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

Route to Success for care home staff

The first in our series of practical guides for improving end of life care in various settings has now been sent to 18,000 care homes.

The *Route to Success in end of life care*, produced by the Programme in partnership with Age UK's My Home Life, provides care home staff and managers with useful tips and information which will help them care for residents at each step of the end of life care pathway.

We intend to produce similar practical guides for other settings over the next few months – including editions for acute hospitals and hostels for homeless people. The series will also include a guide for carers working with people with dementia.

The guides focus on the practical rather than theoretical because we know that is the sort of support staff need in their busy working lives.

Each edition will look at the core components for success in the care pathway and key interventions that make a difference to the experience of the individual. For a copy of the 16-page care homes edition of the *Route to Success* series email information@eolc.nhs.uk.

Support sheets accompanying the series are available on the programme's website at www.endoflifecareforadults.nhs.uk



Goodbye to Isabel

Sadly we will be bidding farewell at the end of May to Isabel Quinn, who has led on workforce development and a number of other projects for the last 18 months. Isabel is moving on to pastures new. We wish her every success and thank her for all the work she has undertaken while with the Programme.

We're happy to say that Glenis Freeman, who is Cancer and End of Life Care Workforce Policy Lead at the Department of Health, will continue to advise and be involved in the implementation of workforce issues at the Programme. Glenis is contactable at glenis.freeman@dh.gsi.gov.uk or on 01934 710140.

Good practice plea

Do you know of examples of end of life care good practice in the fields of learning disabilities or acute care? Or are you involved in an end of life care initiative relating to people in BME communities? If so, we would like to hear from you – with a view to posting them on our website and as part of Route to Success series. Please contact information@eolc.nhs.uk or phone 0116 222 5103.

New project on learning disabilities

A new initiative to find out more about the issues surrounding end of life care for people with learning disabilities will be getting under way shortly.

The project will map the current situation and then identify resources, support and good practice models that staff can be signposted to.

The work, which was commissioned by the Programme, will be carried out by Enfold C.I.C. and will involve two steering groups – one made up of key stakeholders and the other of people with learning disabilities. It is hoped to produce two publications at the end – one designed for professionals and carers and an 'easy read' version specifically for people with learning disabilities.

Current research suggests that people with learning disabilities are likely to encounter all the major life-threatening diseases at least 5-10 years ahead of the general population and survive less long.



Claire Henry
National Programme Director
May 2010



National Awareness Week hits home

Thousands of people from around the country took part in a week of events to mark the Dying Matters Coalition's Awareness Week in March.

The initiative started with a launch event and National Forum meeting in London, attended by representatives from all the three main political parties, which unveiled the results of a national survey of public attitudes to death (covered in the March newsletter).

It also saw the premiere of a 5-minute film, entitled *A Party for Kath*, demonstrating the benefits of greater openness around death and dying. The film tells the story of a son, his mother and an extraordinary party, which aims to highlight the essence of the coalition's message.

The launch was followed by a range of activities around the country, including conferences, workshops, art displays and a tea party at the House of Commons.

The coalition has published a new book, *Dying to Know: Bringing Death to Life*. And it is working on producing a lesson plan focused on issues of death and dying which could be used as part of the PHSE component of the national school curriculum.

View the Coalition's film at www.dyingmatters.org/site/party-for-kath

Hospices to receive £40 million boost to environment

A total of 123 hospices in England are to benefit from Department of Health funding aimed at enhancing and equipping hospice environments and supporting hospices' work with care homes and caring for people in their own homes.

This could include installing specialist bathing apparatus, improving gardens to enable patients and families to spend time outdoors or large-scale refurbishments.

The projects, which were funded as part of commitments made in the End of Life Care Strategy, will begin in April 2010 and will be completed by 31 March 2011. The total funding made available is £40 million.

Local hospices played a central role in the delivery of end of life care, said David Prail, Help the Hospices Chief Executive, and they welcomed the new funding.

'Although hospice care is more than just a building – with many services being provided in people's homes – the building itself gives hospice care an important physical presence in the community.'

New unified DNACPR policy is agreed across South Central

South Central SHA launched a new region-wide Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy in Oxfordshire in March.

The policy and documentation, which come into force across the region on September 1, have taken more than two years to see the light of day.

Mark Roland, the SHA's Clinical Director for End of Life Care, explains that before the decision was taken to introduce a unified approach as many as 30 different DNAR policies were operating across the region.

'You could have one policy in the patient's home, another in

the ambulance and a third in the hospital they were taken to. And none of the documents talked to each other.'

The result was often confusing, leading to distressing situations and sometimes meant that staff attempted to resuscitate patients inappropriately.

In September 2008 the SHA agreed to review all local policies with the aim of establishing a single unified way forward. The resulting policy and documentation are based largely on the Resuscitation Council UK template but have been modified to take account of input from stakeholders around the region. A patient information

leaflet is also based on the RCUK template.

Dr Roland says a few organisations across the SHA have yet to approve the policy but he is confident everyone will be on board by September. Those who have already signed up will start participating shortly.

He believes the process of debating the new policy has been invaluable in itself. 'It's acted as a catalyst for discussions about end of life care generally. Communication between the sectors is crucial for all end of life care and the unified DNACPR policy will help trigger information-sharing where it has not happened in the past.'

Results of mass consultation bring Good Death charter for North East a step closer

The results of the first-ever UK public consultation around end of life care show that almost 70% of North Easterners have experienced a bereavement in the last five years – but most are unprepared for their own death.

The consultation sought people's views about the Good Death charter, which is being developed in the North East and which sets out proposals for the kind of care and support which people who are dying, their families and carers, can expect to receive.

It reveals that two thirds of North Easterners have not discussed their wishes or made plans for the care they would like to receive, the kind of funeral they would like to have or made any financial arrangements. Almost 2,500 people had their say during the consultation which ran between October and December 2009.

The consultation also revealed that nine in ten would want to be told if they had a terminal illness, more than half would prefer to die at home and those aged between 35 and 44 are most likely to have an organ donor card.

A Good Death charter will be used by NHS North East and its partners to guide the provision of the right services and support to meet people's needs at the end of life.



Joint initiative to help kidney disease patients

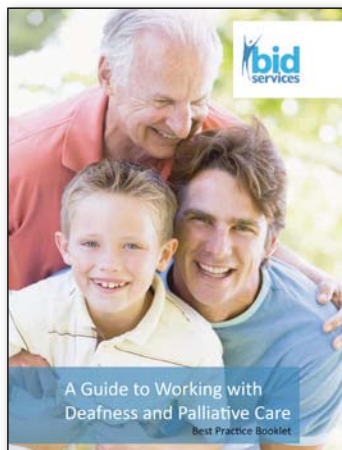
The Cheshire & Merseyside Kidney Care Network has begun a project to implement the North West end of life care model for patients with advanced kidney disease. The money comes from the SHA's Regional Innovation Fund.

An Implementation Group has been established to oversee the 12-month project. The group has started developing a training package which will be rolled out to all levels of staff in primary care and in dialysis and satellite units throughout Cheshire and Merseyside. An End of Life Care Project Implementation Manager dedicated to the Kidney Care Network will shortly be recruited.

The bid was submitted because kidney care clinicians had expressed concerns over end of life issues such as prognostication and breaking bad news. It was also felt that kidney patients were often unaware of their poor prognosis which could lead to them having unrealistic expectations of their disease.

The North West model of delivery uses a whole systems approach for all adults with a life-limiting disease regardless of age and setting, moving from recognition of need for end of life care to care after death. The pathway model identifies five key phases: advancing disease, increasing decline, last days of life, first days after death and bereavement.

For further information, please contact debbie.moores@wirral.nhs.uk



New guide to caring for deaf patients

A new booklet offers support and guidance to palliative care professionals who are caring for deaf patients at the end of their lives.

Nearly 9 million people in the UK – or 16% of the total population - are deaf, deafened or hard of hearing but their needs are often overlooked by healthcare staff because of a lack of understanding.

The 24-page booklet, produced by deaf support organisation BID Services, provides information and advice on how to communicate more effectively with deaf people and seeks to raise awareness of the difficulties faced by deaf people when communicating in the hearing world.

A Guide to Working with Deafness and Palliative Care also contains 10 tips to professionals on how small things can make a big difference to communication. These include using gestures and body movement, making sure your face is always fully visible, reducing background noise, not using jargon and not shouting.

BID Services has also produced a DVD, entitled *Cheryl and Philip's Story*, which offers a personal perspective on communication problems and how they can be remedied. The booklet and DVD can be ordered free by sending £1.50 to cover postage and packing to: BID Services, Deaf Cultural Centre, Ladywood Road, Birmingham, B16 8SZ or phoning 0121 246 6100.

This month's focus is on nursing. We look at the wide range of specialist and generalist palliative care roles through a series of Day in the Life vignettes. We also report on a successful community matron initiative, a new bereavement protocol for community nurses and how everyone can benefit from end of life care e-learning

'It's a huge accolade but also recognition for disability services'

Dorothy Matthews is still in a state of shock when I speak to her five days after she won the *International Journal of Palliative Nursing's* coveted Palliative Care Nurse of the Year Award at a glittering event in London.

'It was so exciting to be nominated and short-listed, but to actually win it was unbelievable,' she says. 'It's a huge personal accolade but it's also recognition for disability services and that's just as pleasing.'

Dorothy has worked with people with learning disabilities for over 30 years and has been in her current Macmillan Nurse role, covering all Northumberland, for the last six years.

In that time she has worked to bring together all the relevant services needed to ensure that people with learning disabilities have the same choice and receive the same quality of care at the end of life as everyone else.

One principal objective is to enable people with learning disabilities to stay in their preferred place of care. 'If a person is in hospital and then discharged for palliative care, for instance, it's about thinking widely and developing strategies so they can go back to their own home.'

Dorothy's role involves not only informal support, but also education about palliative care, the particular illness and its trajectory. 'Often there needs to be education for the carer of how they can best support the person with a learning disability and how best to answer the inevitable questions.'

Her typical day begins at around 8am with the usual round of phone calls and email responses. She will then check on her clients to ensure there have been no crises overnight and embark on her home visits. She has about 20 people on her caseload at the moment although the frequency of visits will vary depending on individual needs.

Much of her work involves organising and coordinating different services to ensure the individual's wishes and best interests are met. She describes how one elderly woman with advanced oesophageal cancer was facing frequent visits to the general hospital, involving a 60-mile round trip that left her exhausted and isolated from her friends and carers.



Dorothy Matthews, Macmillan Clinical Nurse Specialist Palliative Care, Learning Disabilities

Dorothy discussed the issue with the local GP and community services and agreed to place her on the nurse-led admission pathway since this would allow nursing or medical interventions to take place in the nearby cottage hospital. 'It meant that when the lady developed an infection, for instance, she could be admitted to the cottage hospital, allowing carers and friends to pop in to see

her. But the majority of the time she was able to spend at home.'

The woman eventually died peacefully in the cottage hospital as her needs became more complex, but, says Dorothy, she appeared happy with this. 'She wasn't isolated as she still had her friends and care team around her.'

One of the main differences in working with this client group is that often they are unable to articulate how they feel, which could lead to poor symptom control. With this in mind she and her colleagues have devised the Disability Distress Assessment Tool (DisDat) which helps staff understand when someone with a learning disability is distressed. 'It means staff have a record of the person's usual methods of communication when they are content and distressed,' she explains.

Despite the huge scope of her job Dorothy is confident she is making a real difference. 'I'm really proud of the networks I have built up and the clinical expertise and support I can bring to patients. I think I have also been able to facilitate more timely access to mainstream services.'

The work can be stressful but there are always positives to be taken from any situation. 'Of course we all aim for good end of life care and a good death. It's also important to realise you can't always make that happen for everyone all the time. But you can always learn from that experience to ensure things improve for the next person.'

- Dorothy and her colleague Lynn Gibson, in partnership with the NHS North East and University of Edinburgh, have produced a resource pack for those supporting people with a learning disability at the end of life. The pack is available as hard copy, CD Rom or download from a number of websites, including the National End of Life Care Programme website. tinyurl.com/y23nsrr

'We are definitely moving in the right direction'

Sharon de Caestecker

remembers all too well an early experience of working at night as a student nurse on a ward where a patient was dying in a side room.

'I was petrified in case he died while I was on duty,' she recalls. 'I just remember feeling paralysed, not knowing what to say or what to do.'

The experience made her determined to learn more about caring for the dying patient. And when she did it was a revelation – 'there is so much satisfaction in that area of work. It's a huge privilege when people are sharing their stories with you.'

It could be said that night on a general ward led indirectly – via, among other things, being a care manager at a day hospice and a hospital Macmillan nurse – to her current role as Head of Education at LOROS, the Leicestershire and Rutland Hospice.

It also gives personal insight into her chief priority of the moment, which is raising the level of end of life care among the thousands of generalist health and social care staff in Leicestershire and Rutland and beyond. That is often a matter of developing people's skills and knowledge, she says. 'But perhaps the biggest issue is developing their confidence.'

Sharon has led the Education Team at LOROS for the last eight years. When she arrived she was the education department, she admits – it has now swelled to 16 staff.

Officially she works a four-day week but, she admits, 'it's a lot more than that in practice...the job requires a certain degree of flexibility!'

On one typical day last month, for instance, she was in her office at 8.30am to meet and brief two new recruits to LOROS' practice development team – which operates in the workplace rather than the classroom – and to discuss with the whole department different ways in which they might disseminate learning across all care settings.

She also chaired a multidisciplinary palliative care group that covers education for health and social care staff across Leicestershire and Rutland. The group, which has operated since September 2009, works to develop and coordinate action plans on educational issues.

She then had a meeting with the Hospice Chief Executive to discuss the contents of a promotional



Sharon de Caestecker, Head of Education, LOROS

DVD marking the hospice's 25th anniversary and designed to be launched at a match in April at Leicester City's football ground.

She underlined the key messages she wanted to get across in the DVD. 'The first is that most people don't require specialist palliative care when they are dying but they do need staff to have a basic level of skills and knowledge. Second, we want to assure our donors that their funds go directly into patient

care; the education department is financially self-sufficient.'

Sharon's role involves not only setting up and overseeing courses and other educational activities but also working strategically with organisations such as the local health care workforce deanery, higher education institutions and health and social care providers.

The launch of the End of Life Care Strategy in 2008 has significantly increased educational opportunities but at the same time widened the scope of work. 'On the back of the strategy and the additional money there seems to be a huge interest in education and we're trying to seize those opportunities.'

That's allowed the hospice to reach staff groups who were previously outside their orbit. 'Care homes, for instance, have no money to support education so no matter what you put on, they can't afford to pay. As a result of the End of Life Care Strategy, though, we've been able to fund staff to come on these courses.'

Sharon is particularly proud of one of LOROS' new initiatives which will involve running a total of 63 three-day advanced communications skills courses over 2.5 years specifically aimed at bands 5 and 6 across health and social care.

The initial courses have now been evaluated and received an enthusiastic response. 'People are changing the way they're working as a result. They're saying they have got the skills but they're now developing the confidence to take on those end of life care discussions. That is so encouraging.'

She derives huge job satisfaction from what she is doing. 'When you see things clicking with students and when you hear people saying I've been able to put this into practice and that's had an impact, it makes you realise you're doing a worthwhile job. We are definitely moving in the right direction.'

"There's a huge interest in education and we're trying to seize those opportunities"

'End of life care is part of everyday practice. It's in the ether'

Helen Meehan admits there just aren't enough hours in the day to do everything she wants to do as the Lead Nurse for Palliative Care in Solihull Care Trust.

As the principal standard bearer for palliative care in the joint health and social care trust, Helen is responsible for a team of six specialist palliative care Macmillan nurses as well as leading service improvement and strategy around palliative and end of life care.



Helen Meehan, Lead Nurse (Palliative Care) Solihull

Since last year she has also been Clinical Champion for End of Life Care, working as a clinical adviser for commissioning. Officially that role, which emerged from the Darzi report, takes up five hours a week but Helen admits it's not always possible to keep it so neatly within those limits.

The result is she starts her working day early and often continues until late. 'I'm usually in at 8 and should finish at 5 but almost invariably you don't.'

Typically she will spend the first half hour or so dealing with administrative matters and emails that have piled up overnight before checking in with her Macmillan team ('who are now three flights of stairs below me so that helps keep me fit!').

The team gets new referrals almost every day so Helen always likes to touch base first thing. 'I try to be as visible as I can to support them with any queries or concerns they might have about patients or complex family situations.' She has also been closely involved in interviewing applicants for two vacancies on the Macmillan team.

Another task is drawing up a policy for administering subcutaneous infusions to patients in the community. This has involved meetings with the IV therapy lead nurse and specialist palliative care pharmacist followed by an extensive email correspondence to hammer out the detail. A draft policy has now been sent to district nurse leads for consultation. The aim is to have it approved by May.

In addition Helen has been working with some of the Macmillan team and the specialist pharmacist to review the trust's policy on using syringe drivers for subcutaneous medications. Again it is hoped to have an updated policy in place by May.

She receives regular inquiries from other PCTs wanting to know more about Solihull's many end of life care initiatives such as Comfort Care and Just in Case boxes, patient care pathways, training

programmes or the intranet site.

Last year, for instance, she responded to requests from 40 different trusts. That can be time-consuming 'but if we have done something that works then it's nice to share that with other organisations – as well as telling them how we might have done things differently!'

Helen took up her present role in 2004 after five years as a Macmillan nurse. She

admits she sometimes misses hands-on patient contact. 'But I do get a buzz from seeing the outcomes from service improvement and feedback from patients and carers.'

She also really enjoys being part of the Macmillan team – 'and they're very supportive of me. I can be a bit like a dog with a bone - when one project ends I immediately want to get another started!'

Perhaps the biggest frustration is that there aren't enough hours in the day and everyone's priorities differ. 'I am passionate about end of life care but for GPs and district nurses it's just one part of their job. You are competing with so many different priorities.'

Nevertheless she has no doubt her team are making real progress. 'You can become very frustrated at the day-to-day pace of change which seems really slow. But when you think that five years ago patients didn't have Just in Case boxes or anticipatory drugs and we didn't have a care pathway or end of life care tools, then you realise we actually have come a long way.

'The profile of end of life care in the organisation is now really high. And if we get end of life care right it impacts on so many other ways we work.'

Helen is concerned to extend end of life care support to the many patients who remain in danger of being overlooked – such as those with heart failure, respiratory disease, stroke, dementia and the elderly frail.

'There are still gaps in the pathway where patients fall through the net but our baseline is much higher than it was five years ago. If a patient is recognised as being in the last six to 12 months of life then we'll be proactive and support them whether their problem is a physical one or not.

'In 2003 end of life care and GSF was still seen as a project. But now it's part of everyday practice. It's in the language, it's in the ether.'

"If we get end of life care right it impacts on so many other ways we work"

'We're guests in their home. We're not there to take over'

As a district nurse working in Tunbridge Wells **Madeleine Stuart** says she has an increasing number of patients expressing the wish to spend their last days in their own home.

She reckons that a third or more of her work is now devoted to caring for patients with life-limiting conditions. And it is work that, despite the emotional stresses, she finds hugely rewarding.

'It's never easy when a patient passes away,' she says. 'But I do get a lot of job satisfaction if I feel a patient has passed away peacefully and comfortably in their own home or in a hospice and that's what they wanted.'

Madeleine is Care Manager for Community Nursing Service in the Tunbridge Wells, Kent area. She sees her role as not only as providing expert care to the patient in their own home but also acting where appropriate as patient advocate and liaising with other services to ensure everything is there for the patient when it is needed.

Her first visit today, for instance, is to a young mother with MS who is recovering from an acute attack that left her wheelchair-bound. Madeleine has been involved over the last few weeks in organising carers to help the woman with showering and dressing and arranging for OTs to visit to sort out aids such as grab rails and assessing the shower room for modifications, as well as a ramp to allow her access to her garden. She's also trying to sort out a medication review, speed up an appointment with the neurologist and organise a benefits re-assessment.

In addition Madeleine offers the woman and her husband emotional support – 'she's understandably pretty low at the moment' – and puts her in touch with the MS specialist nurse and the MS Society.

Later in the day she visits a middle-aged patient who has just started her second session of chemotherapy following a diagnosis of cancer. With the help of her husband she is largely able to look after herself but Madeleine still plays a vital role liaising between patient, hospice and her local GP.

'I'm monitoring the situation and being there for her and her husband,' she explains. 'I can also act as signpost to different services they may need.'

So, for instance, she has referred her to the OT to have a home assessment for equipment and aids to make life easier. The woman has also indicated she would prefer to be cared for at home so if



Madeleine Stuart, Care Manager for District and Community Nursing Services, Tunbridge Wells

things did deteriorate Madeleine would arrange for a hospital bed to be brought in and ensure all the necessary equipment, including overnight oxygen, and medication were readily available.

At the moment she is only visiting this patient once a fortnight but is always at the end of the phone should things take a turn for the worse. In fact all patients receiving palliative care have a list of phone numbers, including the district

nursing team and the evening and night services, which they can access at any time.

Madeleine's final visit is to an elderly man in the advanced stages of cancer who is in his last weeks of life. He has been gradually deteriorating over the past three months and Madeleine now drops in every day to see how he is.

Here her involvement is much greater. It includes ensuring all the equipment needed is available, liaising with the oxygen company to have oxygen 24 hours a day, contacting the clinical nurse specialists from the local hospice and the patient's own GP and pharmacy to have the right drugs on hand, bringing in night sitters to give the family a break and making sure through careful titration of his analgesic that the patient remains pain free.

The patient indicated at an early stage that he would like to die at home if possible. Madeleine is determined to ensure that his wishes are carried out – even if he changes his mind and eventually wants to go into a hospice. 'I need to reassure him that will happen. Nothing is set in stone.'

All members of the district nursing team receive regular training and updates in palliative care. There is also a strong support network to deal with the inevitable stresses of this work.

Madeleine derives immense satisfaction from her job. 'I may not always be the most important person in a person's care. But if I'm able to give good care when I'm there and act as a signpost to other services, then that is sufficient reward.'

Nursing people in the community is very different from looking after them in hospital, she feels. 'You get to know people in their own homes as well as family and carers. We are very much guests in the home. We're not there to take over. We're there to support them. And if they don't want to go into hospital then it's up to us to take the measures necessary to avoid that. It's just a matter of being there for people.'

"I get a lot of job satisfaction if a patient has passed away peacefully and comfortably"

'We're all trying to improve care and alleviate suffering'

"I get a real buzz seeing nurses with whom I work turn into expert practitioners"

The best bit of clinical advice **Katherine Hopkins** ever received was that if you find you're juggling too many balls you should put one in your pocket – it's much better than dropping it.

In her role as Macmillan Nurse Consultant in Palliative Care at the Royal Free Hospital, London, Katherine finds that a valuable thought to bear in mind. In addition to her consultant post she is also lead clinician for this integrated hospital and community service, the trust lead for end of life care and provides senior leadership for the bereavement service.

It makes for a busy life. 'It can be very easy to get caught up in all the different demands,' she admits. 'But the reality is that you can't do it all and you have to leave things sometimes. It's about working to priorities and keeping patients at the centre of everything you do.'

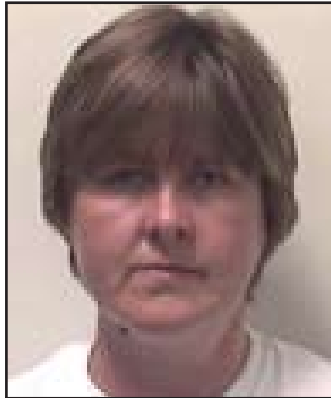
Her workload on a fairly typical Monday last month indicates the breadth of her activities. Her day begins at around 8.30 am with half an hour devoted to checking emails and prioritising urgent actions or responses.

At 9 she takes part in the clinical handover where the on call specialist nurse reports back on the main issues that have cropped up over the weekend. This is followed by a 'board round' where Katherine receives a brief resume of the hospital's clinical workload. During these meetings Katherine is assessing the whole service workload, spotting highly complex situations and ensuring staff under pressure are supported.

By 9.30 she is at her first full-scale meeting of the day, a research group looking at the experience of the family and carers of patients with end stage renal failure. An hour later she is back in her office to undertake a case review with a clinical nurse specialist in palliative care of a patient who has suffered an adverse reaction to the drug he is currently on. They discuss the possible options and agree an alternative.

The next couple of hours are spent with members of the hospital Patient at Risk and Resuscitation Team discussing progress on a long-term nurse-led project examining the treatment of acutely ill adult patients within the 800-bed hospital.

The project aims to help doctors and nurses manage acutely ill patients in the most appropriate way and examine how patients respond to various interventions. 'Where patients are not responding and it looks as if they may be entering the end of life stage we try to help staff look at their decisions and perhaps change the paradigm from active to



Katherine Hopkins, Consultant Nurse Palliative Care, Royal Free Hospital

palliative care,' Katherine explains.

The initiative has involved exhaustive audits of care of place of death within the hospital as well as joint teaching undertaken by the two teams to help nurses and doctors recognise when a patient may be entering the final stages of life. One element of this is a teaching programme every August for new registrars that is already having an impact on practice.

After a late lunch she takes a call from the matron at the Royal Free's satellite neuro-rehabilitation unit. A patient with a chronic degenerative neurological condition has been admitted on the LCP to one of their continuing care beds. The matron is concerned to get expert input from the palliative care team and Katherine arranges for someone to visit the next day to assess the patient. They also take the opportunity to discuss educational support for the service on end of life care.

Her next trip is to the North London Cancer Network where she discusses the development of a commissioned neuro-oncology pathway with one of the network's officers. Finally, she returns to her office to spend an hour with a palliative nurse colleague from a neighbouring service and a senior specialist palliative care social worker discussing specialist social work roles and considering the education needs of clinical nurse specialists in palliative care. Then it's time to call it a day. By the time she gets home she is, she says, 'shattered'.

Katherine qualified as a nurse 31 years ago and first moved into palliative care work in 1987. She became Lead Nurse for Palliative Care at the Royal Free in 2000 and took on her consultant post in 2003. She admits she doesn't do as much clinical work as she would like but the variety of her work offers immense compensations.

'In the past I would have said the greatest buzz came from my work with patients. But I get just as much of a buzz seeing nurses with whom I work develop into expert practitioners. I take a tremendous pride in that.'

She would never want to give up direct involvement with patients altogether. 'It is work with patients that grounds me. That's why I do everything else,' she says. 'You always have to remember why you're doing this job. At heart what we're all trying to do is improve care and alleviate distress and suffering.'

Sometimes, she acknowledges, it can be difficult in her job to see the wood for the trees. 'But the bottom line is that I know that our team is providing a good service and making a real difference,' she says. 'And that's the most important thing.'

Community matron scheme is making an impact

Evaluation of a palliative care community matron scheme in Oxfordshire indicates it is saving money and meeting unmet needs. Andrew Cole reports

An Oxfordshire community matron scheme aimed at supporting patients with palliative care needs is helping to focus attention on unmet need, service gaps, staff knowledge and skills deficits.

Liz Clements has been working as Community Matron across the county since December 2006. During that time she has helped more people to die where they wish and in a 12-month period saved an estimated £64,000 in reduced hospital admissions.

The aim of the Community Matron Supportive and Palliative Care Service, which is the result of a partnership between Oxfordshire PCT and Sue Ryder Care, is to help people at the end of their life manage their symptoms effectively and die in the place of their choice.

Referrals can be made by any health care professional. An evaluation covering the first year of the service revealed that just over 58% of those referred had a cancer diagnosis with the other 42% having a mixture of palliative conditions including respiratory disease, cardiac disease, motor neurone disease, Parkinson's disease and dementia (the split is now closer to 50-50) . The average time on the community matron caseload was five months, ranging from two days to two years.

Liz received 128 referrals in her first year of whom 20 were supported and then discharged to other services and 78 died. More than half have been supported from referral to death.

Of the 51 people who identified where they wished to die, 49 were able to achieve this objective. A further six were unable to express a preference but those closest to them believed they died where they would have wished to.

The evaluation also calculates that the new service saved around £41,000 in 2008 through providing intensive support in the community, which prevented a hospital admission, and a further £23,000 by facilitating discharge of those patients who were admitted.

Liz works closely at all times with a range of other health and social care services. She also delivered 15 formal educational sessions to nursing homes, intermediate and continuing care as well as providing one-off support to primary healthcare teams where required. She has actively promoted advance care planning in nursing homes as well as with patients on her caseload. She has also been leading a rapid response initiative and is working on a dementia end of life care pathway.

The new post has been very well received despite initial concerns over possible duplication of roles from one group of professionals. It is particularly popular with patients and carers. One carer



Liz Clements...service is saving over £60,000 a year

commented: 'We simply could not manage without her.' The fact that so many patients have been referred suggests the role is justified.

'If there are existing specialist services that can support the patient I will happily back out,' says Liz. 'But most of the time I don't because there's something for me to do. We have clearly identified a need for the role.'

Perhaps the biggest impact of the post has been on patient choice. 'If patients want to be at home we try to sustain that and prevent crises as well as ensuring patients are discharged from hospital as quickly as possible.'

In fact the post, which was initially for just three years, has been so successful it has now been made permanent. Moreover, hopes are high that one or even two additional community matrons will be appointed to ensure all of Oxfordshire is fully covered for its end of life care needs.

The service was initially designed to cover only SE and SW Oxfordshire but a subsequent reorganisation of trusts meant that by the time it was set up it extended to the whole county. This has meant Liz has had to take on a caseload of nearly 50 and raise the threshold for referrals.

The evaluation recommended that a team of community matrons be created to cover the county, taking on a caseload of no more than 40 patients each. It also proposed that GSF and integrated care pathway facilitators should work closely with the community matron to help identify educational needs and ensure continuity in end of life care.

"We have clearly identified a need for the community matron role"



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Gloucester's bereavement protocol for community nurses

A new standardised protocol is helping community nurses to support the recently bereaved, says Gina King, Gloucestershire's Clinical Facilitator for End of Life Care

Supporting bereaved relatives following the death of a loved one can often be a neglected part of end of life care. At NHS Gloucestershire we would be the first to admit that until recently our bereavement services left something to be desired.

A baseline audit last year of services in the community and community hospitals revealed there was no standardised bereavement follow-up as well as a lack of information. A survey commissioned by the bereavement charity CRUSE also indicated that the PCT's referral activity was patchy.

As a result a working group was formed in September 2009 consisting of CRUSE, hospice and specialist palliative care representatives and a cross-section of community nurses from all localities in Gloucestershire. The group's purpose was to develop a standardised bereavement protocol that would support community nurses in their practice and would be in line with the Liverpool Care Protocol 'Care after Death' Section.



The Gloucestershire End of Life Care Team (left to right): Maggie Martin, Gina King and Karen English

The aim was to develop a standard focusing on bereavement support from community nurses and not the provision of counselling by a trained counsellor. Using a framework developed by a Gloucestershire GP surgery, the group first agreed the key principles of care.

These were: respect for the individual; recognising and acknowledging loss; provision of information through the LCP Resource Pack; support; ensuring environment and facilities are appropriate, and 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 document to record vital information between the identified key worker and bereaved relative that would provide evidence for signposting. A prompt sheet was created to support the nurse in asking key questions that would indicate if the relative or carer was at risk and needed further bereavement support. Answers would be recorded on the audit tool for future reference.

In addition a standardised letter for those who did not respond or who had left the area was devised and a contact card 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.

The protocol and the supporting documentation have now been approved by the Clinical Governance and the District Nurses Operational Group. The LCP resource packs are being reproduced so all district nurses in Gloucestershire will have supplies to ensure standardised practice.

We have also developed our own Advance Care Planning (ACP) document to support the Preferred Priorities of Care (PPC) document and advance directives. Our ACP tool, which is now being rolled out across the county, has been adapted from the Weston Hospicecare Advance Care Plan and the PPC.

The document, which was drafted with the help of a wide range of key stakeholders, has been divided into five sections. Each section also contains signposting for individuals to gain further information and guidance.

They are an introduction plus sections on PPC, putting affairs in order, appointing decision-makers and advance decisions. It is made clear that the document can be completed over a period of time, as and when an individual feels comfortable. It is also explained that ACP is a voluntary process and if the document is completed, it needs to be regularly reviewed.

The document was piloted between September 2009 and January 2010 in care homes within the Stroud area and supported by the locality practice-based commissioning group. The leads received training and support throughout the pilot period and targeted new and existing residents.

GP lead for the pilot Dr Sarah Atherton says the ACP document enables residents to die with dignity in their preferred place. 'For most this means not in hospital. Often a small amount of pre-planning can avoid unnecessary admissions.'

A few changes have been made to the document following the pilot. A short life implementation group has now been set up to oversee its roll-out.

'Bite-sized' e-learning package hits the spot

Feedback from staff and educators who have tested out the new e-learning sessions on end of life care has been enthusiastic, reports Chris Mahony



Nothing beats a little hands-on experience. That has proved the case for well over 1200 people who attended roadshows around England to introduce the landmark e-learning system for end of life care. Most training providers, education leads and clinicians who have tested e-ELCA (End of Life Care for All) at the 10 roadshows have emerged impressed.

Around 80 individual learning sessions are currently available to staff working for NHS organisations signed up to the National Learning Management System (NLMS). More than 20 new sessions will be added over the next few months. People accessing the package through the e-Learning for Healthcare Management System, CLIX, can access 123 sessions.

The package was launched in January and work is continuing on expanding access to all the 2.5 million people across health and social care whose work brings them into contact with people nearing the end of their lives. The project has been developed by e-Learning for Healthcare (e-LfH) and the Association for Palliative Medicine.

Twelve learning sessions are available via an open access website which does not require registration and are open to anybody keen to improve their end of life care skills and knowledge. An announcement on access for the social care workforce across the public, voluntary and private sectors is expected shortly.

The learning sessions, which typically take between 20 and 30 minutes to complete, are divided into four core modules covering advance care planning, assessment, communications and symptom management. A fifth module covers integrated learning.

Isabel Quinn, who leads on workforce development for the National End of Life Care Programme, says feedback has been very positive. 'People welcome the bite-sized nature of the sessions which means nurses and other busy care workers can learn at their own pace and at a time that suits them.'

'It is particularly heartening that educators are telling us the content complements existing learning and training. One person, for example, thought it would be very difficult for e-learning to have much of a role in communication skills training but she was won over after testing those sessions.'

If you work for the NHS and are not already registered to use other e-LfH resources, check to see if your organisation has signed up to NLMS. Many hospices and voluntary groups such as Marie Curie Cancer Care and Sue Ryder Care are currently registering large numbers of their staff with e-LfH to allow access to e-ELCA.



You can visit the e-ELCA website at:

- www.e-elca.org.uk

"The bite-sized nature of the sessions means people can learn at their own pace"

Helping staff with effective assessment of spiritual well-being

One of the e-ELCA sessions within the assessment module is *Assessment of Spiritual Well-being*.

Written by two senior nurses in palliative and end of life care at Guy's and St Thomas' NHS Foundation Trust, it takes participants through the central elements of effective assessment of spiritual well-being, one of the four core domains of an holistic assessment in end of life care.

The session starts by asking the participant to reflect on how confident they feel about discussing issues which many see as the preserve of the chaplain or faith worker. It moves on to look at definitions of spirituality and religion.

The session stresses the need to discover an individual's own approach to their faith and its rituals. Where people declare no attachment to a particular religion, the session explains how you can look to their other interests which might be a substitute for faith and provide an opportunity to

explore therapies as a form of support.

Among the benefits of a thorough spiritual well-being assessment, it suggests, are:

- Ensuring that patients with a religious belief are able to practise according to their faith
- Helping the patients examine questions around the meaning of their illness and support them, if possible, to find meaning in their situation
- Identifying supporting and coping strategies for the patients
- Helping patients recognise a sense of value in the world
- Enabling patients to engage confidently with their past, present and future.

As with many of the sessions, participants can read case studies and watch videos of assessments in progress. Another session which complements this is one entitled 'Why me?', which discusses spiritual distress, in the Communication Skills module.

News in Brief

Cancer inequality



The National Cancer Equality Initiative has produced a new report setting out the next steps for tackling inequalities in cancer, as well as promoting greater equality. *Reducing cancer inequality: evidence, progress and making it happen* is available at tinyurl.com/yhvf7vh

PPC evaluation

NHS West Essex has published an evaluation of the use of Preferred Priorities for Care (PPC) within the trust between July 2008 and October 2009. The evaluation showed that 83% of those with a PPC died where they wanted to. See tinyurl.com/y3auu23

Network Partnership

A draft version of the Network Partnership Group measures for inclusion in the Manual of Cancer Services has been issued for consultation. See tinyurl.com/y84brxs

User involvement

The Department of Health has produced a new paper on service user involvement in cancer care. It will be used to help revise the 'service user involvement' standards that are integral to National Cancer Peer Review measures. See tinyurl.com/y4qz8d9

Patient engagement

A new on-line tool has been launched to help the NHS use effective patient and public engagement to improve quality and productivity in healthcare. *Invest in Engagement* is produced by the Picker Institute Europe and funded by the Department of Health. www.investinengagement.info

Social care report

A new report from the House of Commons health committee looks at the present social care system, its shortcomings, meeting future demands and costs and the plans for reform. *Social care: third report of session 2009-10* is at tinyurl.com/ykntkr

Substance abuse

St Nicholas Hospice is holding a national conference on managing palliative and chronic pain in substance abuse on Thursday 17 June at Bury St Edmunds, Suffolk. Contact: Rachel Brown, St Nicholas Hospice Care on 01284 715591 or email rachel.brown@stnh.org.uk

Volunteering vision

The Department of Health has produced its strategic vision for tapping into the potential for volunteering in the health and social care sector. *Volunteering: involving people and communities in delivering and developing health and social care services* is available from tinyurl.com/y8e63kn

Renal conference



Imperial College Healthcare NHS Trust is holding a two-day conference in July on supportive care for the renal patient. The conference will be at the Hammersmith Conference Centre in London from 7-8 July. More details: www.imperial.nhs.uk/hcc

Learning disabilities

Valuing people now sets out the Department of Health's strategy for people with learning disabilities for the next three years. It also responds to *Healthcare for All*, the independent inquiry into access to healthcare for people with learning disabilities. tinyurl.com/9tkrzh

Care White Paper



The Department of Health's White Paper on social care, *Building the National Care Service*, sets out plans to radically reform care and support across England over the next few years. For more info see tinyurl.com/ybdwaf2

Discharge guidance

Ready to go? Planning the effective discharge and transfer of patients from hospitals and intermediate care updates guidance on discharge practices for nurses and other practitioners. See tinyurl.com/y7dotlg

New registration

The Care Quality Commission's full legal powers are now in force, meaning all 378 NHS trusts in England have to be registered with the commission in order to provide care. See tinyurl.com/yd3ulzh

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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