

#### IN THIS ISSUE:

##### 1 National Update

##### 2 News

##### Features

##### SOCIAL CARE

- 4 Pressing ahead with the social care agenda
- 6 Eight social care test sites:
  - Hospice at home personal budgets
  - Key worker competences for domiciliary care workers
  - Mentoring workshops
  - Integrated palliative care service
  - Community discharge planning at the end of life
  - Health and social care operating, commissioning and delivery plan
  - Social work end of life care leads
  - End of life intervention skills
- 10 Meeting the end of life needs of people with MND
- 11 A protocol to support bereaved carers
- 12 Testing out e-ELCA in a large acute trust
- 13 News in Brief

## National Update

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

### Preparing for the effects of cold weather

The government has launched its *Cold weather plan for England*, which aims to protect people's health throughout the cold winter months.

The cross-government initiative – which will be jointly run with the Met Office and Health Protection Agency – reminds all local communities and the NHS how best to prepare to keep people healthy and warm in their homes.

“Every year, there is a 20% increase in deaths in the winter in England,” said Health Secretary Andrew Lansley. “By working together, this co-ordinated plan will help protect those most in need.”

Severe cold weather can be dangerous for vulnerable groups such as older people and those with serious illnesses and can also increase the pressure on the NHS. It is therefore a particularly relevant for staff caring for people at the end of life. Now is the time for hospital teams to liaise with social care and community staff to ensure discharge procedures are in place and that services are fully co-ordinated.

### Awareness Week

The theme of the Dying Matters Awareness Week next year will be *Small Actions, Big Difference* and it will run from 14-20 May 2012.

Over the coming months the Dying Matters website will be highlighting a range of ways in which people can get involved. Dying Matters will also hold an event in central London on 22 February to help prepare for the event.

All staff are urged to see what their organisation can do during

the week and ensure it is built into organisational planning between now and then. Dying Matters has a number of [posters](#) to help promote the week.



Dying Matters also celebrated the Mexican Day of the Dead on November 1 with a colourful event aimed at encouraging community involvement. The afternoon featured a series of presentations on Dying Matters community initiatives, as well as round table discussions and an art exhibition.

The event ended with a talk by a Mexican woman and her English husband on what the Day of the Dead means to Mexicans. “We bring food and flowers to the grave, we sit and talk to them,” she said.

### QIPP seminar

The QIPP End of Life National Workstream is holding a special seminar in London on 6 December designed around sharing best practice in community interventions at the end of life.

The free event, which runs from 12.30pm to 4.30pm, will feature presentations from five organisations that are already achieving high quality outcomes for their end of life patients at reduced cost per patient and will aim to stimulate debate about which factors make a real contribution to a better experience at lower cost. To reserve a place, please [book online here](#).

### Environment awards

We are delighted to announce that two of The King's Fund's Environments for Care at End of Life projects have won awards at the [Building Better Healthcare Awards](#), the main UK awards for healthcare building and design.

The bereavement suite project at York Teaching Hospital NHS Foundation Trust won the award for best interior design while the Time Garden at Frimley Park Hospital NHS Foundation Trust won the best landscape/external space award.

In addition two projects were highly commended: Ward 9 at James Cook University Hospital and the Garden of Gifts at Barnet and Chase Farm.



### Caring for our future

The deadline for responding to the government's engagement exercise, *Caring for our future: shared ambitions for care and support*, is 2 December. For more information visit the [Caring for our future](#) website.

### Prisons RTS

An updated version of the *Route to Success* guide to end of life care in prisons is now on our website. Click [here](#) to access the guide.

Claire Henry  
National Programme  
Director  
November 2011



# News

## ONS launches national survey of bereaved carers

The Office for National Statistics last month launched the first-ever national bereavement survey to measure care at the end of life.

The survey will give important information for key services that provide end of their life care, to help improve people's experiences at this sensitive time.

Commissioned by the Department of Health, the survey is being sent to 49,000 people across England – one in seven of all those who registered a death between November 2010 and June 2011. It seeks their views on the care that their loved one received, as well as the care and support they were given themselves.

This survey will provide an opportunity for those who have cared for a loved one at the end of their life to make a contribution to improving services for others. The information will be treated in confidence and if anyone is distressed by the questions they can contact the ONS inquiry line or Cruse Bereavement Care helpline.

The Department of Health has funded the ONS to undertake this survey, fulfilling commitments in the End of Life Care Strategy and the NHS Outcomes Framework. The strategy highlighted the importance of improving the data available on end of life care service provision. It identified seeking the views of bereaved people about their loved one's, and their own, experiences of care as one way to do this.

The survey is based on the tried and tested VOICES (Views Of Informal Carers - Evaluation of Services) questionnaire, which was developed by Professor Julia Addington-Hall, and has been adapted into a shorter version (VOICES - Short Form) for national use.

It will run from October 2011 to January 2012 and the results are expected to be available by the end of March 2012.

For more information visit the National Bereavement Survey (VOICES) page on the ONS [website](#).



## 'Butterflies' scheme wins top nursing award

Nurses at Portsmouth Hospital Trust's A&E department have won this year's *Nursing Times* emergency and critical care award for a simple method of improving the experience of bereaved relatives.

The department has introduced a display of pictures of butterflies as a way of creating calm in a busy environment for those who have just lost a relative.

The idea, which was inspired by the personal experience of one staff nurse, has proved to be extremely effective, receiving positive feedback from relatives and staff. "The idea is easily transferable to other wards and departments for little or no cost and, ultimately, it has helped to enhance this fundamental aspect of nursing care," said the citation. Staff nurse Lee Campbell (centre

left) and consultant nurse Chris Walker (centre right) are pictured receiving their award.

Over 800 professionals were at the awards ceremony earlier this month at the Hilton Hotel in London. Two other end of life care initiatives were highly commended in the older people category: Greater Manchester West Mental Health Foundation Trust for developing an end of life care pathway in an acute mental health care setting, and the Aneurin Bevan Health Board which has ensured that 95% of older people die in their preferred place of care.

Nottinghamshire Healthcare Trust and Sherwood Forest Hospitals Foundation Trust were highly commended for their end of life care work in the learning disabilities category.

## NICE issues new guidance on chronic heart failure

NICE has published a new [quality standard](#) for chronic heart failure which includes access to palliative care services.

The institute has also produced new guides for commissioners on services for people with chronic heart failure and services for people who need cardiac rehabilitation.

The [guide](#) on the commissioning of services for people who need cardiac rehabilitation updates and replaces the previous NICE guide, published in 2008. The [guide](#) on the commissioning of services for people with chronic heart failure reflects the NICE quality standards for chronic heart failure and changes to recommendations within NICE clinical guideline CG108 on chronic heart failure.

Within each commissioning guide, an interactive tool provides data for local comparison against the benchmark and resources to estimate and inform

the cost of commissioning intentions.

Dr Hugh McIntyre, Consultant Physician and Chair of the Topic Expert Group which developed the NICE quality standard for chronic heart failure, said: "Heart failure is increasing in prevalence. This is partly due to reduced mortality as a result of major advances in treatment but also because of ageing of the population, and longer survival of people with conditions that can directly lead on to heart failure. As a consequence the demand for services for people with chronic heart failure and for people who need cardiac rehabilitation will increase."

NICE has also recently revised the commissioning guides for people with COPD and dementia and is currently developing generic end of life care commissioning guidance which will be underpinned by the new quality standard for end of life care, due to be published this autumn.

## UK bereavement alliance moves a step closer

Representatives from a wide range of bereavement organisations met in London this month to discuss the possibility of a UK-wide bereavement alliance.

The move follows the disbanding of the Department of Health Bereavement Working Group earlier this year.

Dawn Chaplin, Vice-Chair of the Bereavement Services Association, said members feared that one result of the working group's dissolution was that there would be no "national voice" for bereavement.

The organisations behind this month's workshop were the Bereavement Services Association, the Association of Anatomical Pathology Technology and the Association of Bereavement Services Co-ordinators.

A report will now be produced examining the feasibility of a new alliance and this will be discussed in more

detail at a further conference in April 2012. If there is general agreement, it is hoped that such a working alliance could be in place later in 2012.

The new alliance would be a recognised group that could give expert advice and support on all bereavement matters as well as signposting to other organisations where appropriate, said Dr Chaplin. The workshop had agreed in principle that an alliance was a good idea but much still had to be decided, she added.

"Bereavement is an integral part of end of life care but it is not always seen as such. This is about making sure bereavement has a national voice. An alliance would make it more visible and ensure that the wealth of work that goes on in this sensitive area is recognised and supported."

For more information email [dawn.chaplin@uhb.nhs.uk](mailto:dawn.chaplin@uhb.nhs.uk). Tel. 0121 371 4752



## Health watchdog calls for action on failings in older people's care

The Care Quality Commission has called for a system-wide response to the failings highlighted by its [recent inspection](#) of the care of older people on hospital wards.

Its spot inspection of 100 hospitals earlier this year found that fewer than half were fully compliant with the essential standards of dignity and nutrition. Only 35 met both standards and some of them still needed to make improvements in one or both areas.

Meanwhile one in five did not meet one or both standards. Major concerns were identified in two cases: Sandwell General Hospital in West Bromwich and Alexandra Hospital in Worcestershire.

A follow-up inspection of Alexandra Hospital found that action had been taken but a visit to Sandwell General revealed further evidence that people were not being treated with dignity, including one person who had been incontinent remaining unwashed for an hour and a half, despite asking staff for help.

Commenting on the report, Dame Jo Williams, Chair of CQC, said: "Too often, our inspectors saw the delivery of care treated as a task that needed to be completed. Those responsible for the training and development of staff, particularly in nursing, need to look long and hard at why the focus has become the unit of work, rather than the person who needs to be looked after - and how this can be changed."

"The fact that over half of hospitals were falling short to some degree in the basic care they provided to older people is truly alarming and deeply disappointing. This report must result in action."



## GSF in acute hospitals is making an impact - report

Introducing the GSF into acute hospitals has brought significant benefits, including improved confidence and awareness and better cross boundary communication, according to the newly released Phase 1 Pilot GSF Acute Hospitals Training Programme 2009/10 report.

Fifteen hospitals (12 hospital wards and three outpatient departments) took part in the pilot project, funded by the GSF Centre, with detailed evaluation in four areas - comparative staff confidence questionnaires, comparative after death/ discharge analyses, hospital PAS/ HES data and monthly feedbacks - together with qualitative feedback through interviews, questionnaires and narratives.

The report and feedback from participants was generally very positive and showed real progress in end of life care on the hospital wards. However, given the high demands and turnover of staff, the report stressed the need to support better training, improve the evaluation and

sustain the progress made.

One hospital, Southport, introduced GSF across the whole hospital and made significant progress in whole system cross-boundary care. Interviews also highlighted real benefits for patients.

Some of the overall findings were:

- Significantly improved staff confidence and awareness
- Earlier recognition and better care planning in line with preferences
- Improved co-ordination of care with primary care and care homes
- Improved documentation and increased use of LCP or an equivalent pathway
- Improved use and recognition of advance care planning
- Greater use of rapid discharge plans.

Phase 2 of the GSF programme is currently under way and Phase 3 is planned for early 2012. A Phase 1 film is available from the GSF Centre and an introductory video clip can be seen on the [website](#).



## Social care

This month our theme is social care. There are an estimated 1.5 million social care staff, ranging from social workers to domiciliary staff and support workers. And all have a role to play in end of life care.

Below we look at how the Programme's eight test sites were set up and some of the common themes and on subsequent pages we describe what each of the projects accomplished

## Pressing ahead with the social care agenda

The task of taking the end of life care message to the social care workforce is a huge one. Margaret Holloway and Tes Smith describe the impact of the eight test sites. On the following pages we summarise their key lessons

It is remarkable to think that 18 months ago no-one had heard of the Programme's end of life social care framework *Supporting people to live and die well* and none of the eight sites set up to address its key objectives had even started.

Things have changed significantly in the meantime. The framework, which was published in July 2010, is now an integral part of the end of life care agenda. And over the same period the test sites have not only been launched and completed but their lessons are now being disseminated.

The test sites were announced last summer and in most cases began their work before the end of the year, concluding between April and May 2011. But from the start, say NEO-LCP joint social care leads Margaret Holloway and Tes Smith, they saw this as being an integral part of phase one of the project.

"The test sites weren't stage two of the process," says Margaret. "We always had in mind that part of the framework would be the pilot projects. The scope of the task in raising the profile and performance of social care in end of life was and is such that we needed to advance on multiple fronts."

Underlying this thinking was the sheer scale of the project. There are an estimated 1.5 million workers in social care, ranging from social workers to domiciliary staff and support workers. And all of them to a lesser or greater extent have a role to play in end of life care.

The main criterion for choosing the successful test sites was therefore not so much geographical spread as ensuring that as many elements of the framework's 10 key objectives were covered as possible. It was also important the initiatives could be sustainable and had the potential for national dissemination.

One of the biggest challenges in achieving this was time. Tes and Margaret were keen that all sites completed their work by the spring so that the lessons could be disseminated but getting the green light was a laborious and often bureaucratic process. "Basically

none of the sites had enough time," admits Margaret.

This was not helped by coinciding with a time of major upheaval in both the NHS and social services as well as financial constraints. But, says Tes, they had always been aware they would face challenges of this sort – "it was a case of being flexible enough to cope with the changes".

The key to getting a project off the ground, they quickly discovered, was the engagement and support of senior managers. "We were trying to involve the social care workforce," explains Margaret, "and the only way to get that was through the support of senior managers.

"Those sites that were fortunate in that way were able to steam ahead. But where they struggled with that it became an inhibiting factor."

All this was hardly surprising, says Tes, given the low priority that many organisations have traditionally given to end of life care. "For some places it wasn't even on their radar."

One of the themes to emerge from many of the sites were the low levels of knowledge and confidence among many social care staff about addressing end of life care issues.

"This wasn't necessarily about things like supporting people at the end of life but more their lack of knowledge about the national strategy, the Programme and framework and all the end of life care tools," says Tes.

"They tended to see all that as being to do with the NHS and not part of their world. As a result their level of confidence about engaging with people at the end of life was much lower than the project leads had anticipated."

What the projects amply demonstrated, though, was that with appropriate training and support it was possible to improve staff skills and knowledge dramatically. "One of the greatest achievements of the whole project was the increased levels of awareness and motivation to engage that resulted," says Margaret.

Another encouraging finding from the test sites was that joint working across health and social care boundaries was possible and effective – provided the focus remained on the needs of the individual.

“The feedback we received was that once different staff were engaged and had actually made contact with each other, they worked really well together and became motivated to find one joint way forward rather than five separate ways,” says Tes. “It helped to bust a lot of myths.”

Joint working has been a “perennial problem” that has often blocked progress in the past, Margaret acknowledges. “But we found in the sites that when they started on quite small-scale things there were often quick wins. People were able to identify the obstacles at this level and start to do something about them.”



“One of the greatest achievements of the whole project was the increased levels of awareness and motivation to engage”

Margaret Holloway

Tes Smith



She and Tes are now focusing on phase two of the implementation plan, which includes further analysis of the data from the pilot sites, supporting local and regional initiatives, spreading the message through education and information resources and establishing a country-wide network of end of life care champions in social care.

Some local authorities have started to take

this forward. Essex County Council, for example, has already created 40 champions. But it is hoped to extend this to every region in England by next year. Work is also under way to increase the number of social care champions and integrate them into the NEoLCP’s end of life care facilitators’ network.

Perhaps the biggest challenge, says Margaret, is to maintain the momentum and enthusiasm created by the test site work. “It’s so easy to lose that if we’re not careful. This is now about getting down to detail and sustaining things.”

They are both optimistic about the future. “The feedback we’re getting is that people in social care now know what the *Supporting People to Live and Die Well* framework is about and they’re pleased it exists,” says Tes.

But there is still a huge amount to be done. Tes quotes the Dowager Countess of Grantham from *Downton Abbey* saying she prefers to “take my fences one at a time”. “The problem is that in this area we can’t afford to do things one at a time. We have got to push all these developments along simultaneously and at quite a rapid pace if we are to make real progress.

“As we enter the next phase we know there is much more to achieve and we remain much heartened by the good practice that is happening or being developed out there.”

Another common theme was the need for culture change within organisations. Many of the leads were shocked when they realised how great the cultural shift would need to be to make the changes they envisaged, reports Margaret.

“But we were also very, very heartened to see that shift beginning to happen without having to set up very costly interventions. If you just changed the mind-set and confidence levels and had the support of managers, then it was possible to make huge gains.”

One of the more intractable problems remains the fact that many social care staff have been deskilled and demotivated in recent years by a “tick box” culture, says Tes.

“Many in this workforce have been pigeon-holed into doing conveyor belt assessments and are unclear about their skill base and exactly what the local authority will allow or support them to do with an individual.

“This is where confidence has been lost. A lot of these staff have core skills but the conveyor belt mentality is in danger of eroding them. We need to get the message across that social care staff do have skills and they are vital in end of life care.”

In fact the test site work showed time and again that some of those social care values of choice, dignity and person-centred care lie at the heart of good end of life care.

“There is a long tradition of using a psychosocial approach in social care and that’s at the heart of holistic

#### MORE INFORMATION

To access *Supporting People to Live and Die Well* click [here](#).

## 1 Hospice at home personal budgets pilot

Lancashire CC, Rossendale Hospice

The aim was to give everyone accessing hospice services the opportunity of planning their support through personal budgets. Only people receiving social care support were approached so social workers were the key professionals in identifying who would benefit from the project.

The team found most of the 27 individuals referred to the hospice at home service were too close to the end of their life to benefit from personal budgets. The remaining seven felt it would be too complicated or cause additional stress.

However, the team was more successful with people attending hospice day therapy. As a result five are now using personal budgets. There has also been increased flexibility in their use with one person, for instance, using part of the budget to pay for respite care.

As a result of the intervention people have been more involved in planning their support and there has been increased access to community and low level preventive support.

Although the take-up of personal budgets has been relatively low, those who have used them have been positive in their response.



The project will continue but with the emphasis now on those who are accessing day therapy services and those known to social care who have deteriorating long-term conditions. There will be more emphasis on identifying people in the last year rather than last few weeks of life.

At the same time access to signposting services through Help Direct, which provides information and support to promote independence, has proved to be more important than first thought since many people were unaware of the low level community and preventive support that is available.

### Key messages:

- Planning with people needs to start at an earlier stage. Those already receiving personal budgets who have a deteriorating life-limiting condition need to be given the opportunity to discuss advance care planning and their preferred place of care as part of the support planning process
- A more co-ordinated approach is needed to the support that people are receiving, often from multiple agencies
- More emphasis should be placed on accessing universal preventive support and the impact this can have in helping patients and carers to stay in their own home.

## 2 Key worker competences for domiciliary care workers

Hull and Wakefield PCTs and partners

It has been suggested that domiciliary care workers (DCWs) play a pivotal role in end of life care in the community and may have many of the skills and insight needed to be some people's key worker.

To test this out, PCTs and adult social care in Hull and Wakefield District joined forces to examine whether domiciliary care workers are well-placed, through an everyday relationship of trust, to take on elements of a key worker role. They also wanted to see if they already had the essential end of life care competences and if so, how their work might be aligned with healthcare colleagues.

Wakefield District used focus groups, surveys and work-shadowing to find out how people used social care and then establish their needs. Hull drew upon the [Living Well](#) tool as an aid to person-centred planning and care. It also looked at the DCW's role as a patient advocate in primary care GSF meetings.

The project concluded that end of life care competences do exist, including communication skills, assessment and care planning, symptom management and maintaining comfort and well-being. It is possible for the DCW to be a key worker and this is already taking place in an informal way. With the use of person-centred tools DCWs' confidence increased so they were able to engage in conversations about end of life care. Meanwhile people at the end of life and their families reported satisfaction and felt they were being listened to and supported. As a result key worker competences were developed for DCWs, using a person-centred approach.

The learning from the test site is already being used to inform recruitment to the extended and newly integrated 24-hour palliative and end of life care domiciliary care service in Hull. Meanwhile Wakefield will take on board the recommendations when it draws up end of life care competences for the multidisciplinary team. It also plans to test out the use of DCWs in GP practice through GSF meetings.

### Key messages:

- Consider the role of DCWs within a more integrated primary care team. Look at how systems are set up within your area for working between health and social care. The lower level care required to support someone is the most time-consuming but can in the long run prevent emergency situations
- Health and social care commissioners/providers need to identify and develop the social care workforce aspects of core competences and recognise the triggers for conversations about end of life care
- Agree and develop practice/policies/tools for person-centred thinking to support advance care planning and the links to personalisation
- Use established relationships of trust to test new ways of working. Consider integration for health and social care that does not involve full scale redesign but fuller understanding and effective communication
- Establish ways to collect individual stories across health and social care to support the population needs analysis for your area.
- Develop a shared definition of key worker and be specific about the requirements of the role in your local area.

### 3 Mentoring workshops for adult social care workers and fieldwork support assessors

Sue Ryder Care, Leckhampton Court Hospice, Gloucestershire

Although social workers and fieldwork assessors often find themselves responsible for assessing and managing the care of people at the end of life, few have accessed generic end of life care training.

The Gloucestershire project sought to overcome this by offering mentoring workshops to these professionals to build their skills in communications and to reflect on the palliative care aspects of their roles. The workshops were based on the 4-level social care model and were run by Sue Ryder Care together with Gloucestershire County Council.

The team spent some time before the workshops attempting to engage the social workers' operational managers, recognising this was a key to attendance. In the event 66 social workers and fieldwork assessors attended the six workshops, which were held over a three-week period in March to April 2011.

Early evaluation suggests that the workshops have been successful with the size and mix of staff working well. In addition participants reported that their confidence in key end of life care competences had increased significantly.

One problem was that more time than had been anticipated was spent on basic teaching about end of life care issues, which meant that the mentoring element had to be reduced. This will need to be followed up if improvements in confidence and competence are to be sustained.

The pilot also shows that when social workers are specifically targeted and offered a relevant workshop format that is facilitated by experienced palliative care social workers, the problem of access to training can be overcome.

Gloucestershire CC has now agreed to fund the specialist facilitation for a second round of mentoring workshops this autumn and it is hoped this will become a regular six-monthly training programme.

#### Key messages:

- Many participants were not aware on starting the workshop of the end of life care pathway or that end of life care starts before the final few weeks of life. It is crucial to find appropriate means of educating social care staff. This workshop format has demonstrated an effective option for increasing knowledge at the same time as building the value and skills base needed for effective practice
- A significant, measurable improvement in confidence of staff can be achieved in a cost-effective time frame of half day workshops. But this improvement will need to be sustained by a six-monthly rolling programme of mentoring sessions
- Reflective practice and effective supervision are critical to sustaining good practice in end of life care.

### 4 Implementation of an integrated palliative care service in North Norfolk

Norfolk CC, Norfolk NHS

The project, which built on work already done in the area by the Marie Curie Delivering Choice Programme (DCP), sought to identify, share and develop good practice around the commissioning and delivery of person-centred, integrated care. It also aimed to promote supportive communities and develop professional expertise in palliative and end of life care in the area.

In order to establish staff competences and the current level of care, the project team carried out a series of interviews and workshops and surveyed 176 adult social care and domiciliary and residential care staff. It also produced 10 case studies.



The results were discussed within multidisciplinary workshops and the community support available to people with end of life care needs was mapped out, based on the Marie Curie DCP toolkit.

The project team made a number of recommendations, including encouraging domiciliary agencies to set up palliative and end of life care teams that are specially trained in supporting people with end of life care needs.

An implementation plan for the future has now been drawn up. A meeting with palliative care champions has also taken place to agree the future direction of the initiative.

#### Key messages:

- Use the GSF framework as the focus for co-ordinating palliative and end of life care. The GSF's scope should extend beyond cancer patients and involve social care staff in MDT meetings
- Develop a joint training and delivery strategy with the SWIFT (Strategic Workforce Investment Funding for Tomorrow) end of life training programme, which is delivered locally to multi-agency groups
- Co-location of practitioners would help integration. Joined-up information and communication is also important
- Watch out for the ripple effect. For example, new and changing roles impact on traditional roles which in turn need to be updated and changed
- Embrace and develop partnerships with NHS, voluntary and independent sectors. Leadership is important and palliative care and end of life issues need representation at a senior social care level to ensure there is a strategic link-up between health and social care.

## 5 Delivery of integrated health and social care community discharge planning at the end of life

West Essex Community Health Services, Essex CC and partners

Partner organisations in West Essex had already been working to improve integrated management of end of life care but it was recognised that more needed to be done, particularly in relation to the discharge of hospital patients with life-limiting conditions.

A discharge facilitator was appointed at the start of the project which ran from March to May 2011. The facilitator sought to raise awareness of end of life and the preferred priorities for care and encouraged referrals from both the hospital and the community. She worked with a range of agencies to support discharges from hospital of those who wished to die elsewhere and in some cases accompanied the patient home.

During the project 78 referrals were made of which 87% were appropriate – making an average of 7.5 referrals each week. Of these 64.6% were discharged within 48 hours of referral and 47% of these were within 24 hours. Nearly 90% were discharged to their preferred place of care.

The project has helped to dispel a number of myths and engender greater trust between the different sectors. It has also raised awareness of the role of social care at the end of life and the value of an integrated approach to service delivery.

### Key messages:

- Adopting a holistic and integrated approach can make a significant difference to the quality and efficiency of discharge for people at the end of life in a short space of time
- Early discussions about disease management in the later stages of a life-limiting illness would help prevent crises
- Many people are willing to verbalise their preferences for care but not formally commit those to a document. Not having a formal document should not militate against delivery of choice
- Until there are shared IT and communication systems, integrated working across organisational boundaries will be challenging
- Clinicians need to be more aware of prognostic indicators in long-term conditions and how to apply them in clinical practice
- Out of hours services need greater focus
- Those who facilitate or co-ordinate discharge for end of life care need formal channels of supervision.



## 6 Delivery of an integrated health and social care operating, commissioning and delivery plan

Essex CC, Essex Community Health Services and partners

When the project began in September 2010 Essex County Council had no overall strategy for end of life care. By the time it finished in May 2011 a strategy was in place together with delivery and action plan.

This was greatly helped by developing 40 end of life care champions across the county to raise awareness among staff. In addition mandatory end of life care training was introduced for all county council staff as well as a workforce training pathway.

The project has also worked to develop end of life care guidance for travellers and an end of life care pathway for the local prison. Links were also made with all six local hospices.

The project team has worked with a range of organisations, including acute hospitals, community health services, PCT commissioners and providers, QIPP plan managers, mental health trusts, domiciliary and residential care providers and the prison services.

The pan-Essex end of life care strategy has ensured the county council has a clear and concise delivery and action plan for end of life care. The council has also decided to continue the role of the project manager – now entitled Service Delivery Operational Service Manager in End of Life Care.

### Key messages:

- Having a clear and robust communication plan helps to raise awareness
- Implementing mandatory e-learning end of life sessions underlines the need for staff to engage
- Local hospices delivering further end of life training options encourages relationship building
- The action plan needs to remain flexible
- End of life work should be a partnership between local authorities, health boards, GP consortia and statutory and voluntary provider organisations
- Partnership, communication and engagement are vital.

## 7 Exploring the role of end of life care leads in social work teams

The Modernisation Initiative End of Life Care Programme, Lambeth and Southwark boroughs

The aim of the project was to identify social work leads for end of life care in every team, to establish their training needs, test out their role and set up a facilitated learning network between the social care and district nursing leads.

It was hoped that those engaged in the pilot would be able to disseminate good practice, develop their own skills and experience and influence decision-making at strategic level.

The project ran from late October 2010 to May 2011 and during this time the project identified 21 social care leads who link directly to 250 colleagues.

An initial audit revealed that the potential leads' knowledge of end of life care was fairly low. Most were unfamiliar with the GSF, ACP, LCP and the AMBER care bundle. A number of networking meetings between social care and district nurse leads were held over the course of the project. In addition all social care leads were encouraged to take up places on St Christopher's *Challenging Conversations* training course as well as accessing their library and e-learning facilities.

As a result social care leads' knowledge and confidence levels have risen significantly. A new role description has been agreed and there has also been improved multidisciplinary team working. But all leads acknowledge that the biggest challenge will be wider partnership working and influencing practice.



### Key messages:

- Ongoing senior management commitment and involvement is key to success
- Active involvement of service users and carers, third sector and health colleagues will inform and energise project work
- Keep the lead role definition simple but allow for flexibility and ensure managers' responsibilities are clearly stated
- It is important to support all social care staff to reflect on their role in relation to all aspects of end of life care.
- If social care workers are to engage with end of life care they need the right supervision and support
- Both professionals and service users need up to date information about local service provision. Speed networking is a highly effective way of informing staff, developing working relationships and motivating people
- A Route to Success for Social Care should be developed.

For more information visit: <http://bit.ly/aPkNRp>

## 8 End of life intervention skills consultation and intervention

St Christopher's Hospice, London

The aim of the project was to work towards meeting the end of life learning and support needs of adult social care staff in Lambeth and Southwark.

St Christopher's worked closely with the Modernisation Initiative (see previous case study) which had identified social care leads in the two boroughs. The leads came from community- and hospital-based teams as well as Care Line services and sheltered housing.

Initially the training and support focus was to be exclusively on social care leads. But it soon became clear that managers and other members of the social care teams also had training needs.

Between October 2010 and April 2011 St Christopher's provided three sessions of training (lasting 2.5 days) to social care leads as well as free places on its multi-disciplinary training courses, access to its library and a helpline on end of life care issues. There was a particular focus on promoting earlier end of life planning as well as holistic assessment and holistic understanding of well-being.

It also provided an away day and a half-day review meeting for a total of 13 managers and half-day sessions and on-site visits to 134 members of adult social care teams.

The training has proved popular and feedback indicates there have already been changes in day-to-day practice such as improved communication and confidence and remodelled assessment tools. The two boroughs are now planning to commission additional training and further develop the organisational links.

### Key messages:

- It is vital to interest and involve senior managers in end of life issues so that the initiative can be developed at all levels within teams
- Facilitate hospice visits as these help promote cultural change and encourage positive feedback to service users
- Visits to teams are important for dissemination of information but also to indicate that end of life issues are everybody's responsibility
- Leads/champions are key to giving the work an impetus within teams but the role needs ongoing support and training
- Line managers may also need training
- Issues of loss need to be incorporated into any training programme on end of life care but are particularly relevant to every area of social work
- Partnership working (health and social care particularly) will be essential if the successes of the project are to be maintained
- Providing opportunities for practising communication skills is essential. If professionals can successfully develop confidence in this area they can transfer this confidence and skill set to other areas of social work
- Developing broader skills such as presentation skills should be supported.

# Meeting the end of life needs of people with MND

Careful co-ordination between all the services involved is vital to good end of life care for people with motor neurone disease. Farah Nazeer from the MND Association tells Andrew Cole what needs to be done to make that a reality

Motor neurone disease is a devastating condition that can rapidly lead to almost complete physical paralysis while usually leaving the individual's cognitive faculties largely unaffected.

Around 5,000 people in the UK have the condition at any one time and half of these will be expected to die within 14 months of diagnosis.

It can be seen that for many people with MND this means that palliative and end of life care are likely to follow rapidly in the wake of a diagnosis. Yet sadly, according to the MND Association's Director of External Affairs Farah Nazeer, the statutory services' record of dealing promptly and knowledgeably with people with MND is patchy.

This extends from lengthy delays in diagnosis in the first place to poor understanding about the disease among many professionals to a lack of access to specialist palliative care and consequent gaps in the end of life care that people receive.

be required with more frequent hospitalisation.

In one dramatic example a trust that decided not to invest in the £12,000 cost of respiratory equipment for two people with MND found it was faced with a £1.2 million bill when both patients ended up in intensive care for lengthy periods as a direct consequence.

One result of unco-ordinated care is unnecessary and expensive hospital admissions, particularly out of hours, because carers and relatives panic when there is an apparent crisis and dial 999 instead of being able to call on specialist support services. In some cases all that is needed is a reassuring phone call, Farah suggests.

This also means that many people with MND end up dying in hospital rather than at home where they would prefer to be. That is unacceptable, says Farah. "With MND you know it is happening so there really isn't a reason for home deaths not to be planned. But sadly people don't always have access to advance planning or to palliative care nurses who understand the condition."

The most pressing need in her view is for guaranteed access to specialist palliative care. "If a person has access to palliative care and a multidisciplinary team delivering appropriate and timely care, then you have a much better chance of a good death."

This in turn relies on commissioning appropriate and reliable services. Given the rapidity of the disease these need to be able to anticipate future needs. "Timing is everything," says Farah. "There is a concern that the new structures may result in commissioning decisions made by those who don't have a good understanding of MND and its challenges."

The association currently funds 19 MND care centres for people with MND across the country. It also employs 25 regional MND specialists whose brief is to educate health and social care staff, link in with hospices and seek to influence commissioning decisions.

Last year it held a summit on end of life care and MND which resulted in a list of nine key recommendations being sent to Health Secretary Andrew Lansley. An all party parliamentary [report](#) on the same topic announced its findings recently.

They included a call for end of life care registers to be the norm, the development of a quality standard specifically for MND and that 24/7 community nursing should be a key indicator of quality. "Organisations like the NEoLCP will be critical to implementing the recommendations in this report," says Farah.



Mark Carr, who has motor neurone disease, is pictured with his carer

There are of course exceptions. But, says Farah, "in most areas where care is good it has been either because of the direct intervention of our association or where there is a champion in the area. The fact is that good palliative care is not often embedded into the system."

The consequence of this can be deeply distressing for the person with MND as well as their immediate family and carers. "Time and time again the association's experience has been that if the care and co-ordination aren't available people can be left with little or no support.

"It's not only very distressing, it can lead to families splitting up, depression and people's basic needs not being met."

In addition, poor care can be very costly. The MND Association calculates that the average person with MND needs up to 18 professionals working in close co-ordination to give them the best care and quality of life.

This package of care is likely to cost around £16,500 a month. But if that care is not on offer, the costs are likely to rocket because more crisis interventions will

## MORE INFORMATION

If you would like to discuss how to improve palliative services for people with MND in your area, please contact the MND Association.

- [www.mndassociation.org/index.html](http://www.mndassociation.org/index.html)
- [farah.nazeer@mndassociation.org](mailto:farah.nazeer@mndassociation.org)

# A protocol to help nurses support bereaved carers

Gina King describes how NHS Gloucestershire produced a new bereavement protocol to support community nurses as well as an LCP resource pack providing help and information for staff, families and carers

NHS Gloucestershire has developed a bereavement protocol to help community nurses in their practice and standardise the information and support provided to bereaved relatives and carers in the last days of life and after death.

The standard highlights the essential practicalities of community bereavement follow-up and includes contact information, access to ongoing support and communication pathways across a multidisciplinary team.

The new standard was produced after a baseline audit of services revealed there was no standardised community bereavement follow-up as well as a lack of information provision. A survey commissioned by the bereavement charity CRUSE also indicated a lack of a structured approach and some ignorance about available services.



One of the NHS Gloucestershire bereavement documents contained in the resource pack

As a result a working group was formed in September 2009 consisting of CRUSE, hospice and specialist palliative care representation and a cross-section of community nurses from all localities in Gloucestershire.

The aim was to develop a standard that concentrated on bereavement support and not counselling. Community nurses are skilled professionals who can provide follow-up support to allow the bereaved to discuss their experience and provide closure to the episode of care. Counselling from other

agencies may be required if issues have been identified relating to the bereavement and a trained counsellor can enable reflection and resolution.

Using a framework developed by a Gloucestershire GP surgery, the group first agreed the key principles of care:

- Respect for the individual
- Recognising and acknowledging loss
- Provision of information – Liverpool Care Pathway (LCP) resource pack
- Support
- Ensuring the environment and facilities are appropriate for the bereaved
- Review and audit.

The second section of the protocol focused on the essential practicalities of community bereavement follow-up, including contact information, access

to ongoing support and communication pathways across a multidisciplinary team.

To support the community nursing teams in using the protocol two tools were developed to help assessment and to document the follow-up visit. An audit tool was adapted from the acute trust critical care unit. A prompt sheet was also created to support the nurse in asking key questions that indicate if the relative/carer needed further support from CRUSE or another identified bereavement service. Answers are recorded on the audit tool for future reference.

In addition a standardised letter was devised for those who did not respond or who had left the area and a contact card produced to inform the bereaved of the planned follow-up. A resource file was produced with all the necessary documentation and information leaflets for when the LCP was begun.

NHS Gloucestershire has also produced a resource pack about the introduction of the LCP to support the bereavement protocol. The resource pack is used when the multidisciplinary team has agreed the person is to be placed on the LCP so the information can be offered when appropriate to the relative or carer.

It provides useful information to families and carers in the form of leaflets about the LCP, what to do after a death and bereavement, as well as a contact card explaining standardised follow-up. It also has useful tools for the nurses, including an LCP guidance sheet, a prompt sheet, a bereavement documentation tool and a letter of unresponsive contact.

The resource pack, which has been in use since June 2010, has been recognised by the NHS South West and within the Department of Health booklet *When a person dies*. Colleagues in other parts of the South West region are also considering using the standard in their own practice.

Bereavement is an essential part of the end of life care pathway and although grief is a normal process for many individuals, everyone will require some kind of support at various points following a bereavement. This standard ensures that every relative or carer will be aware of the services and support at a time that suits them. It is also helpful to know that grief is a normal process and that time and support will carry people through.

The current standard focuses only on community nurses. However, the NHS Gloucestershire end of life care steering group is now working to develop a standardised approach to bereavement follow-up across the whole county.

## ABOUT THE AUTHOR

**Gina King** is Clinical Facilitator for End of Life Care, NHS Gloucestershire

## MORE INFORMATION

All resources are available at <http://bit.ly/tW4szr>

# Testing out e-ELCA in a large acute trust

Does e-learning offer a cost-effective way of disseminating end of life care skills to the general workforce? Tracy Wild and Cathy Thorman describe the findings from their project to test the use of e-ELCA in an acute trust

Everyone should be able to expect high quality care at the end of their lives. One of the keys to ensuring that, as the [End of Life Care Strategy](#) makes plain, is knowledgeable, well-trained staff.

The Pennine Acute Hospitals NHS Trust is a large, four-site organisation with approximately 10,000 staff, many of whom would benefit from additional education in end of life care.

At a time of increasing economic pressure the e-ELCA e-learning package (End of Life Care for All) was seen as a potential vehicle to achieve this ambitious goal. The package offers over 150 highly interactive sessions covering four core modules in assessment and care planning, symptom control, communication and advance care planning. A fifth course focuses on integrated learning and topics such as bereavement and spirituality.



Members of the Pennine Acute Hospitals Trust are pictured with fellow palliative care nurses and e-ELCA lead Dr Bee Wee. Left to right they are: John Bramwell, Jennifer Forsythe, Janice Sedgewick, Kim Wrigley, Gillian Birch, Tracy Wild, Cathy Thorman, Jennifer Bright, Bee Wee

To explore the feasibility of this approach a project team of nurse specialists and education staff developed a pilot study to discover how staff would react to the e-ELCA approach. Twenty six members of staff including nurses, allied health care professionals and health care support workers were recruited to take part between March and May 2011.

Participants chose one of the four key modules and progressed as far as they could. All four modules were covered in the pilot. A pre-pilot workshop was held for participants to 'have a go' in a supportive environment. Participants were able to apply for remote access, enabling them to study at home if they wished.

The evaluation was through pre- and post pilot questionnaires and participants' attendance at a post-evaluation workshop where they gave verbal feedback. Participants returned 58% of pre-pilot and 60% of post-pilot questionnaires. Feedback was positive, with 94% stating they would recommend e-ELCA to others and 47% saying they would definitely continue further study.

Participants felt the e-ELCA was of excellent quality

and "at the right level", with one participant saying it "met my expectations and beyond".

Although most participants completed the e-ELCA on an individual basis, 25% used a combination of individual and group study, demonstrating the flexibility of e-ELCA. Despite the project team having identified the need for participants to have some study time, only a quarter of participants had time allocated. This had a significant impact on completion of modules, with many participants feeling unable to progress as well as they had hoped. Indeed, 75% of participants identified lack of time as a significant difficulty and one of the main drawbacks of the e-ELCA.

Despite the difficulties some participants experienced in getting started because of technical issues, the post-evaluation workshop showed that many were energised and enthused not only about transferring their learning into practice but also continuing their studies using e-ELCA. Participants reported they had increased confidence and that they could be more assertive and an advocate for their patients.

This was a small-scale pilot study within a large organisation. However, it has provided the project team with valuable data and feedback about the experience of using e-ELCA within the acute setting and this has been shared locally and across the regional cancer network.

Some lessons learned from the pilot have already been addressed, with the development of support sessions for staff in using e-learning and improvements made to IT access and use of equipment. This is clearly essential to ensuring people can use e-ELCA successfully.

The project team has gained agreement for a further roll out of e-ELCA within the trust and plans a series of meetings to feed back findings from the pilot study to managers, especially around the issue of allocation of study time. With each individual session taking 20-30 minutes to complete, we will be emphasising the flexibility and time-effectiveness of e-ELCA.

Workshops are now planned for each of the core modules. These will be aimed at supporting staff to integrate learning into practice. We will also be developing some 'top tip guides' which will include useful information and frequently asked questions.

This pilot demonstrated that e-ELCA is a useful tool for enhancing the delivery of end of life care education within large acute healthcare organisations and the team is committed to ensuring it is successfully implemented.

## ABOUT THE AUTHORS

**Tracy Wild** and **Cathy Thorman** are Macmillan Specialist Palliative Care Nurses at The Pennine Acute Hospitals NHS Trust

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Phone: 0161 720 2814

# News in Brief

## New volunteers research

Lancaster University is collaborating with the Institute for Volunteering Research, London, to study volunteer management in palliative care settings. The research, funded by the Dimbleby Marie Curie Cancer Care Research Fund, will examine the challenges of involving volunteers in palliative care roles which require direct contact with patients or their families. Further information: Dr Sara Morris ([s.m.morris@lancaster.ac.uk](mailto:s.m.morris@lancaster.ac.uk)) or Matthew Hill ([matthew.hill@ivr.org.uk](mailto:matthew.hill@ivr.org.uk))

## 30 million stars website



ACT and Children's Hospices UK have launched a new 30 million stars [website](#) and resource hub to support professionals who work with life-limited or life-threatened children, young people and their families. The new name for ACT and Children's Hospices UK, which merged in October, is [Together for Short Lives](#).

## World Alzheimer Report 2011

The [World Alzheimer Report 2011](#) shows that there are interventions that are effective in the early stages of dementia, some of which may be more effective when started earlier, and that there is a strong economic argument in favour of earlier diagnosis and timely intervention.

## Kidney care guidance

NHS Kidney Care has launched a new guide to help GPs and primary care professionals provide high quality end of life care to patients with advanced kidney disease. The guide includes '10 Top Tips' designed to raise awareness about the needs of kidney patients nearing the end of their lives. They also signpost GPs to more information where needed.

## Global report maps

To mark World Hospice and Palliative Care Day, the Worldwide Palliative Care Alliance has launched a [report](#) mapping the levels of palliative care development throughout the world.

## Memory services

Following publication of the first national audit of dementia services, the Department of Health is providing £10m of additional support to social care for memory services. For more information visit the Department of Health's [website](#).

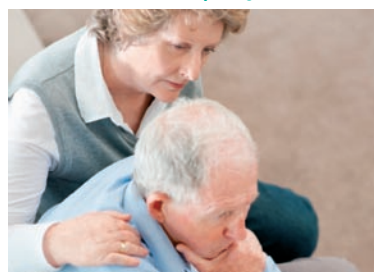
## Call for submissions

The NIHR Service Delivery and Organisation (SDO) [programme](#) is calling for submissions on three topics - innovations in secondary mental health services, improving clinical productivity and rapid evidence syntheses on efficiencies. Submissions should be made by 1pm, Thursday 15 December.

## Clinical governance guidance

The Department of Health is developing new clinical governance [guidance](#) which will provide advice on a number of recent developments, including medical revalidation, responsible officers, clinical performance issues and the new system of death certification.

## Carers' needs project



The University of Nottingham has published a [briefing paper](#) on the findings and recommendations from a research project studying the experiences and main support needs of older carers looking after someone with advanced cancer. The project was funded by Macmillan Cancer Support. A further [briefing paper](#) on the involvement of older carers in research has also been produced.

## Hospice care: future



The Bow Group, a centre-right think tank, and Dr Daniel Poulter MP have published a policy [paper](#) outlining a vision for the future of hospice care.

## End of life care commissioning

The King's Fund has published a [paper](#) on *Issues facing end of life care commissioners*. The paper looks at examples of personalisation of care, clinically-led commissioning and integration of care, and what lessons commissioners can learn.

## Dementia campaign

The government has launched a £2 million [campaign](#) to raise awareness of the early signs and symptoms of dementia. Currently six out of 10 people with dementia go undiagnosed.

## End of Life Journal

The second issue of St Christopher's Hospice [End of Life Journal](#) is now available.

## Current grant programmes

Help the Hospices is offering grants of up to £25,000 for [nurse-led projects](#) aiming to help develop and enhance the leadership abilities of the individual, as well as make hospice and end of life care services equitable for all. The application deadline is 19 December.

## Shadow board begins

The [NHS Commissioning Board Authority](#), a special health authority and the shadow form of the NHS Commissioning Board, is now in operation. It is anticipated the NHS Commissioning Board will become fully operational on 1 April 2013 when it takes on its complete legal responsibilities for managing the NHS commissioning system.

# News in Brief

## New audit tools

Help the Hospices National Audit Tools Group (NATG) will be releasing new audit tools for testing at the beginning of December, focusing on the community and infection control. Any hospice interested in testing these tools should email [a.morgan@helpthehospices.org.uk](mailto:a.morgan@helpthehospices.org.uk)

## Carers action guide



The revised edition of the "Supporting Carers" [action guide](#) for 2011, offering an overview of how practices can support carers within their practice, along with up-to-date policy and good practice, is now available.

## SCIE appeal

The Social Care Institute for Excellence is looking for [examples of good practice](#) for its new end of life care webpage, to be launched at the end of November. It aims to provide a location for information, resources and links to support the development of social care practitioners working with people and their families at the end of life. Please send examples to [pamela.holmes@scie.org.uk](mailto:pamela.holmes@scie.org.uk).

## Out of hours e-learning

Macmillan Cancer Support, in partnership with BMJ Learning, has launched a new out of hours and palliative care e-learning [course](#) for GPs. To access the package subscribers need to register for a free 'learn zone' account.

## New edition of PIG

The fourth edition of the GSF Prognostic Indicator [Guidance](#) is now available on the GSF and RCGP websites.

## Death statistics

The Office for National Statistics has published causes of death statistics for England and Wales in 2010. To view the data click [here](#). Local figures can be viewed in an interactive [mapping tool](#).

## Dementia website

The Palliative Care in Dementia [website](#) has been updated and now includes additional resources.

## GP training report

The Commission on Generalism, established by the RCGP and think tank the Health Foundation, has recommended that specialist training for GPs should be extended from three to five years. The [report](#) says the overall availability of good end of life care needs to be improved and that GP training should specifically include this area. The RCGP will now consult on the report's recommendations, with a formal response expected in 2012.

## Personalisation report

The think tank Demos has produced a new report on personalisation. [Tailor Made](#) shows that while personal budgets may be an effective way of achieving personalisation, they do not guarantee it.

## Change's cancer images



Change – the learning disabilities body working for equal rights – has produced a [CD Rom](#) of all the images in its *Change Cancer* book series. The disc contains over 700 images. For more information see Change's [website](#).

## COMING EVENTS

### NCPC conference

The 6th annual NCPC conference exploring palliative and end of life care for people with dementia will be held in London on 12 December. Find out more [here](#).

### Multi-professional week

St Christopher's Hospice will be running a [Multi-Professional Week](#) in End of Life Care for Advanced Practitioners from 21 to 25 May 2012., price £750.

### World Research Congress



Registration is now open for the 7th World Research Congress of the European Association for Palliative Care. The congress is taking place in Trondheim, Norway from 7 to 9 June 2012. For more information, visit the congress [website](#).

### Marie Curie conference

Abstracts for poster and/or oral presentations for next year's Marie Curie Annual Palliative Care Research Conference can now be submitted. The conference, which takes place on 23 March 2012, will focus on the challenge of symptom control in advanced progressive disease. Abstract submissions must be emailed to [oswin.taylor@mariecurie.org.uk](mailto:oswin.taylor@mariecurie.org.uk) no later than 5pm on 25 November.

### GSFCH conference

The annual Gold Standards Framework Care Homes conference and awards ceremony takes place on Wednesday 25 January 2012 at Mary Ward House, 5-7 Tavistock Place, London, WC1H 9SN. To book a place or for further information, contact the Central GSF Team on 01743 291895 or [info@gsfcentre.co.uk](mailto:info@gsfcentre.co.uk)



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