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<b>Orders</b>  Free from: King's Fund Publications 020 7307 2591 or download at <a href="http://www.kingsfund.org.uk/summaries">www.kingsfund.org.uk/summaries</a>				

# PALLIATIVE CARE

## Perspectives on caring for dying people in London

For dying people and their friends and families, palliative care – care for people in their final stages of life – is one of the most important services offered by the NHS and the voluntary sector. At present levels of community-based support, just under a quarter of people are able to die at home. Research suggests that many more would prefer to do so.<sup>1</sup>

Palliative care should be equally available to all communities.<sup>1</sup> The NHS Cancer Plan<sup>2</sup> has released extra funding for these services, as well as training for district nurses. The NICE Guidance on Supportive and Palliative Care<sup>3</sup> recommends standards for providing palliative care in the community.

But while primary care trusts (PCTs) now have extra funding, they need more support to provide high-quality general day-to-day care to dying people. To commission care and develop services effectively, they need more information about how community-based palliative care services are provided at present, and how and why services vary between PCTs.

This summary presents the findings of a two-year research and development project, supported by a King's Fund grant, examining how London's primary care professionals are working in the community to provide palliative care, and how general practitioners, district and community nurses, and PCT and specialist palliative care professionals view each others' roles. It explores what they think about current services and what changes they would like to see. Its overall aim is to help PCTs commission palliative care more effectively.

### WHAT IS PALLIATIVE CARE?

Palliative care is 'the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families'.<sup>4</sup>

Our research set out to explore the realities of providing palliative care in the community, to help PCTs commission palliative care services effectively. We found that PCTs face many challenges in offering effective care at the end of life. We uncovered variations between how different PCTs organise their community palliative care services, and in the range of services they offer.

PCTs face many competing pressures, and providing palliative care is only one of a wide range of priorities. They must meet national targets set out in the NHS Plan and undergo assessments in the 'star-rating' system, leaving little scope to respond flexibly to local needs. Many have limited resources and management capacity. Working within tight funding constraints means they must focus to a large extent on the Government's list of 'must-dos', such as access and waiting time targets.<sup>5</sup>

- Over one year, in an average-sized GP list of 1,800 patients, about five patients will die from cancer, and 15 from conditions such as circulatory, respiratory or neurological disorders.<sup>6</sup>
- Palliative care can make up a substantial part of the work of district nurses, with as many as four visits a day to some patients.<sup>7</sup>

For primary care staff on the ground, palliative care is just one part of their workload. The average general practitioner (GP) supports five patients dying from cancer and 15 dying from other causes, including progressive non-malignant disease such as heart failure, each year.<sup>6</sup> Eight of these patients may die under the care of the GP and others within hospices and hospitals. For a district and community nurse (DN) with a dying patient, offering palliative care can mean visits up to four times a day or more at the very end of life.<sup>7</sup>

Ensuring adequate care outside surgery hours is another key area of concern. NICE guidelines recommend that access to medical and nursing palliative care at home is available 24 hours a day, every day, with access to specialist advice by telephone as a minimum.<sup>3</sup>

Resources will always be limited, and workforce recruitment and retention are a challenge for London PCTs. Yet providing services for people in the final stage of life is fundamentally important to all of us. Our study found that services are provided in a variety of ways in different areas, but points clearly to the crucial importance of GPs, DNs and clinical nurse specialists (CNSs), and of different service providers working together to provide care.

## Methodology

The aims of our research, conducted in 2003–04, were to:

- **map** current provision of palliative care within primary care across London
- **explore** the attitudes of providers and commissioners to how palliative care is provided within primary, community and specialist services
- **investigate** how GPs and DNs work with specialist palliative care providers, including community CNSs
- **understand** the priorities of participants (including GPs, DNs, specialist palliative care providers, PCT commissioners and voluntary organisations) for the future of palliative care provision, and what they would like commissioners to prioritise within London.

Five London PCTs took part in the project, and we gathered information from a total of 565 people. Our research methods included:

- **needs assessment** – carried out within each PCT, and more broadly across London, mapping services and gathering epidemiological data
- **focus groups** – nine groups, each with DNs from one of the five selected PCTs, with an average of six participants in each
- **structured postal questionnaires** – sent to each GP and DN in the five participating PCTs, with a response rate of 57.1 per cent of GPs (354 out of the 620 contacted) and 52.5 per cent of DNs (179 out of the 341 contacted)
- **semi-structured interviews** – conducted with 32 people working across the five PCT areas, including specialist palliative care providers, commissioners, directors of policy, and voluntary sector representatives.

## Background

- Between 25 and 65 per cent of terminally ill cancer patients need specialist palliative care advice.<sup>9</sup> It is thought that many non-cancer patients would also benefit from this type of support.

This section describes how palliative care is typically provided to people dying in the community and the policy framework within which that care is offered.

### A range of provision

Most people spend the majority of their final year of life at home, under the care of the primary health care team, which includes GPs and DNs.<sup>6</sup> The PCT that employs them, either as staff or contractors, is responsible for providing and developing primary health care services. It also commissions all specialist palliative care services (such as hospice inpatient care and specialist community teams), working alongside other local PCTs and the Cancer and/or Supportive and Palliative Care Network. Overall, PCTs assess the needs of local communities, plan and secure health services, and improve health in their local areas. They also play the leading role in providing and developing effective care at the final stage of a person's life.<sup>8</sup>

#### GENERALISTS AND SPECIALISTS

The staff carrying out palliative care fall into two categories: generalists and specialists.

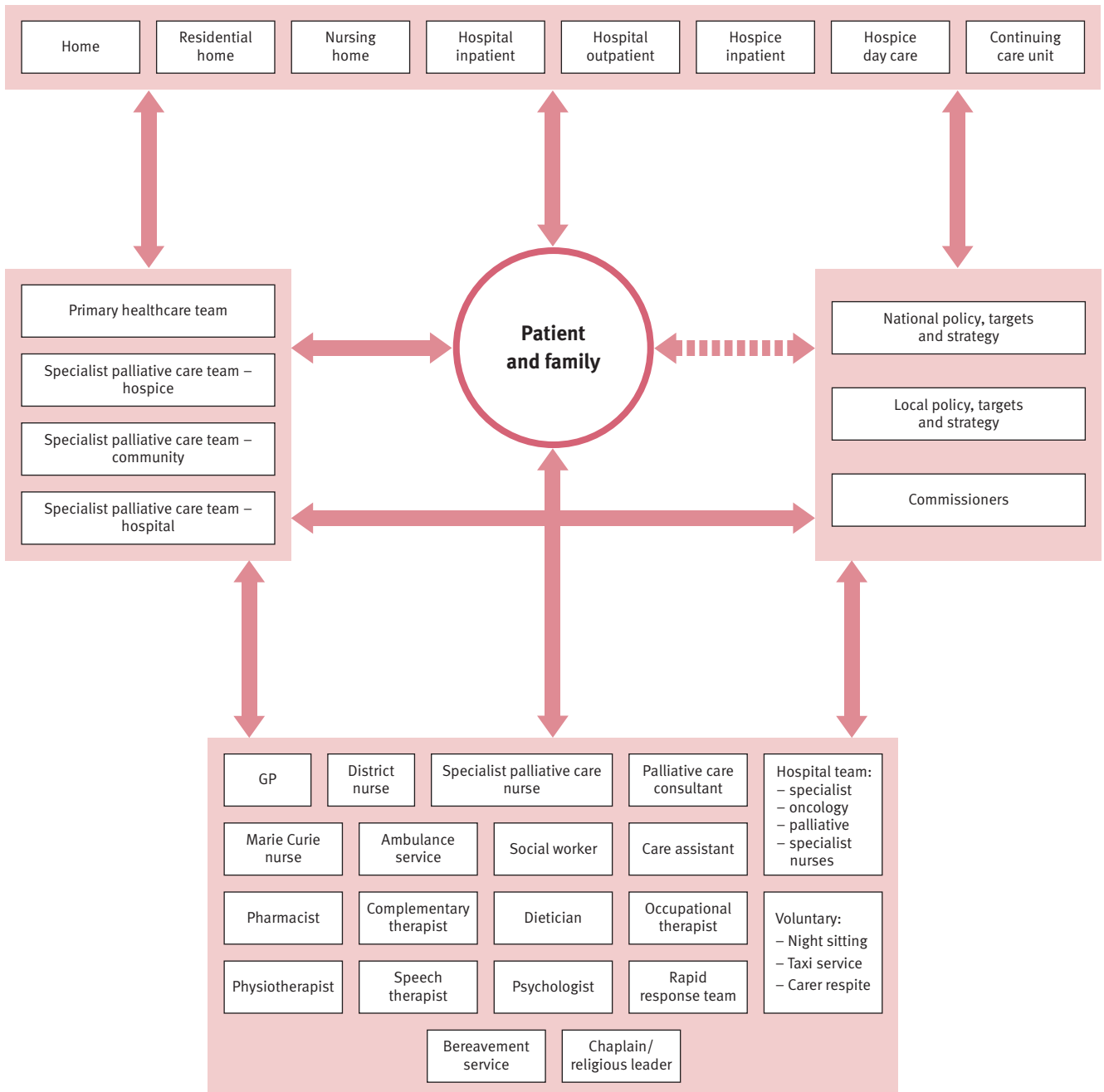
- **Generalists** in palliative care – such as general practitioners (GPs) and district nurses (DNs) – provide day-to-day care to patients.
- **Specialists** in palliative care – such as consultants in palliative medicine and clinical nurse specialists (CNSs) in palliative care, some of whom are known as Macmillan nurses, have specific expertise in complex aspects of care.<sup>3</sup>

Palliative care involves providers across a range of very different sectors, with PCTs, acute trusts and voluntary organisations all making a substantial contribution to service provision. Palliative care patients often have complex needs and may have contact with many organisations and individuals during their final months of life, all providing different aspects of treatment, care and support at home, at hospital and in other locations. Additionally, each patient's 'journey' through care takes place within the wider context of local and national priorities and policies that influence the care they receive.

### Key roles

The three key services that provide palliative care within primary care fit into two categories: generalists (GPs and DNs) and specialists (CNSs). Together, these health care professionals assess, support and care for dying patients

**1 PROVIDING PALLIATIVE CARE: A COMPLEX 'WHOLE SYSTEM'**



## KEY POLICY DOCUMENTS

### NHS Cancer Plan (2000)<sup>2</sup>

- £50 million investment each year over three years, to tackle inequalities in access to specialist palliative care
- £6 million investment over three years to provide education and training in the principles and practice of palliative care for district and community nursing
- Joint investment of £3 million between the Department of Health and Macmillan Cancer Relief to appoint a lead clinician for cancer within each PCT.
- Additional New Opportunities Fund funding for community palliative care projects from 2001 to 2005.

### Building on the Best: Choice, Responsiveness and Equity in the new NHS (2003)<sup>10</sup>

- Pledges action to ensure that all adult patients nearing the end of life, regardless of diagnosis, have access to high quality palliative care so they can choose to die at home if they wish.
- Department of Health End of Life Care Initiative to take this forward, with £12 million over three years towards implementing the Gold Standards Framework<sup>14</sup> and the Liverpool Care Pathway for the Dying,<sup>15</sup> and developing the Preferred Place of Care document.<sup>16</sup>

### The new general medical services (GP) contract (2003)<sup>11</sup>

- The general management of patients who are terminally ill forms an essential service to be provided by all GP practices.
- Practices may transfer the provision of out-of-hours care to PCTs.

### NICE guidance on supportive and palliative care (2004)<sup>3</sup>

- Key recommendations for the provision of palliative care for people with cancer, including access to 24-hour medical and nursing services for patients at home.

at home. The different roles of GPs, DNs and CNSs in providing palliative care are not clear cut. But in most situations:

- **GPs** are the first point of contact for patients, and retain overall medical responsibility for patients cared for at home. They are often the first point of contact for referral to district nursing and specialist palliative care, and are responsible for issuing prescriptions for patients at home.
- **DNs** provide advice, information and emotional support to patients and their families. They provide hands-on nursing care in the patient's own home and often take on responsibility for ordering equipment and co-ordinating other aspects of care. Depending on local policy, they may make an initial assessment of a patient's needs under NHS continuing care.
- **CNSs** provide advice, information and emotional support to patients and their families. They advise GPs and DNs on more complex aspects of a patient's care, and may make an initial assessment of a patient's needs under NHS continuing care, depending on local policy.

Nearly all patients have some contact with their GP over the last months of life. Around 70 per cent of cancer patients and 50 per cent of non-cancer patients receive care from a DN, while 45 per cent of cancer patients and 10 per cent of non-cancer patients receive care from a specialist palliative care nurse. DNs provide most palliative care in the home, and visit more frequently than other services.

Close relationships between DNs, GPs and CNSs are crucial in providing effective support to palliative care patients at home. Recent NICE guidance emphasises the need for a co-ordinated, multi-disciplinary team approach.<sup>3</sup>

## The national picture

Some government policy developments, such as the NHS Cancer Plan,<sup>2</sup> NICE Guidance on Supportive and Palliative Care,<sup>3</sup> and the End of Life Care Initiative,<sup>10</sup> now provide standards and some funding for PCTs to prioritise and develop palliative care services. But others, such as aspects of the new GP contract and changes to out-of-hours arrangements, may conflict with providing effective palliative care.<sup>11, 12</sup> Under the new GP contract, introduced in 2004, all GPs must offer general management of patients who are terminally ill as an essential service. But how patients are handled out of hours has been changed, and where GPs choose to opt out of provision this responsibility has moved from GPs to PCTs.<sup>13</sup>

## Key findings

*I think GPs should be allowed a bigger role and that palliative care teams – including consultants – should share thinking and planning with us more, rather than just asking for prescriptions.*  
GP, questionnaire

Our study suggests there are wide variations in how community-based palliative care is organised in London, and that GPs, DNs and CNSs – the three key providers of services – have differing perspectives on each other's roles. This section looks at how individuals working in the three key roles felt about how palliative care was organised, how services were provided, and the relationships between themselves and the other roles. It also presents their perceptions of the impact of palliative care work on health care professionals and of the priority that these professionals attach to palliative care.

### How care is organised

**Differences between PCTs** The number of specialist voluntary sector and acute trust-based providers varied widely, as did the number of host organisations of specialist palliative home care teams, including PCTs, neighbouring PCTs, acute trusts and voluntary hospices.

**Differences in approach** Some palliative care systems involve few organisations. Others are immensely complex (see Figures 2 and 3), involving a greater number of statutory and voluntary sector organisations. Problems can arise when providers have overlapping or unclear catchment areas and conflicting priorities. In all systems, effective communication between organisations and sectors can be crucial.

### 2 PRIMARY PALLIATIVE CARE SYSTEM: CASE STUDY ONE

Example of services involved in providing palliative care.

**Primary care sector**

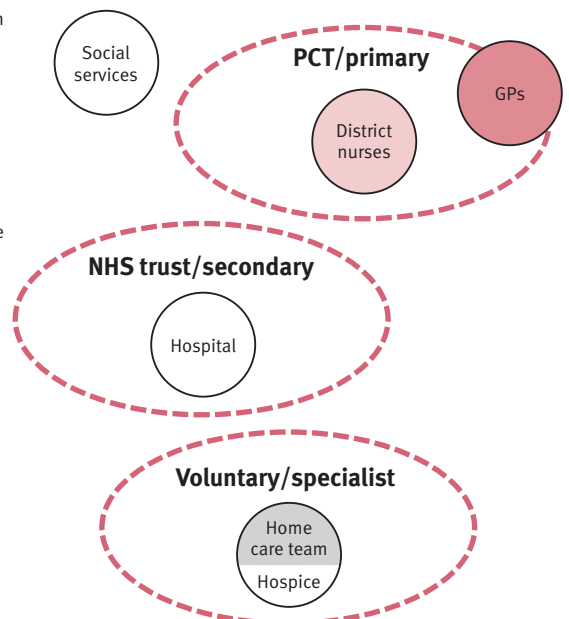
- GPs semi-autonomous but contracted to PCT
- District nurses employed by PCT

**NHS trust/secondary sector**

- One hospital palliative care team serving PCT

**Voluntary/specialist sector**

- One inpatient hospice with home care team serving PCT



*We'll call the Macmillan nurse in for advice or support before we call the GP.*  
DN, focus group

*Some GPs want to be heavily involved in palliative care for their patients, while others pass the work on. Then there are those who take an interest up to a point and then let go, or come in at the very end.*

PCT manager, interview

*I consider palliative care to be in many ways the most important part of my job.*

GP, questionnaire

*You couldn't work as a CNS in community palliative care without the back up of those DNs, because actually, they do it all.*

CNS, interview

*When I first started [work in the community], you would meet up with a Macmillan nurse and they would help you nurse the patient. That was what CNSs' role was: they came out – they helped.*

DN, focus group

### 3 PRIMARY PALLIATIVE CARE SYSTEM: CASE STUDY TWO

Example of services involved in providing palliative care.

#### Primary care sector

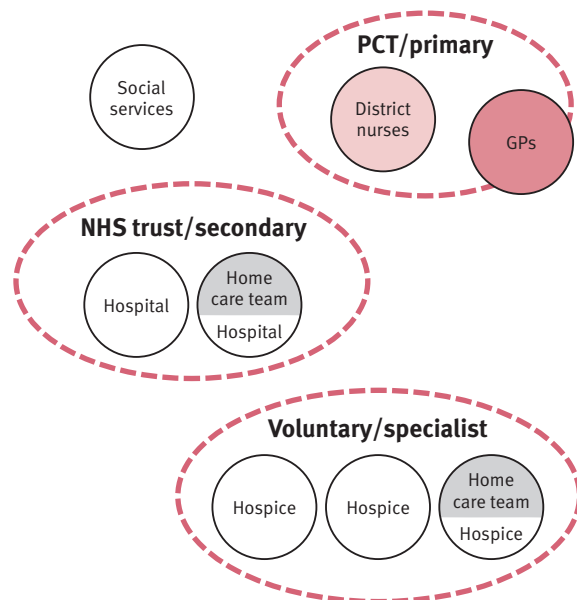
- GPs semiautonomous but contracted to PCT
- District nurses employed by PCT

#### NHS trust/secondary sector

- Two hospital palliative care teams serving PCT – one with home care team attached

#### Voluntary/specialist sector

- Three inpatient hospices serving PCT – one with home care team attached



## Provider perspectives

**Differing perceptions** GPs, DNs and CNSs can have widely varying perceptions of each other's roles, and of the importance of their roles in providing palliative care. This sometimes creates problems in working together smoothly as part of a wider team providing care at the end of life. For example, the individual responsible for prescribing (usually the GP) is sometimes not the same person who is actually making decisions about the prescribing (often a specialist), which can cause tensions.

**The GP role** Almost three-quarters of the GPs taking part agreed or strongly agreed that palliative care was a central part of their role, but over one in four did not. This means that the extent of primary care input that they offered dying people could vary substantially. DNs and other participants said that GPs' levels of involvement and interest in palliative care differed. They distinguished between 'out-of-the-ordinary' GPs with an active interest, those who were happy to 'go along with things' (for example, by signing prescriptions), and GPs who appeared to have very little involvement.

Overall, DNs felt some GPs were on the periphery of palliative care, with little day-to-day involvement with their patients. They felt GPs' main role was in prescribing, but they and CNSs felt that in this area, GPs, as generalists, could lack specific knowledge and relied on specialists to advise and guide them. GPs themselves were divided as to whether palliative care should be handed over to specialists.

**The DN role** Although DNs did not see all palliative care patients, they felt that they played a pivotal role in palliative care. As the professionals who

*I think CNSs see themselves purely as an advisory role – not a hands-on one – that’s the job of district nursing.*  
DN, focus group

*DNs are the main pivot between all the other people involved really – the doctors and the palliative care team.*  
DN, focus group

*I seem to be less and less involved as palliative care teams take over – a situation I am quite happy with.*  
GP, questionnaire

*We have a complementary role really – we’re not instead of anyone else, but working in the background as a complementary service.*  
CNS, interview

saw the patients most frequently, they felt central to providing, organising and co-ordinating care, and making sure that patient’s physical and emotional needs are met. Many other participants agreed, identifying DNs as the crucial professionals in meeting patients’ needs at the end of life. However, two-thirds of GPs disagreed and thought palliative care was not mainly DNs’ work.

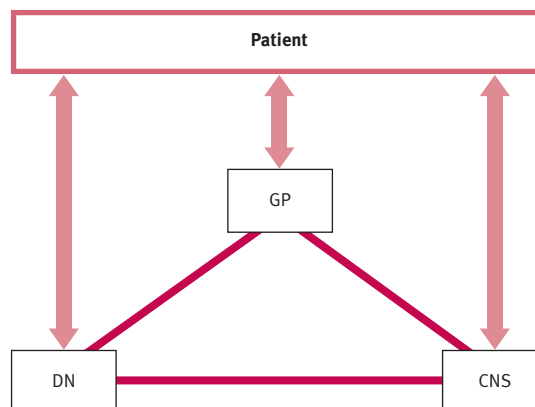
**The CNS role** Most CNSs were unequivocal that their role in specialist palliative care was as an advisory service, supporting the primary health care team and the patient – a view shared by the DNs. Some DNs felt this ‘hand-off’ stance was a change from past ways of working, and many were frustrated by its impact on their workload. However, a few specialist palliative care teams preferred a more active, hands-on role in co-ordinating and providing the majority of patient care, so there was some variation.

## Relationships

**Commitment** Many generalists remained committed to providing high quality palliative care, even within the most pressurised systems, where this priority could be to the detriment of their other patients’ needs.

**The supportive triangle** The three key roles of DNs, GPs and CNSs are linked in a ‘supportive triangle’. How this works varies both within each PCT, and from one to the next. The key factors that weaken how different parts of the triangle support each other include severely over-stressed services and communication breakdowns. We found that where this happens, it can lead to generalists and specialists adopting a ‘them and us’ mentality. In some PCTs, relationships between services were described as ‘close and supportive’, distinguished by well-resourced services and clear communication.

### 4 THE SUPPORTIVE TRIANGLE FOR PALLIATIVE CARE PATIENTS



#### Primary palliative care model

The existence of strong links between and commitment from each service ensures full support from specialists and generalists for patient with palliative care needs.



*With out-of-hours cover, there is a big problem with care of patients with complex illnesses and in particular, those with palliative care needs.*  
GP, questionnaire

*Nurses finish at 11 o'clock in the evening and don't start until 8.30, so what happens during those hours?*  
DN, focus group

*GPs co-ops sometimes don't have access to the relevant drugs to be able to give a patient, so quite often people will just get tipped into hospital if a co-op doctor is called out.*  
CNS, interview

*As soon as you get, say, two terminals on our caseload in a day, your whole time is taken up with them.*  
DN, focus group

**Pressure points** Insufficient GP, DN or CNS involvement with a palliative care patient – for example, as a result of poor referral systems, overwork or poor relationships – can put pressures on how the supportive triangle works and can reduce their ability to meet patients' needs. When generalist and specialist services were located in different trusts (such as a PCT and an acute trust), participants said this created an additional barrier to building relationships.

We found that large caseloads, a lack of understanding of others' roles, and a lack of opportunity to work with named individuals in other roles or to hold regular face-to-face meetings with them were factors that weakened the palliative care 'supportive triangle'.

**Pressures on DNs** These included lack of staff (whether or not there were vacancies); high use of agency staff; a lack of formal support, good senior role models and leadership; poor communication with management and a sense of not being valued; and a lack of 24-hour district nursing provision.

**Pressures on GPs** These included heavy workloads, competing priorities, difficulties in access to services, and lack of peer support. These can be exacerbated where there is limited personal interest in palliative care, lack of knowledge of local palliative care services and resources, and limited information handover from in-hours to out-of-hours providers.

**Pressures on CNSs** These included under-staffed services; multiple commitments (including education and other responsibilities); poor communication channels with generalist services; weak links with other specialist providers in the area; and unclear understanding of boundaries.

## Specialist palliative care

**Variations in availability** The perceptions of GPs and DNs on the availability of local specialist services differed substantially between areas. Between 73.8 per cent in one PCT and 97.1 per cent in another said that specialist palliative care assessment was 'always' or 'usually' available.

Those who perceived a lower availability were often in PCTs with pressurised specialist services and poorer relationships between generalists and specialists.

## Out-of-hours services

**A major issue** Many participants saw current provision of out-of-hours services (outside surgery hours – namely weekdays 8am to 6.30pm) as a major issue. Effective handover of patient information from in-hours to out-of-hours providers – most usually, the local GP co-operative – appeared to be limited. An audit of one GP co-operative found that it had been contacted by 81 patients with palliative care needs during one month but had received a handover form for only one (1.2 per cent).

*We're just expected to see someone who's dying, and then go on and do a leg ulcer!*  
DN, focus group

**Night DN services** Two of the five PCTs we studied did not have night DN services. Participants suggested that it might be possible to develop a new, integrated out-of-hours system, although financial pressures on PCTs would make this a challenge. PCTs that did have a night DN service often experienced morning and evening gaps, causing problems in dealing with patient emergencies.

**Access to drugs** Access to drugs for patients out of hours was a recurrent concern. Many PCTs are taking steps to address this, but the legislation around storing controlled drugs is complex, and it is rare for health care professionals to need access to drugs out of hours, so ensuring a 24-hour supply of drugs for palliative care use is proving challenging.

**Night-sitting services** Respondents told us that the Marie Curie services that provide a nurse to sit with patients at night were excellent, but many DNs and CNSs found that Marie Curie nurses were seldom available. However, Marie Curie as an organisation is aware of this problem and has launched several new initiatives to improve availability.

## Impact on health care professionals

**Workloads** For DNs and GPs alike, supporting palliative care patients can be time consuming and involve urgent and at times complex demands. Trying to fit these demands in with the rest of their workloads – including paperwork, meetings and other patients – can be very stressful, especially for DNs.

**Emotional stress** The strain of switching from care for the dying to providing more routine treatment was at times too much. In a number of PCTs, DNs felt unsupported in this work, and had no formal systems to help them deal with the loss of a patient they may have known for years. These issues are likely to affect GPs too.

## Priorities

**GP perceptions** When we asked GPs about planning future services for palliative care patients, they prioritised specialist services (CNSs, assessment and inpatient beds) and daytime district nursing. Their lowest priority was general practice out of hours, which could reflect their perceptions of a less involved role for GPs in this area as a result of the new GP contract.

**DN perceptions** For DNs, the key priority area was daytime district nursing, followed by Marie Curie nurses, specialist palliative care assessment, and inpatient beds. Like the GPs, the DNs rated GP out-of-hours care as a lower priority for service development, but they highlighted district nursing at night as a priority. DNs also wanted more administrative support for themselves.

**Other priorities** Other participants (particularly specialist providers) stressed the importance of sufficient 24-hour district nursing to meet the out-of-hours needs of palliative care patients. Many also highlighted the need for more education for GPs in palliative care (although they felt that reaching those who most needed it would be challenging), continued education of DNs, and expanding training to other workers, including community hospital and nursing home staff.

## Ways forward

**Services need to work together** The variation in models of care highlighted in this study show that there is no ‘right’ or ‘wrong’ system for the provision of palliative care within primary care. Different PCTs have inherited very different arrangements of palliative care services and some systems may need a boost to bring them up to the recommended standards of service provision. The fundamental importance within each system is how services work together, whatever their configuration, in providing care.

**Ensure strong communication and good relationships** Excellent communication and robust relationships are the key to quality of care. It can be difficult for good relationships to develop when all members of a team are over-stressed. Yet effective working relationships, with clear lines of communication and a reduced risk of duplicating work, can in the long term actually reduce inefficiencies in workload for individuals.

**Clarify responsibilities** Clear responsibilities across the system are critical to co-ordinating effective palliative care, as roles are often interdependent. For example, GPs often have the most in-depth information about who needs palliative care, yet DNs carry out most of the hands-on care.

**Develop standards for generalist provision of palliative care** Developing a framework for care planning can help to formalise roles, responsibilities and communication channels for each case. Some guidance is available for this, such as within the Gold Standards Framework. Where individuals do not wish to participate in these developments, it may be necessary for PCTs to consider alternatives such as delegating the care to GPs with special interests, or extending the role of specialist palliative care services.

**Support palliative care patients out of hours** Within the newly developing out-of-hours systems, there is a need to build in good support and easy access to palliative care patients.



## USEFUL RESOURCES

There are a number of resources for PCTs to draw upon in developing palliative care, including:

- Department of Health (2004). *Cancer in Primary Care: A guide to good practice*. London: Department of Health.
- National Institute for Clinical Excellence (2004). *Guidance on Cancer Services: Improving supportive and palliative care for adults with cancer – the manual*. London: NICE.
- Shipman C, Levenson R, Gillam S (2002). *Psychosocial Support for Dying People: What can primary care trusts do?* London: King's Fund.
- Tebbit P (2004). *Population-Based Needs Assessment for Palliative Care*. London: National Council for Hospice and Specialist Palliative Care Services.
- Department of Health (2004). *Building on the Best: End of life care initiative*. London: Department of Health.

## Endnotes

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