

**WE ARE
MACMILLAN.
CANCER SUPPORT**

ALWAYS THERE?

The impact of the
End of Life Care
Strategy on 24/7
community nursing
in England

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Foreword

Macmillan Cancer Support has been working with many other charities, as well as the NHS and Departments of Health across the nations of the UK to improve the care of those living and dying with cancer. Increasing numbers of patients with incurable disease can live with it for years but around 125,000 people in England still die of cancer every year.

The right support can transform the experience of end of life for everyone affected – the patient, family, carers, and friends. But the best laid plans can fall apart at three o'clock in the morning when a patient or carer feels most frightened and alone. As a doctor, I know that too often a crisis in the middle of the night or a bank holiday weekend can mean an unwanted admission to hospital.

The *End of Life Care Strategy* for England made very important recommendations as to the importance of 24/7 community support, to enable people to continue to be cared for in the place of their choice. Progress is being made, but it is disappointing that this report suggests that in some areas, access to co-ordinated 24/7 community nursing is still not seen as a priority. I hope that this report will convince Primary Care Trusts of the real benefits of end of life care services to patients and their families, and set about putting them in place.

Dr Jane Maher

Macmillan Chief Medical Officer

Executive summary

Macmillan Cancer Support believes that people who are nearing the end of their life should have the right to die at home, and that access to community nursing at any time of the day or night is essential to support them if they wish to do so. Where these wishes are not met it can lead to traumatic experiences for patients and their families.

The importance of 24/7 community nursing to enable people to die at home was recognised in the Department of Health's (DH) *End of Life Care Strategy* for England in 2008. However, despite the strategy calling on Primary Care Trusts (PCTs) and Local Authorities (LAs) to make 24/7 community care available, progress has been very slow.

The National Audit Office (NAO) reported that 24/7 community nursing was available to all patients in their home in around 53% of PCTs in 2006-07.¹ Some three years later, there has been little change: a Macmillan Freedom of Information (FOI) request indicated that 24/7 community nursing is available for all end of life patients in only 56% of responding PCTs.

Of the 44% of PCTs not currently providing this service to all end of life patients, many said they were providing it to some, and 64% have plans to extend their service. However, over a third (36%) of those not currently providing a service to all end of life patients specified no plans to improve this service, which equates to 16% of all responding PCTs.

Macmillan is disappointed that progress has been so slow. This current situation means that there could be up to 19 million people who might not have access to 24/7 community nursing at the end of life should they need it.² Our survey also indicated geographical variations in provision; with results suggesting there is more widespread provision in urban areas than rural areas. It

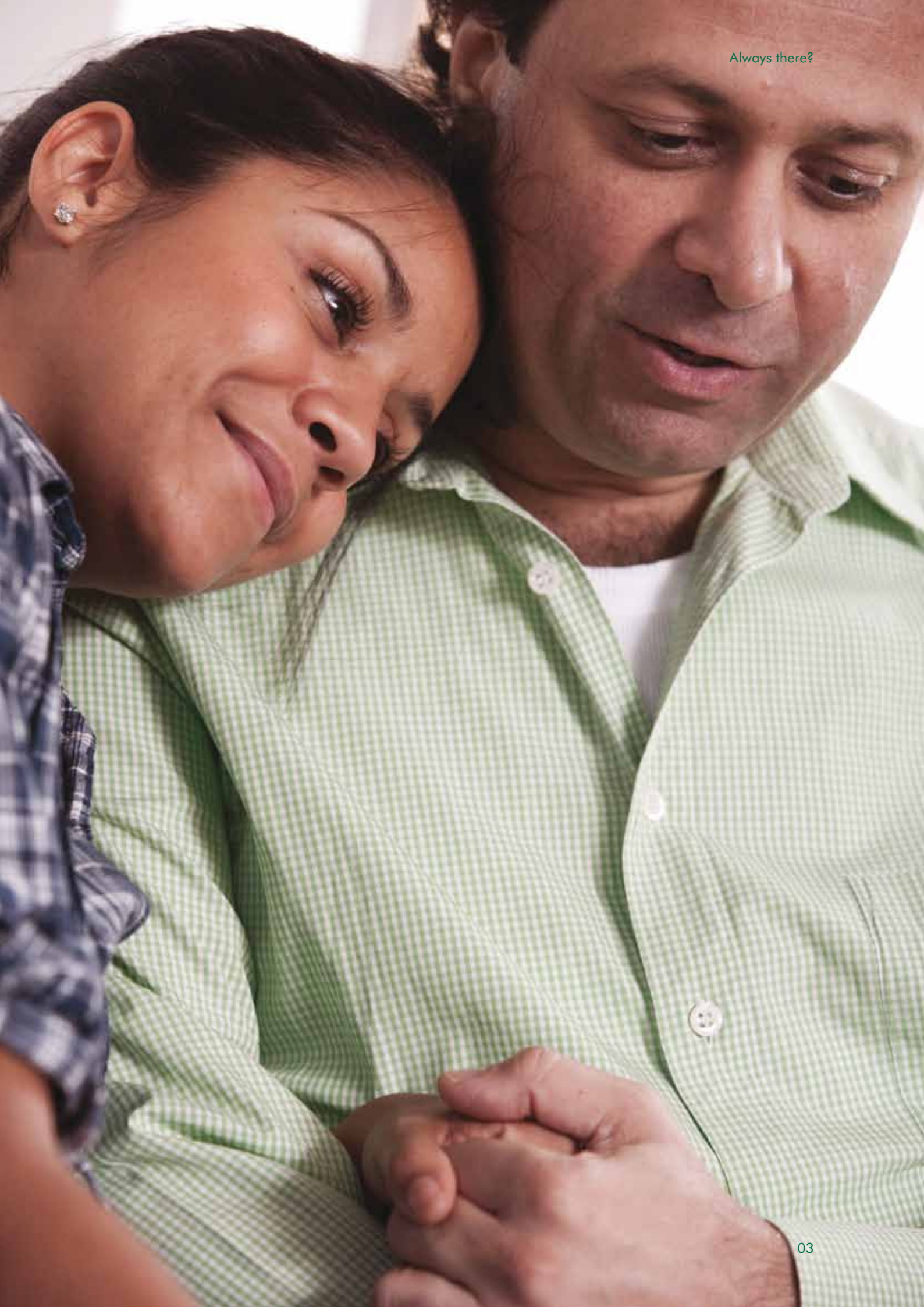
is clear therefore that there is still some way to go before world class end of life care is available to all.

It is worrying that PCTs have not already implemented 24/7 community nursing despite the *End of Life Care Strategy*, which was accompanied by £286 million of additional funds. We believe that the current economic situation presents an opportunity to not only improve the quality of care, but make more efficient use of NHS resources by reducing unnecessary hospital admissions.³

We also found that PCTs are not doing enough to record people's wishes about their preferred place of care, or whether their wishes are met. Our survey responses indicated that almost half of PCTs still do not have a process in place to register peoples' wishes, and less than a third collect data on whether patients were in fact able to die in their preferred place. Knowing this information, and ensuring it is communicated to all relevant health and social care professionals involved in a patient's care, is integral to providing high quality end of life services.

Although there are clearly some areas of good practice, there remain significant gaps that must be addressed urgently in order to achieve full provision of 24/7 community nursing for people at the end of life. It is imperative that people's wishes at the end of life are not ignored and the Government looks at ways to ensure PCTs put the necessary services in place.

Always there?



Why 24/7 community nursing?

Most people would prefer to die at home and not in a hospital – between 56 and 74 per cent according to different sources.⁴ However, the majority of people with cancer die in hospitals (48%), although few have chosen this as their preferred place of death. Recent statistics show that only around 25% of people with cancer die at home.⁵

A right to die at home

Place of death is a personal choice and people may wish to die at home for many different reasons. Some people may not wish to leave the home where they have lived for a long time. They may feel more comfortable being in their own surroundings. Or perhaps they don't like hospitals. Round the clock community nursing ensures that people's wishes or preferences can be realised and that people receive good quality care at the end of life. When these wishes are not met due to lack of services it can be devastating for those patients and their families, as Alison's story on page 5 illustrates. It can lead to very traumatic experiences at the end of life and lasting guilt and remorse for those left behind.

Support for 24/7 community nursing

The Department of Health published the *End of Life Care Strategy for England* in July 2008. The strategy set out a vision for providing high quality care for all adults at the end of life which emphasised the importance of 24/7 community nursing:

*'The range of services (medical, nursing and personal care) which people need to enable them to live and die at home are available, including those which are required 24/7. Particular attention should be given to ensuring that rapid response nursing services are available for people approaching the end of life in areas where full 24/7 community nursing services are not currently available.'*⁶

A report published by the National Audit Office (NAO) in November 2008 highlighted the importance of implementing this call. It concluded that a lack of access to well co-ordinated 24 hour services in the community leads to people who are approaching the end of their lives being unnecessarily admitted to hospital and as a consequence not being able to die in their preferred place of care.⁷ This conclusion was recently echoed in a report by the Kings Fund.⁸ The NAO also found through analysis of an individual PCT that 40% of patients who died in hospital over a one-month period did not have medical needs which required them to be treated in hospital.

The economic benefits

There is also an economic benefit to the NHS in introducing 24/7 community nursing. More efficient use of NHS resources could be achieved if terminally ill patients were not inappropriately admitted to hospital. The NAO has suggested that £104 million a year could be used to meet people's preferences for place of care by reducing emergency hospital admissions for cancer patients by 10% and the average length of stay following admission by three days.⁹ This evidence is supported by a recent joint report by Healthcare at Home and Dr Foster, *Hospital Care at Home*, which estimated £160 million savings for the NHS if end of life care was delivered in the home.¹⁰



Alison's story

Alison's father was first diagnosed with bowel cancer in the 1960s. Nearly 40 years on it returned, spread and his condition was terminal.

'I took on the role of full time carer at home. Overnight care was a real worry to me and the offer of nursing support came too late because he deteriorated dramatically. I felt lost, and was uncertain whether to call an ambulance. As a sole carer, I felt overwhelmed by the responsibility of making that decision.

He did go into hospital in the early hours of the morning but it took several hours before he was moved from a cubicle to his own room. Despite a morphine pump he was in a lot of pain, and an air bed to help give comfort only turned up a few hours before he died. When he passed away it was a blessing.'

Progress to date

Availability of 24 hour, seven days a week, well-co-ordinated, community nursing is crucial to enable people to die at home if they wish to do so.

Community nursing means a person or team of people who are able to:

- Assess the patient.
- Provide medical support which would otherwise have to be provided within hospital – for example taking a blood sample, managing a syringe driver, changing a dressing or putting in a catheter.
- Manage symptoms.
- Provide supportive care.
- Prescribe medication.
- Stay in the house for extended periods of time during the day and night, to allow carers to rest.
- Be linked to the primary care team.
- Provide emotional support.

In the past this support has been provided by district nurses but increasingly this role is played by a team of people with varied skills, including specialist palliative care nurses, health care assistants and other allied health professionals, such as physiotherapists and occupational therapists.

In their 2008 report the NAO presented the results of a survey setting out where PCTs were at in terms of delivering 24/7 community nursing. Its top line finding was that 24/7 community nursing was available to all patients in their home in around 53% of PCTs in 2006-07. Tessa's story on page 7 demonstrates the benefits when this has happened.

In order to determine what progress has been made since this report was published; Macmillan submitted a Freedom of Information request in January 2010 to all PCTs in England. The request covered the provision of 24/7 community nursing, as well as the recording of patients' wishes and outcomes and workforce issues.

The responses varied in terms of the quality and consistency of detail provided; in a number of cases it was apparent from the information provided that although the PCTs said they were providing 24/7 community nursing, this was not in fact the case. The following chapters set out Macmillan's findings from our analysis of the PCT responses, and makes recommendations on how to build on current best practice. We would like to thank the large number of PCTs – 127 out of 152 – that responded; unfortunately we were not able to include two late responses in our analysis.



Tessa's story

Tessa's 70 year old father was diagnosed with lung cancer in the summer of 2008; he died at home just a few months later.

'Our family relied on the kindness of strangers. A flock of angels – carers, district nurses, GPs, hospice staff, and Marie Curie and Macmillan nurses – arrived at our Shropshire door in a steady stream. If we stumbled, there was always someone to pick us up. They attended to all dad's physical needs. As he lost the use of his body, they maintained his dignity with gentle humour and the greatest compassion.

Three times a day his carers came to clean him, help him to the commode, make his bed and make him comfortable, always with infinite patience and gentleness. Each day, the nurses and GPs monitored his medication, helped us think clearly through the fog of emotion and provide every gadget and facility they could think of; and at night, nurses sat with dad through the night giving us the vital sleep we needed to cope with the day ahead. And so, against a hidden backdrop of panic and despair, the 'angels' ensured dad had a 'good' death.'

Availability of 24/7 community nursing

In 2008, the *End of Life Care Strategy* called on PCTs and LAs to make 24/7 community nursing available. However, despite political will and the opportunity to introduce economic and quality benefits, so far slow progress has been made in implementing this recommendation.

Overview of community nursing provision

The NAO reported that in 2006-07 around 53% of PCTs stated that all patients could access district nursing in their home 24/7. Such services were not available in 29% of

PCTs, and only available to some patients in around 18% of PCTs.¹¹

Three years later, our survey found that there had been little change: a full service of 24/7

Case study: Sheffield PCT

The PCT has both a 24 hour district nursing service, and an Intensive Home Nursing Service (IHNS), which provides up to 24 hour care for terminally ill patients to enable them to die at home. Patients registered with a Sheffield GP can access the IHNS for night care when considered to be in the last 6-8 weeks of life, day care when considered to be in the last 2-6 weeks of life and up to 24 hour care for the last week of life. The level of care given is assessed according to need, and takes into account personal and family requirements, by offering tailored care to meet individual needs. The care is provided by a team of support workers, who are co-ordinated, managed, led and developed by a team of senior staff nurses.

The service provides around 500 shifts a month, and cares for around 600 patients a year. The majority of those patients will have died safely at home, the place of their choice, with high-quality supportive care.

Kathryn, whose mother Hazel was recently cared for by the service, said: 'In such a difficult time it was a great comfort and reassurance to have the support of the home nursing service. It meant that my sister and I were able to care for mum at home with the help of district nurses and an amazing GP. We felt secure that the nurses were competent and compassionate in their work. Without the service it would have been a struggle.'

Table 1 Provision of 24/7 community nursing

	Number of PCTs	Percentage of PCTs who responded to Macmillan survey
24/7 community nursing available to all end of life patients	70	56%
24/7 community nursing not available to all end of life patients	55	44%
Total	125	100%

community nursing was available for all end of life patients in only 56% of the PCTs that responded. Where a good service is being provided it is delivering real benefits in terms of high quality care to patients, as demonstrated by the Sheffield case study.

Many of the remaining 44% of PCTs had made progress in implementing the DH recommendation, by already providing a service to some end of life patients, and some were clearly very close to achieving it. However, this is disappointingly slow

progress. In population terms this means that there could be up to 19 million people who might not have access to 24/7 community nursing at the end of life should they need it. Where 24/7 community nursing was not provided, out of hours services varied both by type and times of service available. For example some PCTs provided 24 hour care in some regions and not in others.

Encouragingly, around two-thirds of the PCTs who were not providing 24/7 community nursing to all end of life patients had plans to

Table 2 PCTs' reasons for extending current hours of community nursing

Reason selected (respondents could choose more than one reason)	Number of PCTs	Percentage (of the PCTs in which 24/7 community nursing is not available for all end of life patients)
To improve end of life care services	28	51%
To allow patients to die in their preferred place	27	49%
To reduce the rate of and associated cost of patients dying in hospital	21	38%
To improve service provision in another area of healthcare	11	20%
Increased demand for such services	7	13%
No reason given	1	2%

extend the current hours. As Table 2 shows, three reasons were overwhelmingly selected for doing so.

It is essential that service improvements are implemented swiftly. PCTs that were planning to extend community nursing provision had varied timeframes for doing so: most were expected to be achieved during 2010 or 2011, but six PCTs had longer term plans, and for seven the timetable was unclear.

However, it is particularly unsatisfactory that 20 PCTs (16%) did not specify any plans to provide a full service of 24/7 community nursing for people at the end of life. A number of them cited financial constraints as a reason why it had not been possible to provide such a service. This is of concern, not least given the potential of 24/7 community nursing to produce economic benefits. Others said there was a lack of demand for such a service.

Geographical variations in provision

Macmillan’s survey of PCTs indicated that provision of 24/7 community nursing for people at the end of their life varied substantially between Strategic Health Authorities (SHAs). Good progress had been made in certain SHAs, such as West

Midlands and Yorkshire and the Humber, but in some parts of England more significant progress is yet to be made.

Given that the Lord Darzi’s Next Stage Review included end of life care as one of the eight clinical pathways to be developed by each of the SHAs it is disappointing that better progress has not been made.

A comparison of 24/7 community nursing provision by population density also indicates that there are inequalities between urban areas – where provision appears to be more widespread – and rural areas, as Table 3 illustrates.¹² Surprisingly, only 34% of rural PCTs thought that further government assistance in the form of ringfenced funding for end of life care would be helpful, compared to 42% of urban PCTs. (See Appendix 1 for more details.)

Encouragingly, there appeared to be more widespread provision of 24/7 community nursing in areas with greater health inequalities. As Table 4 shows, the service was provided in almost two-thirds of Spearhead PCTs – the most health deprived PCTs in England – compared with half of non-Spearhead PCTs who responded to our survey.

Table 3 Provision of 24/7 community nursing in urban and rural areas

	Predominantly urban PCTs	Predominantly rural PCTs	Significantly rural PCTs
24/7 community nursing available to all end of life patients	52	8	9
24/7 community nursing not available to all end of life patients	29	12	15
Total	81	20	24

Table 4 Provision of 24/7 community nursing in Spearhead PCTs

	Spearhead PCTs	Non-Spearhead PCTs
Number of PCTs where 24/7 community nursing available to all end of life patients	36	33
Number of PCTs where community nursing not available to all end of life patients	19	37

Reasons for not providing 24/7 community nursing

We asked PCTs who were providing 24/7 community nursing for all end of life patients, what their reasons were for doing so. As Table 5 outlines, the most popular reasons were that the PCT had identified end of life care as a priority, and that there was a high demand for 24/7 community nursing.

Similarly, we asked the PCTs who had not made 24/7 community nursing available for

all end of life patients, why this had not been possible. Financial constraints were the top reason given, albeit by just over a quarter (surprisingly, only just over half of these PCTs said that additional government assistance in the form of ring fenced funding would be helpful). Twenty per cent said that there was lack of demand for such a service, which is puzzling given that around half of these told us that they did not register all patients' wishes. It was disappointing that over a quarter of the PCTs did not provide a reason.

Table 5 PCTs' reasons for successfully providing 24/7 community nursing

Reason selected (respondents could choose more than one reason)	Number of respondents	Percentage (of the PCTs who were providing 24/7 community nursing for all end of life patients)
End of life care identified by the PCT as a priority	54	77%
High demand for 24/7 community nursing	38	54%
Required to by their SHA	6	9%
Other reason specified, e.g. to offer an alternative to acute hospital care, to prevent unnecessary hospital admissions, or to ensure continuity of care for patients	19	27%
No reason given	1	1%

Table 6 PCTs' reasons why it had not been possible to provide 24/7 community nursing

Reason selected (respondents could choose more than one reason)	Number of respondents	Percentage (of the PCTs who were not providing 24/7 community nursing for all end of life patients)
Financial constraints	15	27%
Lack of demand for such a service	11	20%
Lack of appropriately trained staff	2	4%
Lack of an integrated IT system shared between different health service teams	2	4%
Other reason given, e.g. historical working hours, or a fuller service was in the process of being implemented	15	27%
No reason given	16	29%

Helping to extend community nursing provisions

Our survey indicated that there were mixed views on whether further government assistance was required in order to extend community nursing provisions. For example, 49 PCTs thought that ring-fenced funding specifically for end of life care would be helpful, whereas 23 PCTs did not think that further government assistance was necessary. Unsurprisingly, a slightly higher percentage (44%) of PCTs who were not already providing 24/7 community nursing felt that ring-fenced funding for end of life care would be helpful, compared to PCTs who were providing this service (36%). (See *Appendix 1* for more details.)

It was clear from our research that some PCTs are already delivering 24/7 community nursing for people at the end of their life without the need for extra assistance. However, a significant number are not doing so, despite the quality and economic benefits associated with providing this service. The absence of a formal requirement for PCTs to implement the *End of Life Care Strategy* commitment on 24/7 community nursing could be a factor. However the DH has already made available £286 million over the last two years to enable implementation of that strategy and is in the process of monitoring that spend.



Recommendation 1

In order to achieve the quality and economic benefits associated with providing 24/7 community nursing for people at the end of life, PCTs should implement the *End of Life Care Strategy* commitment on community nursing as a priority. A formal requirement for them to do so, for example through official recognition by the Care Quality Commission that this is a key component of high quality end of life care, would assist in achieving this objective.

Recommendation 2

The Government should continue to monitor PCT spend on end of life care beyond 2010 to determine what is being spent explicitly on end of life care provision. This will also ensure that PCTs have to develop an agreed definition of what they mean by end of life care.

Knowing people's wishes

In order to provide end of life care that meets people's needs, care providers need to be aware of people's wishes. Robust data is also required in order to effectively measure whether wishes were able to be met.

Preferred place of care – registering people's wishes

The *End of Life Care Strategy* called for systems to be in place to enable all relevant health and social care staff to access, with permission, information on the needs and preferences of people approaching the end of their life. The NAO's report also highlighted the importance of capturing the wishes of people nearing the end of life and ensuring that their wishes are conveyed to those who need to know. Without this information, particularly in emergency situations, the default would be an admission to hospital.

However, as Table 7 shows, 42% of PCTs still do not have a process in place to register people's wishes regarding where they would like to be cared for as they near the end of their life. A significant number of the PCTs who had either a partial or no process said that they were planning improvements. Given

that registering people's wishes is the crucial first step in providing end of life care, efforts to implement the *End of Life Care Strategy* recommendation must be prioritised.

Collecting data on outcomes

Knowing whether people's wishes were able to be met is equally important as registering people's wishes as they near the end of their life. Accordingly, the *End of Life Care Strategy* recognised the importance of measuring end of life care provision in order to monitor progress and effect change.

Macmillan's research shows that almost half of PCTs do not collect data on outcomes, although around one-third of these said that they had plans in development to address this, or that they planned to examine this issue. Current descriptions of 'home' are also currently too narrow and it should be noted for some a home can be a care home.

Table 7 Registering people's wishes

	Number of PCTs	Percentage of PCTs who responded to Macmillan survey
Process in place for registering people's wishes regarding preferred place of care	73	58%
Partial process in place, e.g. a full process is in the process of being implemented, or some people's wishes are registered	32	26%
No process in place	20	16%
Total	125	100%

Table 8 Collecting data on outcomes

	Number of PCTs	Percentage of PCTs who responded to Macmillan survey
Data collected on the number of patients able to die in their preferred place	38	30.5%
Data partially collected, e.g. for some patients	29	23%
Data not collected	58	46.5%
Total	125	100%

Recommendation 3

PCTs should capture the wishes of people approaching the end of life and also ensure that they record whether these wishes were met and people died in their preferred place. If it were necessary to ensure compliance in this area, one potential way could be to amend the vital signs indicator in the NHS Operating Framework on the recording of deaths at home so it reflects people's preferences and make it mandatory. It is also important to note that 'home' may be a care home in some cases.

Working together to deliver the best care

Effective coordination of care is vital for the successful delivery of 24/7 community nursing for people at the end of their life. This can be challenging as there are often a large number of organisations involved in delivering end of life care for patients in the community.

This can include health and social care professionals, independent hospice staff and the voluntary sector. A number of Macmillan nurse posts also operate both within and outside the NHS (for example in hospices) to deliver palliative care in the community.

The role of IT in providing coordinated care

The *End of Life Care Strategy* noted the importance of using IT to enhance coordination of care and ensure that the wishes of people can be made known. This is essential to ensure that 24/7 community nursing actually facilitates people's right to die at home. Teams who provide end of life care need ready access to appropriate

information, ideally via an integrated IT system, to ensure knowledge around preferences at end of life can be shared.

Indeed, as one PCT commented in response to our survey, 'not having an integrated IT system is a huge problem. Having an effective system would hugely improve communication and coordination of care.'

However, our survey showed that there is still some way to go before integrated IT systems are standard practice. As shown in Table 9, less than 10% of PCTs already had an integrated IT system in place, but a very significant number did not and did not specify plans to introduce one.

Table 9 Integrated IT systems

Status of integrated IT system	Number of respondents	Percentage of PCTs who responded to Macmillan survey
Integrated IT system already in place	10	8%
In the process of implementing or developing such a system	49	39%
Have a system that could be further developed, or have plans to examine this issue	15	12%
Integrated IT system not in place and no plans specified to introduce such a system	50	40%
No response	1	1%
Total	125	100%



Recommendation 4

PCTs should see the development of an integrated IT system as a key part of a co-ordinated system of end of life care. Systems should be a platform for recording patient wishes and ensuring these are accessible by all care providers. In the meantime PCTs should adopt other systems to ensure effective communication between health, social care and voluntary service providers to ensure joined up care.

Skills to meet patients' wishes

Ensuring access to 24/7 community nursing is dependent on having an adequate and well-trained workforce with the required expertise to deal with people nearing the end of life.

24/7 coordinated community nursing is increasingly delivered by a team of people with varied skills, including specialist palliative nurses, health care assistants and allied health professionals. However, as the NAO report recognises, end of life care may only represent a proportion of the role of generalist staff. It was for this reason that the *End of Life Care Strategy* recommended including end of life care in training curricula for all staff groups.

Macmillan believes that there is a definite role for specialist nurses to support and upskill generalists to provide fundamental

end of life care. This in turn would free up the specialist nurses to concentrate their efforts on people with needs that require specialist support.

Training in end of life care

Positively, in response to Macmillan's survey, only four PCTs said that training was not provided to health care staff to aid them in supporting patients in end of life care; one of these was due to commence training later in 2010.

All other PCTs who responded to our survey told us that they provided training to

Examples of good practice:

- A rolling programme of end of life care workshops covering key competencies, delivered throughout the year, aimed towards all health and social care staff involved in end of life care delivery.
- A specialist palliative care team which provides training to student nurses. Both nursing and medical students can shadow members of the team.
- Training in end of life care available to all staff across the PCT and raised in yearly appraisals.
- An ongoing liaison at end of life care link group to identify clinical issues which may require education of information to improve practice.
- An education collaborative for end of life made up of multi-agencies and stakeholders.
- Two-day enhanced communication skills training (end of life care discussion) available to all staff irrespective of employer.

health care professionals, although the staff groups to whom the training was available appeared to vary considerably. Availability of training for nurses and GPs appeared to be widespread, and several PCTs also offered training to allied health professionals and social care staff. Some PCTs reported that they provided placements for medical and nursing students, but otherwise opportunities for student training seemed noticeable by their absence.

Responses to Macmillan's survey indicated that the types of training provided varied from PCT to PCT. A significant proportion of

PCTs reported that they were providing non-clinical training such as communication skills, the importance of which was highlighted in the *End of Life Care Strategy*. Several PCTs highlighted the role played by Macmillan nursing teams in delivering education on end of life issues.

Although anecdotal evidence gained through consultation with Macmillan professionals suggests otherwise, it was encouraging that more than three-quarters (97) of PCTs told us that staff retention in community nursing was not an issue. This also means that it is especially worth investing in training.



Recommendation 5

All staff groups involved in end of life care, including non-registered staff, should receive training in end of life care as both a core component of initial training, and a part of continuing professional development. More should also be done to provide training opportunities, such as placements, for medical and nursing students. In addition, the Department of Health should give consideration to establishing a mechanism to facilitate the sharing of best practice for training in end of life care.

Conclusion and recommendations

This is a difficult time for the NHS, as it faces severe financial pressures. However there is a significant opportunity – by fully implementing the *End of Life Care Strategy* commitment on 24/7 community nursing – not only to improve the quality of end of life care, but also to make financial savings.

The responses to Macmillan’s survey indicated that there is a way to go in terms of PCTs ensuring access to 24/7 community nursing for all people at the end of life. Not prioritising 24/7 community nursing would be to the detriment of the NHS and to millions of people throughout England whose right it should be to die at home if they wish.

Macmillan believes that the following recommendations are necessary to ensure that everyone approaching the end of life is able to have that choice.



Availability of 24/7 community nursing

Recommendation 1

In order to achieve the quality and economic benefits associated with providing 24/7 community nursing for people at the end of life PCTs should implement the *End of Life Care Strategy* commitment on community nursing as a priority. A formal requirement for them to do so, for example through official recognition by the Care Quality Commission that this a key component of high quality end of life care, would assist in achieving this objective.

Recommendation 2

The Government should continue to monitor PCT spend on end of life care beyond 2010 to determine what is being spent explicitly on end of life care provision. This will also ensure that PCTs have an agreed definition of what they mean by end of life care.

Knowing people's wishes

Recommendation 3

PCTs should capture the wishes of people approaching the end of life and also ensure that they record whether these wishes were met, and people died in their preferred place. If it were necessary to ensure compliance in this area, one potential way could be to amend the vital signs indicator in the NHS operating framework on the recording of deaths at home so it reflects people's preferences and make it mandatory. It is also important to note that 'home', may be a care home in some cases.

Working together to deliver the best care

Recommendation 4

PCTs should see the development on an intergrated IT system as an essential part of a co-ordinated system of end of life care. Systems should be a platform for recording patient wishes and ensuring these are accessible by all care providers. In the meantime PCTs should adopt other systems to ensure effective communication between health, social care and voluntary service providers to ensure joined up care.

Skills to meet patients' wishes

Recommendation 5

All staff groups involved in end of life care, including non-registered staff, should receive training in end of life care as both a core component of initial training, and a part of continuing professional development. More should also be done to provide training opportunities, such as placements, for medical and nursing students. In addition, the Department of Health should give consideration to establishing a mechanism to facilitate the sharing of best practice for training in end of life care.

Appendix 1

Further information on PCT responses

Table 1 Government assistance and existing provision of 24/7 community nursing

	PCTs currently providing 24/7 community nursing	PCTs not currently providing 24/7 community nursing
Number of PCTs who thought further government assistance was required in the form of ring-fenced funding for end of life care	25 (36%)	24 (44%)
Number of PCTs who thought no further government assistance was required	12 (17%)	10 (18%)
No answer given	33 (47%)	21 (38%)
Total	70	55

Table 2 Government assistance – views of rural and urban PCTs

	Urban PCTs	Rural PCTs
Further government assistance required in the form of ring-fenced funding for end of life care	34 (42%)	15 (34%)
No further government assistance required	14 (17%)	9 (20%)
No answer given	33 (41%)	20 (45%)
Total	81	44

References

- 1 National Audit Office. *Results of Census of primary care trusts*. 2008.
- 2 This figure was calculated from the PCTs population estimates given on the FOI request forms.
- 3 Department of Health. *End of Life Care Strategy*. 2008.
- 4 Between 56 per cent and 74 per cent from different sources. Higginson I. *Priorities and preferences for end of life care*. 2003. Norfolk Health Overview and Scrutiny Committee. *How we Manage Death and Dying in Norfolk County and Waveney*. 2005.
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Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial help and push for better cancer care.

One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

**Questions about living with cancer?
Call the Macmillan Support Line free
on 0808 808 00 00
(Monday–Friday 9am–8pm).**

**Alternatively, visit macmillan.org.uk
Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
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