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## National End of Life Care Programme Team Briefing

### A roundup of what's happening at the National End of Life Care Programme

#### Liverpool Care Pathway

We have had a number of inquiries from concerned staff about the Liverpool Care Pathway (LCP) following recent media coverage.

We want to emphasise that the LCP is a tried and tested approach that has improved, and continues to improve, the care of patients in their last hours and days. However, the LCP must be followed correctly. Training, skilled assessment, regular review and communication with the families are all essential.

If you follow the pathway LCP will help you and your colleagues to ensure dying patients have comfortable and good deaths.

Having said that, diagnosing dying has never been, and probably never will be, an exact science. For that reason reassessment of the patient at least every four hours is vital as is ongoing training. And staff should ensure the relatives' leaflet, written by the Marie Curie Palliative Care Institute Liverpool team, is made available. The institute's leaflet and more information is available at [www.liv.ac.uk/mcpil](http://www.liv.ac.uk/mcpil)

#### Training DVD

We now have a number of copies of the DVD shown at the competences and principles launch events in July. To obtain a copy, to be used for training purposes only, please phone our main office on 0116 222 5103.

#### Welcome to Katie and Margaret

Welcome to two new members of the End of Life Care Programme. Katie Lindsey (pictured) has just been appointed our Communication Skills Project Manager. Katie, who will be working with the 12 test sites piloting the end of life care communication skills training over the coming year, was previously responsible for managing cancer screening programmes and has a background in physiotherapy and public health.



Margaret Holloway, who has been appointed as our Social Care Lead, will work two days a week for the programme while continuing in her role as Professor of Social Work at the University of Hull. Margaret has an extensive background in end of life care, death and bereavement issues (see page 4).

#### Pathway plans

Work is currently under way in collaboration with the NHS Heart Improvement team on adapting the end of life care pathway to cover those with heart disease. The plans are to publish the pathway in March 2010. If you would like to get involved or share your examples of good practice please contact [information@eolc.nhs.uk](mailto:information@eolc.nhs.uk)

#### Dying Matters

The national coalition set up as part of the End of Life Care Strategy to raise public awareness about death and dying has a new name – the Dying Matters Coalition – and a new slogan – 'Let's talk about it'.

The coalition, which now boasts over 1,000 member organisations, has also appointed a director. Hilary Fisher was previously director of End of Child Poverty.

The new coalition has already been in action, working with NHS North East on England's first-ever charter for end of life care (see p2 for more details). It has also commissioned a survey into public awareness and attitudes, results of which will be released shortly.

The coalition's next forum meeting will be on 15 March 2010 when it will be launching Dying Matters National Awareness Week.

For more details, see the new website [www.dyingmatters.org](http://www.dyingmatters.org)



**Claire Henry**  
National Programme Director  
October 2009



## First end of life care charter for North East

NHS North East has launched England's first-ever charter on end of life care as part of its attempt to involve the public in a wide-ranging discussion about death and dying.

The launch follows national research that reveals that north easterners are the least comfortable about discussing death and the least likely to want to know if they are dying.

The charter, entitled *A Good Death*, sets out proposals for the kind of care and support which people who are dying, their families and carers, can expect. It includes a pledge that end of life care should take place where the individual chooses. 'If the choice is at home then every effort should be made to support this,' it adds. Once agreed, it will guide those who organise end of life care support.

The region has worked with partners across health, social care and voluntary sectors, including patients and carers, to produce the charter. A public consultation on the charter will run until December.

The consultation will centre on a questionnaire and research will also be carried out in towns and cities across the region.

The feedback will help NHS North East and other partners plan work around end of life care. The findings should be available in late January 2010.

A yet-to-be published national survey of attitudes by the Dying Matters Coalition showed that fewer than half of north easterners wanted to be told if they were dying (compared to 78% nationally) and 63% had not discussed how they would like to die. Around half said they would prefer to die at home with only 9% opting to die in hospital and another 4% in care or nursing homes.

For more information on the charter and the consultation, see [www.agooddeath.co.uk](http://www.agooddeath.co.uk)

## New learning disabilities service

A new service has been set up to offer advice and information to anyone – family or professionals – concerned about end of life and bereavement care for people with a learning disability.

Enfold c.i.c (End of life information for people with learning disabilities) is a social enterprise company that was launched in May 2009 and builds on the work of the Macmillan Network Information and Support service, whose funding ended earlier this year.

The service offers help via phone or email and aims to direct callers to relevant services and sources of information. 'We deal with a wide range of issues,' says Director Linda McEnhill, 'from explaining a cancer diagnosis to consent to treatment, caring for someone with a learning disability when a family member is dying, how to assess symptoms and where to find appropriate palliative care services.'

The service also offers consultancy support and training courses ranging from 1-5 days in length. This training is accessed by learning disability and palliative care organisations as well as mainstream cancer services and nursing homes.

For more information phone 01223 573 173 (mobile 07986 377 609) or email [info@enfold.org.uk](mailto:info@enfold.org.uk). Training and consultancy inquiries can also be made by phone or by emailing [training@enfold.org.uk](mailto:training@enfold.org.uk)

## Out of the darkness and into the light

Jason Isaacs, who played wizard Lucius Malfoy in the Harry Potter films, is the narrator for a new DVD aimed at improving end of life care provision in extra care housing.

Jason lent his voice to a 10-minute DVD which complements a resource pack produced by the National End of Life Care Programme and Housing 21. It includes footage of extra care residents and their relatives talking about their future wishes and care preferences.

The pack, which was part-funded by Skills for Care, has been available on both Housing 21 and the programme's website since July. For more on the pack and the DVD go to [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk) or [www.housing21.co.uk](http://www.housing21.co.uk)



## Hospices to receive £40 million to improve physical environment

The Department of Health is making £40 million available in 2010-11 to fund improvements to the physical environment for adult voluntary sector hospices in England as part of the End of Life Care Strategy. The minimum grant will be £25,000 with no upper limit though large grants are likely to be the exception. At the end of the first year of the

programme hospices should be able to point to tangible physical improvements in their environments and show how these contribute to improved care provision for patients, their families and carers.

Deadline for applications is Friday 8 January 2010. For more information see [tinyurl.com/yfz5ym6](http://tinyurl.com/yfz5ym6)

## Cumbria's workshops aim to spread the word

NHS Cumbria is running a series of workshops for the general public aimed at helping participants initiate discussions about planning and preparing for death as a part of life.

The workshops, which began earlier this month and continue into November, are part of a wider programme, entitled Cumbria Conversations for Life, which seeks to raise public awareness about end of life care in general as well as encouraging early conversations about the choices to be considered.

The programme, which is pilot funded by Cumbria PCT, has been led by an interdisciplinary steering group which includes representatives from the PCT, county council, local hospices and Age Concern. It is supported by a website and an introductory 10-minute film which tells stories of how different local families have held or avoided conversations with loved ones.

The workshops represent a vital stage in the process of raising awareness, says Project Lead Mary Matthiesen. 'The fact is that we will all die and we need to talk about how we want that to be if we are to get the care we hope for,' she says. 'The statistics show that at the moment that doesn't always happen and that has huge costs, both emotionally as well as financially.'

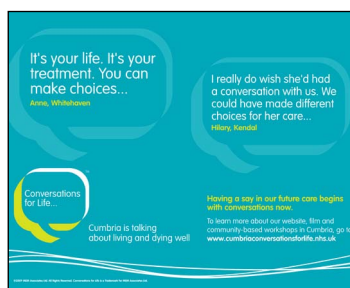
The workshops, which last three and a half hours, are practical and interactive and help people explore and discuss what they want for their future care. All participants receive handouts and a personalised action plan at the end of the session.

Feedback so far has been positive, says Mary, with many participants saying it is a relief to do something about this issue rather than just think about it. As one participant put it: 'It's my life, so it can be my death too.'

It is hoped to incorporate the film and other resources developed by the programme into staff induction courses as well as working in a more concerted way with community groups and associations. There are also plans for the programme to set up as a social enterprise in order to disseminate the messages via partnerships to a wider audience within Cumbria and beyond.

Future workshops will be held at Rosehill Barn, Whitehaven (Wed 4 Nov, 5pm - 8.30pm); Helena Thompson Museum, Workington (Thurs 12 Nov, 5pm - 8.30pm); Millom Network Centre, Millom (Sat 14 Nov, 10am - 1.30pm); Evergreen Hall Community Centre, Penrith (Thurs 19 Nov, 5pm - 8.30pm); The Eco Centre, Cockermouth (Sat 21 Nov, 10am - 1.30pm).

Anyone wishing to attend should register at [www.cumbriaconversationsforlife.nhs.uk/workshops](http://www.cumbriaconversationsforlife.nhs.uk/workshops) or call 01539 722323 or email [events@cumbriaconversationsforlife.nhs.uk](mailto:events@cumbriaconversationsforlife.nhs.uk)



## Dementia report points to unnecessary hospitalisation

A new report examining the care of people with advanced dementia in the London borough of Haringey suggests they are often rushed to hospital unnecessarily – to the detriment of their own health and quality of life.

*End of Life Care for People with Dementia*, produced by Marie Curie Cancer Care in partnership with a number of local and national bodies, says that hospital is often seen as the only option in times of medical or social crisis. But the authors' analysis suggests these admissions are not cost effective and often unsuitable.

Acute hospital staff appear not to have sufficient training and skills to provide good end of life care to people with dementia and carers often have to provide basic nursing care.

On the basis of a detailed review of nine cases, the study calculates average health and social care costs for someone with dementia in the last six months of life are £25,000 with hospital admissions responsible for 18% of this.

It calls for a holistic dementia care pathway in the borough. But it adds that small changes to local health and social care services could significantly improve end of life care for people with advanced dementia as well as providing greater value for money. A fuller report will appear in the next newsletter.

For more information see: [www.mariecurie.org.uk/dementiaproject2009](http://www.mariecurie.org.uk/dementiaproject2009)



The National End of Life Care Strategy for England, published 18 months ago, emphasised the important role social care services and their staff play in helping to ensure those nearing the end of their life get the care and support they need. Below we explore the strategy and what it means for social care, starting with an examination of some of the new initiatives that can help social care staff play their full part in good end of life care.

## Bridging one great divide as life nears its end

In a society where for generations most deaths have taken place in hospital, it is no surprise that social care services left end of life care issues to health care.

Publication of the first National End of Life Care Strategy for England in 2008 sought to challenge this and make end of life care everybody's business.

In his foreword, the then-health secretary, Alan Johnson, emphasised the need to bridge the Great Divide between health and social care: 'We know that although some people receive excellent care at the end of life, many do not. One of the fundamental problems is that services are not always joined up and as a result communication between staff and agencies can break down.'

Two key areas for adult social care departments are commissioning services for those nearing the end of their life and training the staff whose work touches those individuals and their carers.

Local authorities, working in partnership with primary care trusts, should look to build into their contracting arrangements with independent sector care homes some expectations around quality end of life care.

The National End of Life Care Programme (NEoLCP) commissioned an independent research project on the provision of end of life care in nursing homes. The project team reported back earlier this year.

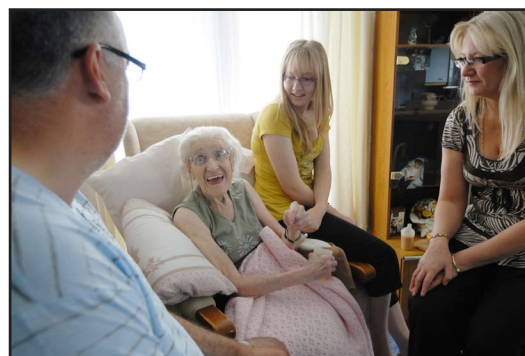
While finding many areas of good practice, it identified issues which arose from the isolation of care homes, pointing out the role end of life care facilitators could play.

A summary of the report that the programme's Care Homes Forum sent out to members said: 'Most nursing homes have a clear vision about key priorities for improving end of life care. Help from key personnel in local health and social care communities is critical in achieving these.'

In commissioning services, local authorities and primary care trusts should ensure adequate arrangements are in place for medical and nursing support – and for 'the provision and accessibility of training for care home staff... to be examined urgently'.

Sheila Joseph, the programme's care homes lead, said: 'With some 17% of deaths in England occurring in care homes, it is imperative that local authorities and PCTs try to engage with care homes and provide support around training.'

'In commissioning places, local authorities should be asking searching questions about end of life care arrangements but in return they should make sure they have an end of life care lead who can communicate and support care homes which too often feel isolated.'



Respect for the individual's wishes are at the heart of good end of life care

Staff development was another key priority identified by the strategy and the NEoLCP is taking forward practical approaches to support staff whose work involves any contact with those approaching the end of their lives.

The national strategy says this figure could be up to 2.5 million people across health, social care and care homes. It called for 'a cultural shift in attitudes and behaviour to end of life care in the workplace'.

In June the national programme - in conjunction with the Department of Health, Skills for Care and Skills for Health - published core competences aimed at both social and health care staff.

The core competences are seen as a common foundation for staff and employers to build on in care homes, extra care and sheltered housing, domiciliary care – as well as NHS facilities and hospices. Areas covered include communication skills, assessment and care planning, advance care planning, symptom management and comfort and wellbeing.

Valerie Anderson, Care Services Manager at Housing 21's extra care housing scheme in Gateshead, Callendar Court, says: 'We are now looking at how to develop individual end of life care plans with people so they can have their wishes met. Having appropriately trained staff is an important part of this work and the competences help us put the individual's needs first. They were very helpful in helping us to identify core areas for development.'

The documents include a set of principles which

should underpin the implementation of those competences, all of which emphasise respect for the person's individual wishes – for example, around spirituality – and good team working.

Equally importantly for care homes and domiciliary care agencies with high staff turnover and who find it difficult to release staff for long training sessions, January sees the launch of a suite of e-learning resources developed by e-learning for health.

The e-learning resources will be available in bite-

size, 20-minute segments to encourage staff and employers to improve their skills and knowledge.

The final strand of the current workforce development programme, a package aimed at helping staff develop and improve those all-important communication skills, will be published later in 2010.

With support, social care now has the chance to help implement and deliver better quality of care in an area that will one day affect us all.

## Changing attitudes is key, says new Social Care Lead

### Social care must recognise that quality of life is also about quality of dying, says Margaret Holloway

The National End of Life Care Programme has its first Social Care Lead – and Professor Margaret Holloway (pictured) is eager to help transform the culture around death and dying in adult care.



Professor Holloway, who will work two days a week for the programme while continuing in her role as Professor of Social Work at the University of Hull, has an extensive background in end of life care, death and bereavement issues and is particularly interested in spirituality and cross-cultural issues.

Of her new challenge, she says: 'In terms of social care and end of life care the key challenge is to change attitudes. People need to see that planning for this final phase of life is not ageist or morbid but the opposite – it is empowering. The young social worker coming in to do the assessment might not be thinking about death but the 89-year-old service user will be.'

Social care has to recognise that quality of life is also about quality of dying. It is, she suggests, as important to the adult care services agenda as child protection is to children's and families' services. That inevitably raises the perennial issue of the relationship between health and social care.

'Our enduring problem in delivering personal social services is getting health and social care to work together. I never worked in palliative care social work but I was a hospital and community social worker and my experience taught me that we need to mainstream thinking about end of life care into social care. Change (in an older person's health) can happen very fast and we need to prepare for that.

'It is part of the social care staff member's job when working with an older person to talk about choice, independence and quality of life. I call it the

dying phase of life which is not the same as those who are dying. Medical advances have raced ahead and other case services have not kept up.'

One way of improving that, she suggests, would be research into the pathways travelled by those who are nearing the end of their life. 'I am not talking about clinical pathways but the pathway across health and social care. It is quite likely that even people being cared for at home with a live-in carer will have hospital stays at some point. It is more complicated than people just dying at home or in hospital – there are "homeliness" factors which could be taken into other settings and social care has a big role to play in that.

'There are lots of initiatives through the modernisation programme for pooled budgets to encourage working together. That has been happening in other areas but not ends of life care so the potential is there. It is about finding the connections between health and social care when people get to this stage of life.'

The 'historically fraught' relationship between GPs and social workers also needs to change. 'They are in this together to support older people in the community,' she says.

The core competences and principles document which the programme launched in the summer should help achieve Professor Holloway's wish for all social care staff to have a basic grounding in end of life care. That, she suggests, could be backed up by a skills audit. She would also like to see the excellent social work services based in hospices working more extensively with community social care services.

A large part of her new role, she acknowledges, will be working to improve end of life care planning and provision in care homes. While emphasising that care home staff must not feel such sensitive responsibilities are just 'dumped' on them alone, she says local authorities should include end of life care planning arrangements in their contracts with homes. It's all just part of that cultural revolution which Professor Holloway seeks to encourage.

*"Our enduring problem in delivering personal social services is getting health and social care to work together"*

## Lancashire's seamless service provides home comforts

### A new service working across health and social care has enabled 70% of those referred to die at home

Lancashire County Council has linked with East Lancashire PCT to provide a seamless service to all patients with malignant or non-malignant disease who wish to die at home.

The service, which has been operating since September 2005, aims to provide the care and treatment needed to ensure that those who want to can remain at home. Since it began 70% of those referred have died at home and only 13% in hospital.



Rossendale Hospice, which is central to the new initiative

Hospice@Home care service is designed to meet the health and social care needs of palliative care patients. As their needs change the level of care progresses from social to a combination of social and nursing, leading to enhanced palliative nursing care. Referrals are accepted where death is

expected in the next six months.

A service level agreement (SLA) with social services funds the social element of the service with additional contributions from the PCT and the hospice. Care is available 24 hours a day with the core service operating between 8am – 8pm. Additional care, including night support, is arranged on an individual basis.

There have been occasional problems because funding has to come from different budgets. For instance, late referrals necessitating end of life care do not meet the criteria for the social care aspect of the service.

The service has received excellent evaluations from both carers and professionals. It has also led to better relations between staff in the different organisations and improved patient care.

It also seems to be achieving its principal aim of allowing people to choose where they die. From October 2005 to May 2007 132 patients were referred, of which 70% died at home, 13% in hospital, 14% in hospice or residential care while 3% died before care was implemented.

#### Contact details

Further information from Victoria Beard at [vicki.beard@rossendalehospice.org](mailto:vicki.beard@rossendalehospice.org)

## Foundation degrees offer social care staff new opportunities

### A new foundation degree will provide a boost for thousands of social care staff

Support staff working in social care settings in the community and residential care are to be given the educational backing needed to care for people at the end of their life.

Opening up training and education to hundreds of thousands of support staff in a variety of settings - from hospices to care homes - will both improve the care of those at the end of their lives and boost the professional pride and confidence of the workforce.

That is where foundation degrees in palliative and end of life care services come in.

Piloting of a new foundation degree approach which fdf (Foundation Degree Forward) has developed with Help the Hospices is now underway in Somerset, Suffolk and Cheshire.

The Leicestershire and Rutland Hospice (LOROS) has already worked with fdf to develop with the University of Northampton a foundation degree in palliative and supportive care.

It is based around delivering on the principles for quality outlined in the 2008 National End of Life Care Strategy.

The LOROS foundation degree's modules include the principles and practice of palliative care, inter-professional learning, health and wellbeing, ethical and spiritual perspectives, symptom management, evidence-based learning and responding to loss. A new module on communication skills is just being validated.

Sharon de Caestecker, Head of Education at LOROS, said: 'The real strengths of this type of degree are that it encourages students to reflect on their practice and ask why they and their organisations have always done things in a certain way.'

'Because it draws people from such a range of care settings it also helps break down barriers and the large element of work-based learning and assessment means they can really relate what they learn to their work.'

## How Luton is raising the bar and widening choice

### An ambitious initiative to empower district nurses to provide high quality end of life care is starting to reap dividends. Andrew Cole reports

Everyone agrees that no matter how much specialist care input you have, the real day to day burden of palliative care will fall on generalist staff such as district nurses, GPs and social care staff.

The problem of course, is that these groups already have to balance busy workloads and competing priorities and are therefore not always in the best position to deliver the key recommendations within the end of life care strategy.

One trust that has tackled this issue is NHS Luton community services which, through its Raising the Bar initiative, is placing its district nursing teams at the very heart of its end of life care programme and aiming to equip them with the skills to ensure all patients can be guaranteed the same standards of care. The aim is to increase the proportion of total home deaths to 30% by 2011/12.

Eighteen months after its launch that approach is beginning to bear fruit with more people being given a choice of where they should die and some evidence that more are dying at home. But as the project leaders are the first to admit, there is still a long way to go.

Jackie Tritton has been the Palliative Care Lead Nurse with NHS Luton community services and the Luton and Dunstable Foundation Trust for the past five years. She says the integrated specialist palliative care service has always worked closely with the generalist services, providing good collaboration between hospital and the community.

Yet despite these strong foundations an audit of district nursing in the area two years ago found its palliative care was patchy. There was a big variation in the number of palliative patients on district nurses' caseloads as well as in the ways they were supporting these patients.

Raising the Bar was launched in 2008 with the specific aim of establishing minimum standards for palliative care patients across all the trust's 10 district nursing teams. It also stated explicitly that district nurses should be palliative care patients' key workers. 'Our overall aim was to empower district nurses who saw palliative care as their bread and butter but wanted the knowledge and time to support their patients,' says Jackie.

A small working group was set up to develop a palliative/end of life care pathway charting each stage of the patient's journey and ensuring that all referrals were made through the discharge liaison team. In addition palliative care response criteria were agreed based on a 'traffic light' system where red indicated a crisis and green meant the patient was stable.

The roles and responsibilities of the 24-hour district nurse service and specialist palliative care 7-day team service were also agreed.

Equally importantly, an intensive programme of education and training was launched to give all generalist staff the knowledge and skills required. All staff – including support staff – now receive a one-day communications skills session. Meanwhile community and senior clinicians are undertaking a palliative care education programme, which includes verification of death, DNAR and syringe driver competencies as well as advanced communication skills.

For Marie Savage, Macmillan Lecturer Practitioner in Cancer and Palliative Care, who has overseen the education programme, one of the specialist palliative team's key roles is to support and empower the district nurses and other generalist staff who will inevitably take on the bulk of day-to-day palliative care work.

'We need to make sure that as specialist care services we stay specialist,' she notes, 'because we simply can't take on the majority of patients.'

At the same time specialist services in Luton have led a number of initiatives to support the generalist teams. They include the rapid response services and palliative care clinics (held in locality health centres) to help patients earlier in their disease pathway.

Eighteen months after the new approach was instituted Jackie detects some encouraging signs of success, including the fact that more patients now have a genuine choice about where they will die. But much more still needs to be done.

'We've done the launching and talked the talk,' she says. 'But now we've got to walk the walk. It's a matter of sustaining the momentum. For instance, according to the pathway every patient in the community should be on the LCP when appropriate. But we know that still isn't happening routinely.'

Another indicator of success - the number of deaths at home - also offers mixed messages. Encouragingly, it shows the proportion of home deaths rose from 16% in 2006 to 20% in 2008. However, in the first six months of 2009 those figures appear to reverse, with only 18.8% dying at home and an increased proportion dying in hospital.



Raising the Bar: specialist and generalist services are working in partnership



Jackie points out that over half of the palliative care patients under the care of the district nurse were able to die at home. However, there are still many people dying in hospital who have not previously been identified as having palliative care needs.

But she also points to a lack of investment in primary care over a number of years. 'Although nurses are better educated and there is greater awareness, there have been some staff vacancies in the last year and that does not help. We know what we need to deliver this [strategy]. The question is: have we got the resources to deliver what we want?'

Another challenge is ensuring the new service reaches all parts of Luton's very mixed community, which according to latest projections is likely to have a majority from ethnic minorities by 2013. So far, says Jackie, the palliative care service has been more successful in reaching the white population.

With this in mind a palliative care consultant is planning to run a clinic in a mosque and it is hoped to appoint a palliative support worker from an ethnic minority background in the near future.

Jackie is proud of the Raising the Bar initiative, which has ensured the specialist and generalist services now work in partnership. 'It is beginning to have an impact,' she says, 'with patients and carers able to discuss their preferred wishes and know what services are available. And the community nursing teams are more confident in raising and communicating these issues.'



#### Contact details

The NHS Luton Community Services Cancer and Palliative Care Team is contactable on 01582 560206 or email Jackie Tritton on [jtritton@nhs.net](mailto:jtritton@nhs.net)

## An education strategy for South East London

### The new education strategy for end of life care in South East London is one of the most ambitious ever launched, affecting most health and social care staff

Education and training lie at the heart of good end of life care – which explains why so much is riding on a new education strategy for South East London, which was officially launched this month.

The strategy aims to ensure that SE London's health and social care workforce have access to a full range of end of life care training and education. Equally importantly, it wants to encourage commissioners to procure this education 'in a systematic and strategic manner'.

Given the number of health and social care staff who have some dealings with dying adult patients, there can be little doubt this represents one of the most ambitious education strategies ever launched in the capital.

The strategy is the result of collaboration between two organisations, the SE London Cancer Network and the Marie Curie Delivering Choice Programme. One of their first tasks when they began to develop the strategy last year was to establish how many staff required some form of end of life care training and what their specific needs were.

In line with the national End of Life Care Strategy, potential recipients of training were divided into three categories – group A who are the specialists, group B generalists who have frequent experience of providing end of life care and group C generalists who have only infrequent experience.

What emerged was something of a revelation. The numbers in group A were surprisingly small – just 214 whole time equivalents – but the combined numbers for groups B and C amounted to more than 67,000 staff across all sectors. That, according to Kath McDonnell, Palliative and End of Life Care Programme Manager with the SE London Cancer

Network, represents at least 90% of the entire health and social care workforce involved with adult care.

At the same time a scoping exercise by the Marie Curie programme indicated that many staff felt unconfident in dealing with end of life care issues because of gaps in their knowledge.

Their concerns included how and when to discuss with a patient their needs and preferences, how to recognise when a patient is entering the end of life phase, and what to do in relation to cultural, social and spiritual care.

And yet it also emerged that SE London is already offering a large number of end of life care courses. A mapping exercise last year revealed that in 2007-8 organisations in the area put on no fewer than 164 separate educational courses.

They ranged from short sessions within induction programmes to fully accredited academic modules and courses but the problem, says Kath, was that they did not necessarily reach the people who most needed them.

'The issue isn't so much about courses not being available, it's more about people who need to know it's available finding out about it. It's about signposting. Also employers and individuals in health and social care recognising the need for education and facilitating access to it.'

In part this is a matter of tailoring the training more closely to the needs of the workforce. The strategy notes, for example, that without the right type of training many staff can feel anxious about death and begin to have negative attitudes towards caring for the dying. For this reason

*'Without the right training many staff have negative attitudes towards caring for the dying'*





Kath McDonnell speaking at the recent launch of the strategy. Also pictured (left to right) are: Janet Shepard, Deputy Chief Nurse, NHS London; Dr Rob George, Palliative Care Consultant at Guy's & St Thomas' Hospital; Isabel Quinn, National End of Life Care Programme Manager and Vicky Robinson, Palliative Care Nurse Consultant, Guy's & St Thomas' Hospital.

successful training must not only focus on meeting knowledge and skills deficits but providing 'transformational' learning opportunities to change attitudes, beliefs and behaviour.

But given the huge scale of the potential demand, providers will also need to be creative in how they deliver this training. The strategy suggests making use of a combination of face-to-face sessions and e-learning as well as 'training the trainer' programmes. Equally vital is the need for a co-ordinated strategy across the sector to ensure the full extent of the need is identified and resources put to their very best use.

Publication of the SE London strategy is, of course, only the first part of the exercise. The real challenge is to ensure its successful implementation. 'We are really keen to build on momentum after the launch of the strategy and will be setting up an Implementation Board to turn recommendations into actions,' says Caroline Gurney, National Programme Manager for the Delivering Choice Programme. 'We aim to publish a more detailed timetable and action plan later this year.'

Some of the challenges now facing the strategy's authors are very practical and immediate. Last year's mapping exercise highlighted a number of barriers to making the most of training including funding problems, lack of protected time to attend courses and poor attendance.

Kath says the strategy aims to counter some of these problems by, for example, embedding the funding needed for education – especially for independent sector programmes – within commissioning plans.

But she accepts that providers and commissioners are so pressured these days that training can become a lower priority. 'This is a strategy amongst many so we need to promote it in a way that catches the eye. It's not mandatory which

means we have to try and enthuse everybody to implement it.'

And of course the current financial climate makes this a tough time to launch any new initiative. But Kath remains optimistic. Local PCTs have just been drawing up their end of life care strategies, she points out, and education and training are central to their successful implementation.

'We're trying to make sure we engage with as many key people as possible. We are also in direct contact with NHS London, which launched its own workforce strategy last year and we see this strategy as complementing that.'

But perhaps the strongest argument of all is that properly trained and educated staff will deliver top quality end of life care. 'I do believe that education and training is fundamental to good end of life care,' says Kath. 'I think if full implementation of the strategy happens we will have a much more confident and knowledgeable workforce, delivering much higher quality end of life care. And that means the patient experience will be better.'

### Contact details

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**News in Brief****Death and dying****Death & Dying**

Making sense of the end of life

The Open University has produced a 24-page booklet on death and dying to link with its course on the subject (K260) and to coincide with two BBC programmes, *Two Feet in the Grave* introduced by Richard Wilson, and *The Art of Dying*, by Dan Cruickshank. It is also running a death and dying survey which is open to all. For more information go to [tinyurl.com/yc9j7pn](http://tinyurl.com/yc9j7pn)

**Core principle workshops**

Skills for Care and Skills for Health are running two interactive workshops, in London and Manchester, to get the views of all parties on a draft set of common core principles upon which good practice with carers should be based. These will then be used to produce training materials available to all staff that come into contact with carers.

The events are on Thursday 5 November at Park Inn Russell Square, London and Monday 9 November at Radisson Edwardian, Manchester. Please contact [carersstrategy@skillsforcare.org.uk](mailto:carersstrategy@skillsforcare.org.uk) or Diane Buddery on 07909 873231 for more details.

**Update on world class commissioning**

The October report on the world class commissioning programme includes updates on assurance year two, revisions to the new practice-based commissioning surveys, an update on integrated care pilots and information on new online and film resources. For further details see [tinyurl.com/yf32h4e](http://tinyurl.com/yf32h4e)

**Social care payments**

Revised guidance on direct payments for community care, services for carers and children's services has now been published to reflect recent legislative changes that extend direct payments to previously excluded groups. The guidance aims to assist local councils in managing and administering direct payments and replaces guidance issued in 2003. A user guide is also available. For more information see [tinyurl.com/qhudej](http://tinyurl.com/qhudej)

**Integrated care pilots guide**

An introductory guide to the national programme of integrated care pilots and evaluation has been published providing a summary of the work each pilot will be doing as they implement and test their models of integrated care. For further details see [tinyurl.com/ycf97c8](http://tinyurl.com/ycf97c8)

**Advice line**

The Relatives and Residents Association for quality of life of older people in care has an advice line offering support and information for anyone in or going into a care home, their relatives and their friends. The advice line is 020 7359 8136 and is available Monday-Friday 9.30-4.30 or email [info@relres.org](mailto:info@relres.org)

**Public awareness workshop**

The Help the Hospices conference in Harrogate next month will be running a public awareness workshop on end of life care issues from 10.30am -12pm on 26 November.

The workshop will give stakeholders an opportunity to learn about the new Dying Matters Coalition and debate issues as well as consider examples of good practice. The conference, entitled *Making life before death matter*, lasts from 24-26 November.

**Revised directions**

Three sets of directions, which came into effect on 1 October 2009, have been issued to underpin the revised national framework for NHS Continuing Healthcare. For more information go to [tinyurl.com/yhmnrgq](http://tinyurl.com/yhmnrgq)

**Commissioning for carers**

High quality services for carers rely on high quality commissioning. With this in mind, the Department of Health has funded a consortium to produce a guide for commissioners on high quality services for carers. Commissioners will find the guide, which is available on the IDEA website, valuable in ensuring not only high quality outcomes, but also achieving their targets in respect of carers. For more information see [tinyurl.com/llauchs](http://tinyurl.com/llauchs)

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For more information on the National End of Life Care Programme, including discussion forums and an events calendar, please visit:

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)