1097*

### GaysCan

GaysCan is a national helpline offering confidential help and support to gay men living with cancer and to their partners, families and friends. The organisation was formed on the assumption that some gay men with cancer will feel more understood and accepted by another person in similar circumstances.

In the health and social care services, gay men still find that assumptions are sometimes made about their sexuality and lifestyle. Additionally, the courtesy and inclusiveness that would usually be extended to a heterosexual partner may not automatically be extended to a same-sex partner.

While many gay men are – and have always been – open about their sexuality, some have grown up living a double life, and if they become seriously ill, some of the people who are close to them may not know about their sexuality. For some gay men, their sexuality is one of the issues that they may wish to discuss with accepting and understanding supporters. The habit of not sharing aspects of their lives with people who are close to them may also affect their ability to talk to family and friends about their illness and associated concerns. Again, sensitive support that takes into account personal experience may be particularly acceptable from another gay man.

*For further details, call 020 8368 9027 or e-mail:  
gayscan@blotholm.dircon.co.uk*

## Appendix 2: Contact details

The following contact details are for organisations and programmes referred to within this discussion paper, which support psychosocial palliative care.

### **Age Concern**

Tel: 0800 009966

Website: [www.ace.org.uk](http://www.ace.org.uk)

### **The Alzheimer's Society**

Tel: 020 73060606

Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **The Assisted Living Foundation**

Tel: 020 7359 7169

Website: [www.assistedliving.org.uk](http://www.assistedliving.org.uk)

### **The Befriending Network**

Tel: 020 7689 2448

Website: [www.befriending.net](http://www.befriending.net)

### **British Red Cross**

Tel: 020 7201 5247

Website: [www.redcross.org.uk](http://www.redcross.org.uk)

### **Cancer Black Care**

Tel: 020 7249 1097

Website: [hosted.aware.easynet.co.uk/contacts/cbc/](http://hosted.aware.easynet.co.uk/contacts/cbc/)

### **Crossroad Carers' scheme**

Tel: 01788 573653

Website: [www.crossroads.org.uk](http://www.crossroads.org.uk)

**GaysCan**

Tel: 020 8368 9027

E-mail: [gayscan@blotholm.dircon.co.uk](mailto:gayscan@blotholm.dircon.co.uk)

**The Macmillan GP Facilitator Programme**

Tel: 01332 541366

E-mail: [GPurland@macmillan.org.uk](mailto:GPurland@macmillan.org.uk)

**Macmillan Nurses**

Tel: 0808 808 2020

Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

**Marie Curie Cancer Care**

Tel: 020 7599 7777

Website: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

**The Motor Neurone Disease Association**

Tel: 01604 250505

Website: [www.mndassociation.org](http://www.mndassociation.org)

**The Multiple Sclerosis Society**

Tel: 0808 800 8000

Website: [www.mssociety.org.uk](http://www.mssociety.org.uk)

**The National Funerals College's Independent Funeral Advisers**

Tel: 0117 954 5558

E-mail: [rheatley@blueyonder.co.uk](mailto:rheatley@blueyonder.co.uk)

**The NHS Beacon Programme**

Website: [www.nhs.uk/beacons](http://www.nhs.uk/beacons)

**New Opportunities Funding**

Tel: 0845 0000 121

Website: [www.nof.org.uk](http://www.nof.org.uk)

## References

- <sup>1</sup> *Shifting the Balance of Power: The next steps*. Department of Health, 2002.
- <sup>2</sup> NHS Executive. *A Policy Framework for Commissioning Cancer Services: Palliative Care Services*. EL(996)85: NHS Executive, 1996.
- <sup>3</sup> Addington-Hall JM & McCarthy M. *Regional study of care for the dying: methods and sample characteristics*. *Palliative Medicine* 1995; 9: 27–35.
- <sup>4</sup> Howse K. *Death and Dying in London*. London: King's Fund, 2001.
- <sup>5</sup> Addington-Hall JM, MacDonald L, Anderson HR & Freeling P. Dying from cancer: the views of bereaved family and friends about the experiences of terminally ill patients. *Palliative Medicine* 1991; 5: 207–14.
- <sup>6</sup> Grande GE, Barclay SIG & Todd CJ. Difficulty of symptom control and general practitioner's knowledge of patients' symptoms. *Palliative Medicine* 1997; 11: 399–406.
- <sup>7</sup> Hinton J. The physical and mental distress of the dying. *Quarterly Journal of Medicine* 1965; 32: 1–21.
- <sup>8</sup> Addington-Hall JM, Lay M, Altmann D & McCarthy M. Symptom control, communication with health professionals and hospice care of stroke patients in the last year of life as reported by surviving family, friends and officials. *Stroke* 1995; 26: 2242–8.
- <sup>9</sup> Hatcliffe S & Smith P. Open all hours. *Health Service Journal* 26.6.97; 40–1.
- <sup>10</sup> Mackrell M. Meeting the needs of dying patients. *Journal of Community Nursing* 1996; 10: 18–20.
- <sup>11</sup> Lowden B. Introducing palliative care: health professionals' perceptions. *International Journal of Palliative Nursing* 1998; 4: 135–42.
- <sup>12</sup> Pugh E. An investigation of general practitioner referrals to palliative care services. *Palliative Medicine* 1996; 10: 251–7.

- <sup>13</sup> Seale C & Cartwright A. *The Year Before Death*. Aldershot: Avebury, 1994.
- <sup>14</sup> Grande GE & Todd CJ. Support needs in the last year of life: patient and carer dilemmas. *Palliative Medicine* 1997; 11: 202–8.
- <sup>15</sup> *The NHS Cancer Plan: A plan for innovation, a plan for reform*. Department of Health, 2000.
- <sup>16</sup> Shipman C, Pearce A & Addington-Hall J. *Primary Care Groups and Trusts Working with Cancer and Palliative Care*. London: Macmillan Cancer Relief, 2001.
- <sup>17</sup> Cartwright A. *The Role of the General Practitioner in Caring for People in the Last Year of their Lives*. London: King's Fund, 1990.
- <sup>18</sup> Grande GE, Todd CJ, Barclay SIG & Doyle JH. What terminally ill patients value in the support provided by GPs, district and Macmillan nurses. *International Journal of Palliative Nursing* 1996; 2: 138–43.
- <sup>19</sup> Barclay S. Palliative care for non-cancer patients: a UK perspective from primary care. In Addington-Hall JM & Higginson IJ, editors. *Palliative Care for Non-Cancer Patients*. Oxford: Oxford University Press, 2001: 172–88.
- <sup>20</sup> Millar DG, Carroll D, Grimshaw J & Watt B. Palliative care at home: an audit of cancer deaths in Grampian region. *British Journal of General Practice* 1998; 48: 1299–302.
- <sup>21</sup> Addington-Hall JM, MacDonald L, Anderson HR & Freeling P. *Op.cit.*
- <sup>22</sup> Field D & McGaughey J. An evaluation of palliative care services for cancer patients in Southern Health and Social Services Board of Northern Ireland. *Palliative Medicine* 1998; 12: 83–7.
- <sup>23</sup> Gaze H. Final challenge. *Community Practitioner* 2000; 73: 630–1.
- <sup>24</sup> Kelly TA & O'Leary M. *The Nursing Skill Mix in the District Nursing Service*. Value for Money Unit, NHS Management Executive, HMSO, 1992.

- <sup>25</sup> Mackrell M. Meeting the needs of dying patients. *Journal of Community Nursing* 1996; 10: 18–20.
- <sup>26</sup> Seale C. Community nurses and the care of dying. *Social Science & Medicine* 1992; 34: 375–82.
- <sup>27</sup> Seale C, Cartwright A. *The Year Before Death*. Aldershot: Avebury, 1994.
- <sup>28</sup> Addington-Hall JM. *Reaching Out: Specialist palliative care for adults with non-malignant disease*. London: National Council for Hospices and Specialist Palliative Care Services, 1998.
- <sup>29</sup> Goodman C, Knight D, Machen I & Hunt B. Emphasising terminal care as district nursing work: a helpful strategy in a purchasing environment? *Journal of Advanced Nursing* 1998; 28(3): 491–8.
- <sup>30</sup> Wilkes L *et al.* Community nurses' descriptions of stress when caring in the home. *International Journal of Palliative Nursing* 1998; 4: 14–20.
- <sup>31</sup> *Hospice and Palliative Care Facts and Figures, 2002*. Hospice Information. London: St. Christopher's Hospice, 2002.
- <sup>32</sup> Dix O & Glickman N. *Occasional Paper 13*. Working Party on Psychosocial Care. London: National Council for Hospices & Specialist Palliative Care Services, 1997.
- <sup>33</sup> Lloyd-Williams M, Friedman T & Rudd N. A survey of psychosocial service provision within hospices. *Palliative Medicine* 1997; 13: 431–2.
- <sup>34</sup> Higginson IJ. *The Palliative Care for Londoners: Needs, experiences, outcomes and future strategy*. London Regional Strategy Group for Palliative Care, 2000.
- <sup>35</sup> Cullen L. *The Work of Volunteers in Home Care Services for Terminally Ill People*. London: King's Fund, 1998.
- <sup>36</sup> McKenna H, Keeney S & Nevin L. Perceptions of GPs and DNs on the role of hospice home-care nurses. *International Journal of Palliative Nursing* 1999; 15: 288–95.

- 37 Higginson IJ. *Op. cit.*
- 38 Higginson IJ. *Palliative and Terminal Care. Health Needs Assessment.* Oxford: Radcliffe Medical Press, 1997.
- 39 Jones R *et al.* Death from cancer at home: the carers' perspective. *British Medical Journal* 1993; 306: 249–51.
- 40 Seale C & Cartwright A. *Op.cit.*
- 41 Field D. Special not different: General practitioners' accounts of their care of dying people. *Social Science & Medicine* 1998; 46: 1111–20.
- 42 Addington-Hall JM. *Reaching Out: Specialist palliative care for adults with non-malignant disease.* London: National Council for Hospices and Specialist Palliative Care Services, 1998.
- 43 Higginson IJ. *The Palliative Care for Londoners. Op. cit.*
- 44 Shipman C & Dale J. Responding to patients with particular needs. In Salisbury C, Dale J, Hallam L, editors. *24 Hour Primary Care.* Oxford: Radcliffe Medical Press, 1998.
- 45 Munday DF, Douglas A & Carroll D. GP out of hours co-operatives and the delivery of palliative care. *British Journal of General Practice.* 1999; 49: 489.
- 46 Thomas K. *Out-of-hours Palliative Care in the Community.* London: Macmillan Cancer Relief, 2001.
- 47 *First assessment – A review of district nursing services in England and Wales.* London: Audit Commission, 1999.
- 48 Griffiths J. Meeting personal hygiene needs in the community: a district nursing perspective on the health and social care divide. *Health and Social Care in the Community* 1998; 6(4): 234–40.
- 49 Henwood M. *Future Imperfect? Report of the King's Fund Care and Support Inquiry.* London: King's Fund, 2001.
- 50 Barclay S. Palliative care for non-cancer patients: a UK perspective from primary care. In Addington-Hall JM & Higginson IJ, editors. *Palliative Care for Non-Cancer Patients,* Oxford: Oxford University Press, 2001: 172–88.



- <sup>51</sup> Shipman C, Addington-Hall J, Barclay S, Briggs J, Cox I, Daniels L & Millar D. Educational opportunities in palliative care: what do general practitioners want? *Palliative Medicine* 2001; 15: 191–6.
- <sup>52</sup> *The NHS Cancer Plan: A plan for innovation, a plan for reform.* Department of Health, 2000.
- <sup>53</sup> *Ibid.*
- <sup>54</sup> Wilkin D, Gillam S, Coleman A, editors. *The National Tracker Survey of Primary Care Groups and Trusts 2000.2001: Modernising the NHS?* The University of Manchester, 2001.
- <sup>55</sup> *Shifting the Balance of Power: The next steps.* Department of Health, 2002.
- <sup>56</sup> *Ibid.*
- <sup>57</sup> Thomas K. *Op. cit.*
- <sup>58</sup> *The NHS Cancer Plan: A plan for innovation, a plan for reform. Op. cit.*
- <sup>59</sup> New Opportunities Fund: *Palliative care for adults programme.* Guidance notes, England. [www.nof.org.uk](http://www.nof.org.uk), 2002.
- <sup>60</sup> *Shifting the Balance of Power: The next steps. Op.cit.*
- <sup>61</sup> *The Dead Citizens Charter*, National Funerals College, 1998.
- <sup>62</sup> Heatley R. *Funeral Advisers – Is there a need?* National Funerals College, 2001.
- <sup>63</sup> *Funerals – A report of the OFT inquiry into the funerals industry.* Office of Fair Trading, July 2001.

# King's Fund

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The King's Fund is an independent charitable foundation working for better health, especially in London. We carry out research, policy analysis and development activities, working on our own, in partnerships, and through grants. We are a major resource to people working in health, offering leadership and education courses; seminars and workshops; publications; information and library services; a specialist bookshop; and conference and meeting facilities.

People with life-threatening illnesses – malignant or otherwise – have spiritual, social and practical needs that are often overlooked or are difficult to meet in community settings. Only a quarter of those who wish to die at home can do so, and few benefit from joined-up health and social care services. If the NHS is to live up to its promise of a cradle-to-grave service for all, it will need to ensure more equitable and consistent services for dying people in the closing stages of life.

This discussion paper examines psychosocial provision in the community for dying people, and argues that the new-found commissioning powers of primary care trusts (PCTs) are the key to unlocking better, more integrated care. PCTs are now in a prime position to:

- strengthen clinical governance within new NICE guidelines
- improve education and training in palliative care provision for primary care professionals, and enhance the role of District and community nurses
- identify and spread good practice from hospices, specialist care providers and charitable organisations
- work with social services to strengthen and expand provision
- manage and direct resources.

One of the outputs of a two-year, London-focused research project examining what constitutes a 'good death', this paper will be of interest to providers and commissioners of care services for dying people, including primary care, voluntary sector and social services professionals working in this field.