

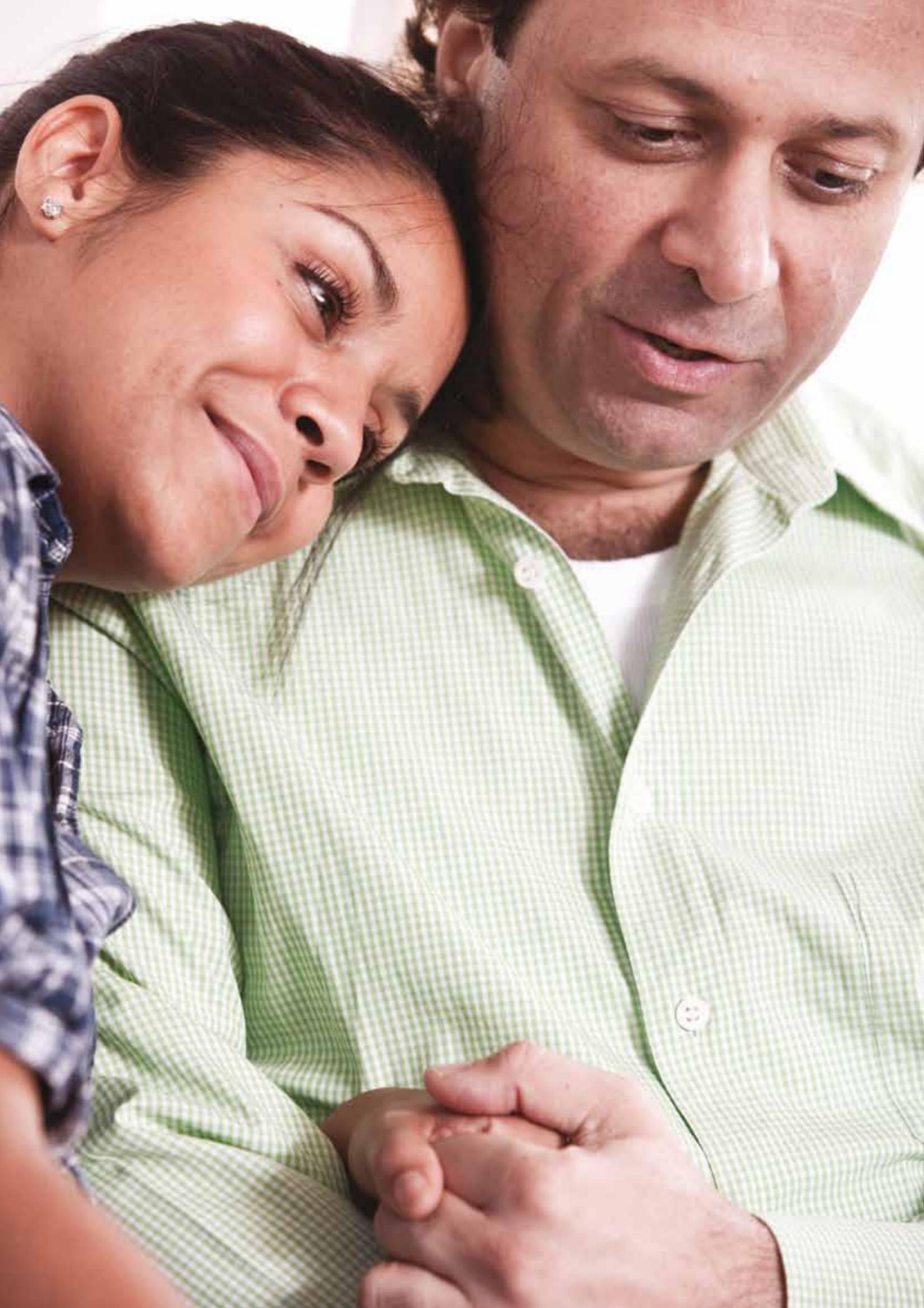
Dying out-of-hours 24/7 care at the end of life conference report

A joint conference hosted by The National Council for Palliative Care and Macmillan Cancer Support 3 March 2011

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Executive summary

There is wide acceptance that high-quality care can make a huge difference to patients nearing the end-of-life, and to their families, carers and friends. 24/7 care was recognised in the 2008 End of Life Care Strategy for England as a cornerstone of palliative and end-of-life care best practice and vital to enabling people to die at home if they wish to do so. However, access to end-of-life care outside of normal office hours is variable across the country.

Most people would prefer to die at home and not in a hospital – between 56% and 74% according to different sources¹. However, recent statistics show that only 25% of people diagnosed with cancer die at home². Yet survey evidence suggests that 73% of people with cancer said they would prefer to die at home (such as access to pain relief, round the clock care, and support for their family and carers) were addressed³.

In a recent survey by The National Council for Palliative Care of provider organisations, 57% of respondents reported there were gaps in 24/7 access to local specialist palliative care nursing. A survey undertaken by Macmillan Cancer Support in 2010 found that nearly half of all Primary Care Trusts (PCTs) do not provide 24/7 community nursing to people approaching the end-of-life⁴.

Quality palliative and end-of-life care is realised when strong networks exist between specialist palliative care providers, generalist health and social care providers in local communities, enabling health and social care organisations to work together to promote a good quality of life and a good death.

The importance of co-ordinated and integrated services for people with palliative and end-of-life care needs, whenever they need them day or night, cannot be underestimated. There is recognition that needs of people at the end-of-life and families and carers cannot be met in a standard 9–5 model of service delivery. The National Council for Palliative Care and Macmillan Cancer Support believe that people should experience the same high quality care both in-hours and during the out-of-hours period, which constitutes 76% of any given week. People with complex needs, such as cancer, depend heavily on out-of-hours services to provide advice, treatment and support to manage medical, emotional and practical problems as they emerge.

The *Dying out-of-hours – 24/7 care at the end of life* conference was designed to share learning and knowledge about best practice in delivering co-ordinated, 24/7 care for people nearing the end-of-life. This report is a summary of the discussions and presentations shared at the conference and makes recommendations as to how excellent end-of-life care can be achieved on the ground. The conference forms part of wider work of The National Council for Palliative Care and Macmillan Cancer Support to improve access to 24/7 end-of-life care. This is an agenda shared by the Government and many partner organisations. All presentations from the conference are available for download at ncpc.org.uk

Recommendations

The following recommendations have been developed by The National Council for Palliative Care and Macmillan Cancer Support, to reflect the perspectives shared and feedback provided at the *Dying out-of-hours – 24/7 care at the end of life* conference.

Recommendation 1 **Necessity of 24 /7 out-of-hours care and nursing**

Every patient who is defined as being at the end-of-life should have access to a person who is sufficiently trained, whatever time of day or night, to meet their need for urgent care, advice and treatment. 24/7 nursing care can significantly reduce emergency hospital admissions and enable patients to fulfil their wishes about where they would like to die. In the current financial climate, prevention of unnecessary and costly hospital admissions at the end-of-life is an even greater priority.

To both improve the quality and access of 24/7 care and ensure the best use of financial resources, the Palliative Care Funding Review and the National Institute for Clinical Excellence (NICE) end-of-life care Quality Standard should recognise the importance of access to local 24/7 care and nursing to enable people to die in their place of choice.

Recommendation 2 **Advance planning for patients nearing end-of-life**

Once patients have been identified as moving into the end-of-life phase, there should be a co-ordinated approach to the management of their care, including a documented care plan. Involving patients and their families and/or carers is crucial to high quality anticipatory care. This should include arrangements for meeting needs of pain management, symptom control, and where people want to die. It is imperative that people's wishes at the end-of-life are not ignored.

The NHS Outcomes Framework, Commissioning Outcomes Framework and the NICE end-of-life care Quality Standard should acknowledge people's preferred place of care and death by recommending the use of end-of-life care registers.

Anytime, anyplace, anywhere. You need help, there and then. Not when the office opens.

Recommendation 3 **Working together and communicating**

Patients are likely to experience the best standards of care and support if practitioners, providers and new commissioners work together to: establish the right models of care to meet patient needs; develop examples of good practice; ensure that they have in place a range of services to meet social as well as health care needs and establish guidance to promote understanding of roles and responsibilities between all those involved in end-of-life care.

New GP commissioners need to make sure that end-of-life care is prioritised, by ensuring that each practice has an end-of-life care register, and by implementing local systems to share information across health and social care providers, particularly for out-of-hours services.

Recommendation 4 **Importance of education, training and skill development in end-of-life care**

It is fundamental that there is adequate knowledge of how to care for someone at the end-of-life, and training in communication skills for any professional who cares for patients at or near the end-of-life. Regardless of where end-of-life care is provided, ensuring staff have appropriate support and training will be critical if high-quality care is to be consistently delivered.

To improve the provision of end-of-life care, new GP commissioners should ensure health and social care professionals receive training and support to have the conversation with their patients about their wishes towards the end of their lives, including their preferred place of care and where they wish to die.

Background

There is agreement that end-of-life care in the community must include services that are:

- responsive during out-of-hours periods;
- comprehensive and collaborative in approach; and
- meet people's preferences with regard to their care and their preferred place of death.

At present, services are not in place to enable this to occur.

The National Council for Palliative Care's (NCPC) recent survey of provider organisations revealed that access to home nursing and to pain relief were the most frequently identified priorities requiring service improvement in 24/7 end-of-life care⁵. The survey showed that most service gaps occur overnight with the best out-of-hours cover available during the weekend day time.

- 57% of respondents to the survey reported gaps in 24/7 access to local specialist palliative care nursing.
- 49% of respondents to the survey did not think that all people in their area had 24/7 access to specialist palliative care pain relief if needed.
- 25% of respondents to the survey currently providing some out-of-hours services thought they were likely to be affected negatively by revised funding arrangements over the next 18 months⁶.

Research undertaken by Macmillan Cancer Support in 2010 found that a full service of 24/7 community nursing was available for all end-of-life patients in only 56% of the Primary Care Trusts (PCTs) that responded to the survey⁷. Many of the remaining 44% of PCTs had made some progress in implementing the Department of Health's recommendations by providing a service to some end-of-life patients. However, 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 24/7 for one half of a county but not another.

The research clearly demonstrates that the availability and delivery of out-of-hours care and 24/7 community nursing for people at the end-of-life is variable across England. Where out-of-hours services are provided, at times it does not and cannot meet the need of patients, their families or carers, despite the quality and economic benefits associated with providing this service. Improving access to and quality of 24/7 care can prevent unnecessary and costly hospital admissions for people at the end-of-life, ensuring the best use of financial resources to meet patient need.

For the last few hours and days you want to be a loved one again and not have to play the role of their nurse.

Why is 24/7 care so important? What's all the fuss?

In opening the conference, Ciarán Devane, Chief Executive of Macmillan Cancer Support and Professor Sir Mike Richards, National Director for Cancer and End of Life Care, gave their perspectives on why 24/7 care is so important. This followed a very poignant account of the end-of-life care experience from Jane Campbell, who nursed and cared for her husband, who was diagnosed with Motor Neurone Disease.

Delegates also viewed a presentation prepared by Jo Black from the NCCP, which reflected thoughts and feelings of patients, carers and former carers with experiences of end-of-life care in wide range of conditions and care settings.

Professor Sir Mike Richards, drew the audience's attention to the fact 128 hours out of 168 hours each week fall outside standard business hours of 9–5. This translates to 76% of a week being defined as out-of-hours. Therefore, when the term 24/7 care is used, what does this mean?

Catherine Davies, Programme Director for the Independent Palliative Care Funding Review, launched by the Government in July 2010, talked about how the review team is developing its recommendations for a new palliative care funding mechanism which is fair, encourages community-based services and supports patient choice, in the context of significant demographic change. One of the key challenges in the current system that people have highlighted to the review team is the need for 24/7 access to community services.

'One night he was in particular discomfort. I called the local palliative care nursing number to get some advice. They were nice but didn't really give me any help and I felt totally lost. I knew that if I called an ambulance he probably wouldn't be able to have his last few days at home. At the hospital after several hours in cubicles, he was transferred to his own room, where he spent his last two days. It's not what he wanted. He'd always wanted to live by the sea and at home he could see it. In those last few days that was something he wasn't able to do.'

Alison cared for her father, Ted, at home but when his condition deteriorated he was taken to hospital.

'My dad was the sort of person who never wanted to go into hospital. He really wanted to be at home. When it comes to the end, nobody knows what to do, but the fact that my dad was at home meant we could get out the family photographs and go back over family holidays we'd had. Or we could play his favourite music to him. When he was conscious, he was able to watch football on TV. These are simple things that everyone takes for granted.'

Our family relied on the kindness of strangers; a flock of angels, in the form of nurses, GPs, hospice staff, Marie Curie and Macmillan nurses. They sat with dad in the dark of the night so we could have our sleep, and when they thought the end had come, they would come and wake us up at, even if it was three o'clock in the morning, so he didn't have to be there on his own at the end.'

24 hour care became a safety net for Tessa and her family in the final weeks of her dad's life.

Conference delegates spoke of how patients nearing end-of-life want:

- freedom from pain and control of symptoms;
- options for care both now and in the future and real choice about treatments and services;
- access to appropriate care regardless of where they live;
- someone who can answer their questions;
- support to discuss their concerns and feelings; and
- dignity and respect for culture, lifestyles and beliefs.

At the same time, families and carers want:

- help with their practical needs, home care and respite;
- access to information and support to discuss their concerns and feelings; and
- knowledge that the best possible care and advice is being provided.

The important role of care planning was raised by delegates, in particular, to legitimise key decisions before an emergency situation occurs. This was seen to be fundamental in achieving high-quality palliative and end-of-life care. Delegates also spoke of patients, families and carers wanting to have confidence in the information and care being provided, as well as having skilled practitioners who will communicate with them about what is happening. This theme was raised throughout the conference.

Making it happen? What does 24/7 care look like? Are there examples of good practice?

In the second session, clinical and policy experts from Macmillan Cancer Support discussed the current state of play and how to make the vision of full 24/7 care coverage a reality. Their evidence showed high-quality care at the end-of-life is realised when strong networks exist between specialist palliative care providers and skilled, generalist providers. This is achieved by working together to meet the needs of all people, be they medical, emotional, social, cultural and spiritual.

Adrienne Betteley, Palliative and End of Life Care Programme Manager from Macmillan Cancer Support, presented survey findings demonstrating that 73% of people with cancer said they would prefer to die at home if all their concerns about dying at home (such as access to pain relief, round the clock care, and support for their family and carers) were addressed⁸.

24/7 community nursing enables people to receive care and die in their preferred place. When people who are nearing the end of their life have expressed their choice to die at home, access to community nursing at any time of the day or night is essential to support them fulfil this choice. Where these wishes are not met, it can lead to traumatic experiences for patients, their families and carers.

The delivery of high-quality out-of-hours care in different settings is dependent on health and social care professionals sharing their knowledge and expertise across organisational boundaries. Jan Bolton, a Macmillan Social Care Coordinator from the Northamptonshire Centre for Oncology, described how her role facilitates integration between primary, secondary and tertiary care services to meet the needs of people nearing the end-of-life.

Northamptonshire Centre for Oncology

Jan Bolton, a Macmillan Social Care Coordinator from Northamptonshire Centre for Oncology gave a presentation on the importance of meeting the social care needs of cancer and palliative care patients and their carers.

Approximately 2,200 new patients are referred to the Northamptonshire Centre for Oncology each year. Jan presented activity data from the past three years which demonstrated the reduction of excess beds required and costs saved. With the cost of an oncology bed estimated at £321 per day, an estimated 752 bed days saved resulted in £241,392 saved over three years.

In her role as a Social Care Coordinator, Jan also facilitates hospital discharge, support preferred place of care discussions, and progress the delivery of end-of-life care to patients.

Eve Richardson, Chief Executive of The National Council for Palliative Care led the third session which focussed on small group work, discussing opinions and introducing examples of where 24/7 care is working at its best. A number of key themes can be drawn from the roundtable discussions. Groups identified the importance of:

- 24/7 access to and availability of community nursing and appropriate drugs and equipment;
- Quick responses to requests for help out-of-hours, with access to specialist palliative care advice when needed;
- Good anticipatory care and proactive planning, and efficient transfer of information to and from those working in hours and those working out-of-hours;
- Appropriate advice, information and support to patients about their condition, medication and future management needs; and
- Knowledge of the patient's preferred place of care and death.

The fourth session included presentations from Baroness Ilora Finlay of Llandaff, who is based at the Velindre Cancer Centre in Whitchurch, Wales and Julie Newby from St Benedict's Hospice in Sunderland.

Baroness Finlay focused on the responsibility for all levels of health professionals to care, when required, for people approaching the end-of-life. Effective communication is crucially important, between consultants, specialist nurses, general practitioners and other palliative care providers to ensure the needs of the patient are met.

For example, communication should outline the information necessary for a professional responding during out-of-hours periods who does not necessarily know the patient, to ensure that the patient's care plans and preferences were complied with, regardless of the time of day or week.

7 day Working in Wales

There are 7 day rosters that operate in the specialist palliative care services across Wales. The example from the Velindre Cancer Centre demonstrates that consultant-led clinical teams promoting good anticipatory care and communication can lead to exemplary palliative care. Such a co-ordinated model of care delivery is unlikely to form spontaneously where providers have limited history of working together. It is therefore important that those who have taken an interest in end-of-life care to focus on building ways of working to meet patient need.

Sunderland Palliative Care

Out-of-hours specialist palliative care service at St. Benedict's Hospice is a team of nurses with specialist knowledge and experience in palliative care. The team works closely with GPs, district nurses, specialist nurses of the hospice and acute hospital and the hospice multidisciplinary team. The team endeavour to prevent the need for admission into acute care settings as well as facilitation of rapid discharge home from hospital/hospice. They provide advice, support, care and treatment to enable patients to be looked after in their own home rather than in hospital.

The out-of-hours specialist palliative care service can be contacted every night between 4pm – 9.15am. Visits may be planned in advance or patients/carers can contact the team directly in the event of a crisis during the evening/night. The out-of-hours palliative care service team can often resolve problems over the telephone, putting patients/carers at ease and relieving any worries.

Can 24/7 care be tailored to meet local needs?

The fifth and final session focussed on tailoring care to local needs. Delegates heard from Dr Julian Abel on co-ordinating care and locality registers in South West England and from Samantha Millbank from Healthcare at Home, focussing on experiences in Birmingham. A locality register is a facility that enables the key information about, and patients preferences for care at the end-of-life to be recorded and accessed by a range of services⁹.

Patients should be involved in discussions about their care and agree with the care plan developed. In particular, their response to their illness and the management of their symptoms might influence future decisions about their care. For this reason, patients should have regular opportunities to be involved in reviewing and adjusting their care plan as their circumstances change. This was especially relevant to cardiopulmonary resuscitation (CPR) guidelines and policies – the appropriateness of a patient's status can and should be reviewed on multiple occasions, and should be easily accessible to healthcare professionals – be they GPs, paramedics or specialist nurses.

Samantha Millbank from Healthcare at Home spoke of widening the access to community nursing. Samantha presented examples from Healthcare at Home's work with Birmingham East and North PCT where more patients are dying in the place of their choice, with fewer patients dying in hospital. This in turn reduced the cost of services for the dying and reduced the number of unplanned admissions in the last year of life.

'Everybody provided phone numbers and instructions should we need any kind of help at anytime, and I will be forever grateful.'

Where to from here?

The *Dying out-of-hours – 24/7 care at the end of life* conference acknowledged there are clearly some areas of good practice, however there remain significant gaps that must be addressed urgently in order to achieve full provision of 24/7 care and 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, healthcare providers and new GP commissioners need to look at ways to ensure the necessary services are in place. The 2008 End of Life Care Strategy for England made clear recommendations on the importance of 24/7 care services, to enable people to continue to be cared for and die in the place of their choice.

The Palliative Care Funding Review presents an opportunity for the NHS, commissioners, and all levels of Government to work together to vastly improve the experiences and care of people nearing the end of their lives. The interim report from the Palliative Care Funding Review team released in December 2010 has called for immediate action to address the gaps in 24/7 care services.

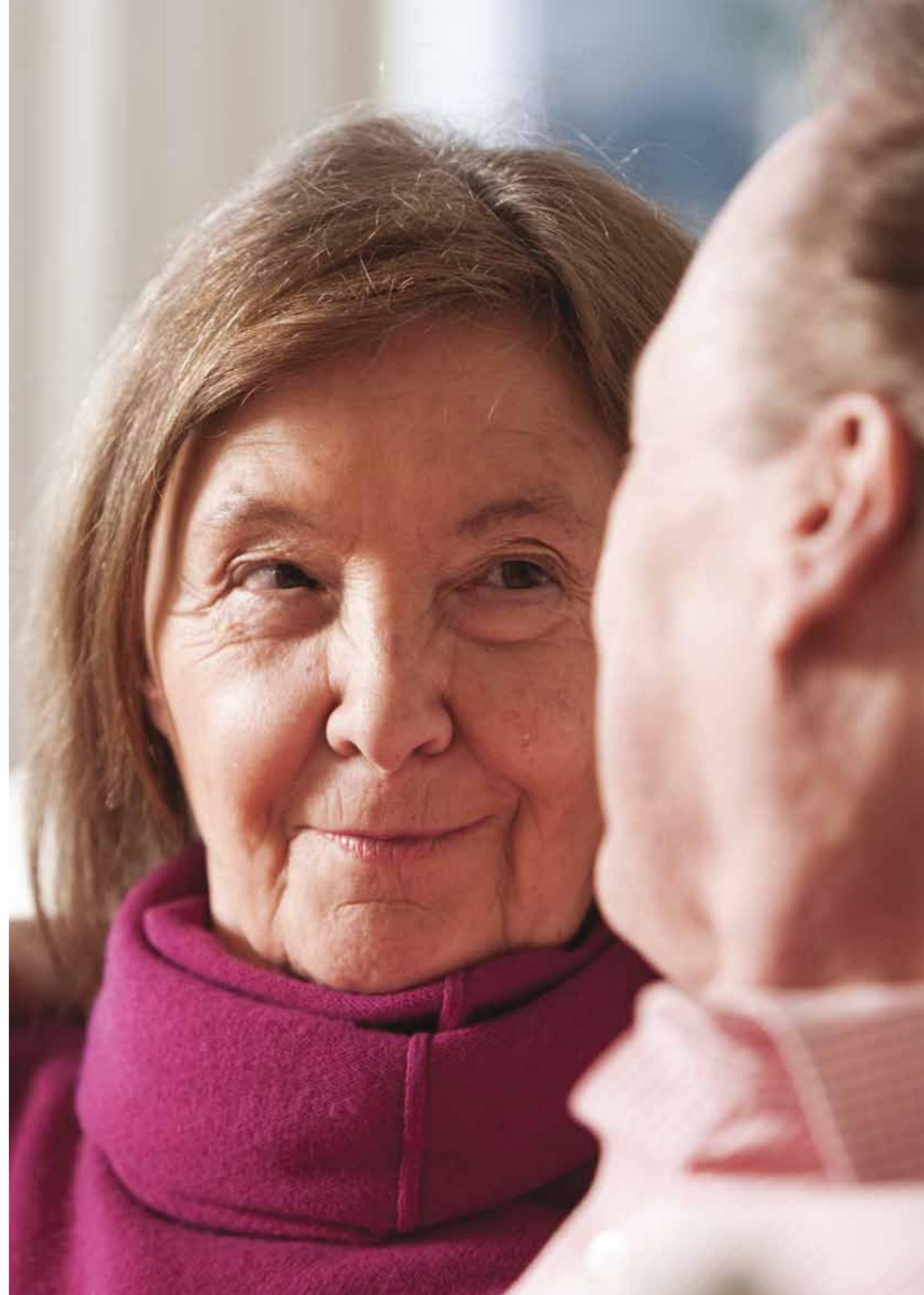
The review of the current funding mechanisms for dedicated palliative care for adults and children currently being undertaken will consider a per-patient funding system, based on an NHS tariff to meet statutory responsibilities. It will also make recommendations on a funding mechanism which encourages community-based services and supports patient choice. In addition, the NICE will review the Quality Standard for end-of-life care in 2011. This consultation presents an opportunity to provide evidence on best practice end-of-life care models.

Further information on the Palliative Care Funding Review can be found at palliativecarefunding.org.uk

'I was able to contact them any time of the day or night any day of the week.'

References

- 1 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.
- 2 National Audit Office. *End of Life Care*. 2008.
- 3 Taken from Macmillan Cancer Support online survey of 1,019 UK adults living with cancer. February 2010.
- 4 Macmillan Cancer Support. *Always There? The impact of the End of Life Care Strategy on 24/7 Community Nursing in England*. August 2010.
- 5 Dying out of hours: summary results from National Council for Palliative Care's survey on out-of-hours care. March 2011.
- 6 Dying out of hours: summary results from National Council for Palliative Care's survey on out-of-hours care. March 2011.
- 7 Macmillan Cancer Support. *Always There? The impact of the End of Life Care Strategy on 24/7 Community Nursing in England*. August 2010.
- 8 Taken from Macmillan Cancer Support online survey of 1,019 UK adults living with cancer. February 2010.
- 9 End of Life Locality Registers evaluation. Ipsos MORI. February 2011.



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.

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end-of-life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end-of-life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end-of-life care for all.

NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.

For more information visit ncpc.org.uk and dyingmatters.org

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Call the Macmillan Support Line free on
0808 808 00 00 (Monday–Friday 9am–8pm)

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Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.



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