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## National Update

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

### Find Your 1% campaign



This month sees the launch of a major campaign, headed by Dying Matters, to help GPs and primary care professionals identify as early as possible those people in their last year of life.

It has been calculated that around 1% of the patients on a GP's list will die in the course of 12 months, yet at the moment only a quarter of those are picked up early enough to enable them to be fully involved in planning how and where they die.

The barriers to early identification are well known. But on page 4 Professor Mayur Lakshani, chair of the Dying Matters Coalition, insists there is room for considerable improvement.

To mark the campaign – which also involves a range of support tools on both the NEoLCP and RCGP websites – the theme of this month's issue is primary care. In addition to articles on the campaign we also look at a dementia awareness initiative and an end of life care training programme for paramedics. See pages 4-7 for more details.

### VOICES update

The last newsletter contained an update on work around VOICES and surveys of the bereaved. We are pleased to say the Office for National Statistics has now been commissioned to run the survey

on behalf of the Department of Health. It is expected this will be rolled out in the early autumn.

It is clearly important to ensure that the bereaved are not approached through both the national survey and local surveys, and knowing the dates from which samples are drawn is key to this. The national survey sample will be drawn from 1 November 2010 to 30 June 2011. To support sampling for possible future national surveys, could anyone undertaking local surveys please let us know by contacting [information@neolcin.nhs.uk](mailto:information@neolcin.nhs.uk), providing details of the sampling, which can then be relayed to the Department of Health.

Finally, if anyone is thinking about undertaking a local survey, please ensure the wording of the questionnaire reflects the gender of the deceased. A questionnaire that makes an incorrect assumption about their gender can understandably cause distress.

### Easy Read version of PPC



A new Easy Read version of the Preferred Priorities for Care document is now available.

This version is designed for use in care homes and community and domiciliary care settings for people who find reading a challenge such as those with learning disabilities or early stage dementia.

The document, which has been

created in conjunction with Change, the learning disability human rights organisation, will be available from the NEoLCP's [website](http://www.neolcin.nhs.uk). A very limited number of hard copies of the Easy Read PPC can be ordered from [information@eolc.nhs.uk](mailto:information@eolc.nhs.uk).

A new NEoLCP support sheet, outlining the key elements of the PPC, is also now available on the [website](http://www.neolcin.nhs.uk).

### We need your views

As we noted last month we are currently working with the Information Standards Board for Health and Social Care to develop a national information standard for end of life care registers or records. This standard supports communication between providers of people's preferences, choices and decisions made for their future care.

As part of this process we would like to get your views on what should be within the information standard.

Please could you spare a few minutes to complete the short online [survey](http://www.neolcin.nhs.uk), giving your views on the information standard and the core content that should be included. The survey will close on Friday 30 September 2011.

If you have any queries, please contact NEoLCP Project Manager Katie Lindsey at [katie.lindsey@eolc.nhs.uk](mailto:katie.lindsey@eolc.nhs.uk).

Claire Henry  
National Programme  
Director  
September 2011



# News



## New guide aims to improve prison end of life care

The NEoLCP has published a good practice tool to help professionals working with people nearing the end of life in prison.

*The route to success in end of life care – achieving quality in prisons and for prisoners* is part of a cross-government drive to improve offender health. It comes at a time when the number of deaths from natural causes in prisons is likely to rise because of the ageing prison population.

The document is intended as a practical guide for both prison staff and health and social care professionals. It emphasises the need for all those involved in a person's care to work across service boundaries to identify those nearing the end of life and respond accordingly.

Regular assessments and reviews, advance care planning and communication between professionals and services are vital to improving end of life care in prisons, it says. It is particularly important that prison and NHS staff working within prisons form good communication channels with local community services.

The guide follows the nationally-recognised six step end of life care pathway, providing points and ques-

tions for prison, health and social care staff to consider at each step – together with case studies highlighting good practice.

The NEoLCP's Social Care Lead, Tes Smith, said: "The twin requirements of custody and care are recognised within the service with initiatives under way to improve health outcomes for offenders. However, those double imperatives can be particularly demanding when it comes to delivering end of life care in prisons.

"This resource sets out how staff, whether prison officers, managers or health and social professionals, can ensure that people in prison who are nearing the end of life receive appropriate and co-ordinated care while being treated with respect and dignity."

The guide highlights some of the specific issues facing those involved in the care of prisoners, including:

- The safety of the environment
- Access to symptom control medication and use of morphine or syringe drivers
- Compassionate release
- Access to training and support for prison staff
- Protecting the dignity and privacy of people nearing the end of life.

## Report highlights risks of suicide

At least 10% of all those who commit suicide are experiencing terminal or chronic disease at the time, according to a [report](#) from the think tank Demos.

The authors found that "there is a greater risk of suicide during the period immediately following a cancer diagnosis, with one study finding that the risk of suicide was highest in the one to three months after diagnosis, and decreasing (but remaining high) in the four to 12 months that follow.

"Another study identified a very close association between physical illness, depression and suicide in older people, while NICE guidance has found that people with chronic illness experience a much higher risk of depression."

The report recommends a closer examination of data on suicides. "It is essential that this information is acted on to improve medical, emotional and practical support for people with chronic and terminal illness who may be considering suicide," it says.

## Dorset's free communication skills training

Dorset Cancer Network will be providing free communication skills training to 160 staff working in care homes across Dorset this autumn.

The training meets the core communication standards for both end of life and social care and will help care homes to achieve high quality end of life care.

The network has also worked with a professional film crew and representatives from the Dorset Cardiac and Stroke Network user forums to develop a training DVD that stresses the importance of communication issues in care delivery.

The funding for the training has been released through a collaborative venture between the NEoLCP and Connect on behalf of NHS Dorset, Dorset Healthcare University Foundation NHS Trust and Dorset local authorities.

"This is an exciting time for us," said Annie Raven-Vause, Project Lead (pictured). "Having the chance to work seamlessly with colleagues across health and social care to design, deliver and evaluate this training has been vital to getting this project off the ground. Everyone has been so supportive – I am sure that together we will make a difference!"

The roll-out of the programme starts in September and spaces are limited. For more information and to obtain your free place contact Lorraine Bailey on 01202 854488 or email [lorraine.bailey@ferndown.nhs.uk](mailto:lorraine.bailey@ferndown.nhs.uk) or Verena Cooper, Lead Nurse, Dorset Cancer Network 01202 851 242.



## Manorlands BME project is making an impact - report

A Department of Health-funded project to increase access to palliative and end of life care services among BME groups is already beginning to have an impact, according to the interim evaluation by Bradford University.

The three-year Sue Ryder project in Bradford and Airedale District began in October 2009. It sought to recruit BME apprentices from unemployed people in the South Asian community in West Yorkshire and train them to NVQ level 2 in health and social care.

The overall aim of the scheme, which is run by a project co-ordinator, is to increase access and referrals to palliative services, make them more culturally appropriate and involve BME people more in the delivery of those services.

So far 10 apprentices have been recruited of whom three remain in post while the other seven have all gone on to full-time employment or higher education. One now works as a health care assistant at the Sue Ryder Manorlands Hospice.

"We have taken people who were unemployed or in casual work and given them a good foundation to enable them to secure permanent employment," said Project Co-ordinator Sikander Hussain (pictured). "None have gone back to the job centre."

The scheme has also increased the

local BME community's involvement in end of life care services, with 400 people taking part in various community engagement events and four people referred to the hospice between May and September 2010.

The report proposes that the project's recruitment strategy should be formalised and shared to enable the charity and national audiences to identify the learning and maximise recruitment from 'hard to reach' groups.

As a result of the project The Sue Ryder charity is also redesigning its awareness and diversity training and disseminating the learning to its other six hospices and neurological services. The project is due to end next year.

To obtain a copy of the interim evaluation, please contact Sikander Hussain at [sikander.hussain@bradford.nhs.uk](mailto:sikander.hussain@bradford.nhs.uk).



## 'Changes needed' to end of life care commissioning

The current system of funding and commissioning of end of life care is inadequate to meet people's needs, says a new King's Fund report to be published at the end of this month.

The report proposes a new approach involving a tariff for the end of life care pathway or package of care with local commissioners specifying outcome measures and encouraging integration through service contracts.

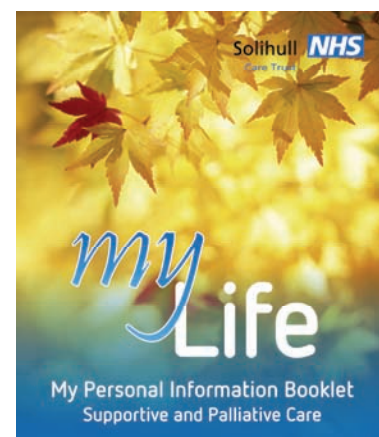
The report's authors caution against the use of personal health budgets for people approaching end of life care because these might be more burdensome than empowering. But they may be more valuable for those using this approach already such as those with long-term conditions.

The report identifies three major challenges to successful end of life care commissioning. These are: defining a discrete episode of care, ascertaining its cost and developing applicable and measurable quality markers.

It also outlines a number of factors that are critical to the success of integrated working in end of life care. These include:

- Shared vision and goals
- Contractual levers
- Appropriate funding mechanisms
- Clinical involvement
- Commissioner or GP acting as broker for co-ordination.

The report will be available on the King's Fund [website](#) from September 29.



## New end of life care booklet for Solihull patients

Many patients with life-limiting conditions in Solihull are now receiving a document – entitled the *My Life Booklet* – which seeks to support information sharing and advance care planning.

The booklet, which was developed locally in consultation with patients, carers and staff, is offered to patients on the practice GSF/ palliative care register and remains the property of the patient.

The booklet includes personal information, a record of professionals involved in the person's care, an advance care plan, an ongoing medication record, a record of advice given, a personal diary and useful contacts and information.

The record of advice given is used by clinicians to provide written information on advice or recommendations to the patient during a consultation. The patient is encouraged to take the booklet with them to any healthcare appointments.

The booklet is being implemented in phases. So far it has gone to those patients referred to community specialist palliative care services, community matrons and the community respiratory team. Phase 2 will include practices and patients supported by community nursing and the heart failure team.

Discussions are also taking place around how the booklet might be adapted to the hospital setting for patients with end of life care needs.

More information: Helen Meehan, Lead Nurse Palliative Care, Solihull Community Services - Heart of England NHS Foundation Trust. Email [helen.meehan@heartofengland.nhs.uk](mailto:helen.meehan@heartofengland.nhs.uk)



## Primary care

Primary care is where the majority of end of life care takes place – and the proportion is only likely to increase in the coming years. In this issue we focus on a new campaign, aimed at GPs, to ensure the 1% of the population who die each year are identified as soon as possible.

We also look at a project that is raising awareness of the end of life care needs of people with dementia as well as highlighting the vital role played by paramedics

## Helping to find the 1% in the final year of life

Around 1% of GPs' patients die each year. Professor Mayur Lakhani outlines a new campaign that seeks to identify end of life care patients earlier. On the next page Professor Keri Thomas discusses how prognostic indicators can help

Despite the many successes of end of life care, of which we should rightly be proud, too many people in the UK still do not receive the high quality end of life care that they need. This is in no small part because as a society we remain inhibited and uncomfortable when talking about death and dying.

At the Dying Matters Coalition, we know from our own research that it is not just the general public who have problems discussing dying but also general practitioners and other health and social care professionals. This is especially concerning as, after close friends and family, it is GPs that people turn to in order to discuss end of life issues.

The Dying Matters Coalition was set up two years ago by the National Council for Palliative Care to raise awareness about the need to discuss dying, death and bereavement.

As a key part of this, Dying Matters this month launched the *Find Your 1% campaign*. This is an innovative and exciting online project aimed at supporting GPs to identify the 1% of their patients who are likely to die in the next 12 months. Hosted by Dying Matters, in association with the NCPC, Royal College of General Practitioners, NEoLCP and QIPP end of life care workstream, the campaign aims to help GPs identify patients in the final year of life, support them in having difficult conversations with patients and carers about end of life issues and help them meet patients' and carers' needs.

Any GP who signs up to the campaign will not only be able to easily access end of life information on a brand new Dying Matters microsite, but will also receive regular emails to help them stay on top of all the latest news and developments in end of life care.

GPs have a crucial role to play in ensuring that more people can have a "good death". Between us we see almost one million patients every working day. And, as a guide, a GP with 2,000 patients will have approximately 20 deaths a year – more than one

every three weeks. The vast majority of these can be anticipated and patients in their last year of life can often be identified.

As a practising GP I know just how hard it is to break bad news to someone that their life is coming to an end or how difficult it can be to discuss their end of life care with someone who is dying. However, avoiding these discussions or failing to make time for them is not in any of our interests.

Talking about end of life issues is vital and the *Find Your 1%* website provides useful support. This follows on from a successful pilot project that Dying Matters led to boost general practitioners' confidence and improve end of life care. At the outset of the project, three fifths of participating doctors said they were not confident in initiating discussions on end of life. By the end of the study 86% of the participating



**“Facilitating a good death is a core clinical role, especially for frontline doctors”**

Professor Mayur Lakhani

doctors reported they felt confident about initiating discussions.

Ensuring team-based good end of life care can be one of the most satisfying aspects of healthcare, providing a great deal of support and relief not only for the patient but also their family. Moreover, early identification by GPs of people approaching the last year of their life can also lead to good end of life management, which can mean fewer inappropriate hospital admissions and has the potential to reduce NHS complaints.

#### ABOUT THE AUTHOR

Professor **Mayur Lakhani** is Chair of the Dying Matters Coalition and the NCPC. He is a practising GP and a former Chairman of the RCGP.

Facilitating a good death is a core clinical role, especially for frontline doctors, whether they are in primary or secondary care. Doctors should use a range of triggers and opportunities to identify their patients who are likely to be approaching the end of life – and this is where I am confident that the new campaign, which has been developed in consultation with a GP

advisory group as well as with a range of partners, can make a difference.

I will never forget the example of Matthew. He was in his 80s, had severe chronic obstructive pulmonary disease and was coming to the end of his life. His wish was to die at home. But during an apparent crisis out of hours, he ended up in hospital via a 999 call and died there shortly afterwards. The *Find Your 1%* campaign is aimed at preventing this kind of situation, by allowing early identification which leads to advance care planning, sharing of information across providers and minimises the risk of “crisis”.

I would urge all GPs to sign up at [www.dyingmatters.org/gp](http://www.dyingmatters.org/gp) to access the campaign website and to receive regular emails. We only get one chance to get end of life care right, which is why this new campaign is so important. This is not specialist territory but part of good general practice.

## How the Prognostic Indicator Guidance helps to identify patients earlier

The National GSF Centre and RCGP will be launching the updated fourth edition of the Prognostic Indicator Guidance shortly with the aim of helping GPs and other clinicians to identify patients nearing the end of life earlier and increase the numbers on the palliative care register.

We know that too few patients are currently included on the GPs' QOF (Quality and Outcomes Framework) palliative care/ GSF registers, and that there are a disproportionately low number of non-cancer patients. But we also know that if patients are recognised early and included on the register they receive better co-ordinated, proactive care that is more in line with their preferences, as confirmed in the recent National Snapshot of Primary Care<sup>1</sup>.

So how can we improve earlier recognition of these patients? The Prognostic Indicator Guidance asks three key questions:

1. **The surprise question.** Would you be surprised if the patient were to die in the next months, weeks or days? If not, what can you do now to support them?
2. Are there **general indicators** of decline and increasing need? These include decreased functioning and activity, reduced response to treatment, refusal of active treatment, repeated admissions, increasing impact of co-morbidities, worsening symptoms and being admitted to a nursing home among others
3. Are there **specific clinical indicators** related to their condition? These could be indicators for conditions such as heart failure, COPD or dementia.

If the answer is yes to any combination of these, then these patients should be included on the palliative care register and ideally prioritised according to need so that support can be more focused. In addition, extra support should be made available, advance care planning discussions begun and the process of proactive planning initiated.

How can we change practice? Using the GSF After

Death Analysis tool or Significant Event Analysis can help increase awareness or practices can be asked the following key questions:

1. What is your register ratio? How many deaths do you have in your practice population and how many of these are included on your palliative care/ GSF register in the course of the year?
2. What is your non-cancer/cancer ratio? How many of the patients on your QOF palliative care register - including care home residents - have non-cancer conditions?

The National Snapshot of Primary Care suggested the answer to both these questions was around 25%. This is good news for the minority that are being picked up early but bad news in that we are still missing the majority of all patients that die. We know we will never predict all, but sudden unpredictable deaths are fewer than most people think (the estimate is about 15%) so if we anticipated events earlier many more patients could be identified and included on the register.

The GSF Centre and the RCGP are involved in a number of other initiatives to encourage best practice. These include the RCGP/RCN End of Life Care Patient Charter that is being distributed to every general practice in England, a dedicated end of life resource on the RCGP website and a new palliative care guidance application - the 'Palli-App' - which can be downloaded onto mobile devices and gives instant guidance on symptom control.

The GSF Centre has also launched its Next Stage GSF Training Programme in Primary Care, *Going for Gold*, to help primary care teams put theory into practice along with the *GSF-in-a-day* crash course and *Better-Together* workshops for GPs and care homes.

#### REFERENCE

1. *End of life care in primary care: 2009 national snapshot*. Omega. National Association for End of Life Care, 2010. <http://www.goldstandardsframework.org.uk/GSFInPrimary+Care>

#### ABOUT THE AUTHOR

Professor **Keri Thomas** National Clinical Lead, GSF Centre CIC for End of Life Care. Clinical Expert End of Life Care, RCGP

#### MORE INFORMATION

The updated Prognostic Indicator Guidance will be available on the RCGP [website](http://www.goldstandardsframework.org.uk).

- [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

# Caring for people with dementia at the end of life

A campaign in NHS South Central to increase awareness of the end of life care needs of people with dementia has had dramatic results. Community Matron Liz Clements explains how it worked – and how it can be sustained

For the past two years the NHS South Central Clinical Leaders Network has focused on increasing awareness of the end of life care needs of people with dementia and their carers. The campaign has had a big impact – but there is still a long way to go.

The network decided to focus on dementia because we were well aware of gaps in the provision of palliative and end of life care as well as in support for patients with dementia and their carers. We also recognised that the number of people developing dementia was growing as was the cost of caring for these patients.

We set out two principal aims: to create a robust and clear dementia pathway and to ensure mass awareness and engagement so that end of life care for people with dementia can be improved.

It was decided that if we were to make progress on this we had to begin by finding out how many patients with dementia were in the last year of life and how many were on the end of life care register/ GSF within GP surgeries. In September 2010 the practices' educators for end of life completed a scoping exercise across Oxfordshire to identify the exact figure.

We were not surprised to find that the initial figure was low since predicting when a patient with dementia is in the last year of life is notoriously difficult. In addition health professionals working in the community and dealing with patients with dementia were highlighting a need for educational sessions on dementia for themselves. A third of practices replied to the exercise which revealed that just two patients with dementia were on the registers. The Clinical Leaders Network decided to set a target of increasing the baseline figure by 30% by the end of 2010.

A robust campaign to raise general awareness about dementia began. Educational sessions took place in

## ABOUT THE AUTHOR

**Liz Clements** is Community Matron Palliative and Supportive Care, Oxford Health NHS Foundation Trust /Sue Ryder Care



“The number of people developing dementia is growing as is the cost of caring for these patients”

Liz Clements

## CLINICAL LEADERS NETWORK

The Clinical Leaders Network for South Central is part of the National Clinical Leaders Network Project which aims to facilitate inspirational change by clinicians who are supported as part of an extended peer network.

Created in 2009, the South Central Clinical Leaders Network, led by Associate Director of End of Life Care Lucy Sutton, focused on improving the end of life care for people with dementia. Clinical leaders from across the region have joined the network. They bring a wealth of experience and their work has led to improvements in the clinical pathway for people with dementia.

the community to help case managers improve their understanding of dementia as well as their ability to support patients and relatives.

I also visited memory clinics across Oxfordshire to link with colleagues working in mental health to promote the inclusion of patients with dementia on end of life registers. The practice development facilitators for end of life care also actively promoted the use of the GSF and end of life registers, both within GP surgeries and across nursing homes within Oxfordshire.

In addition community hospitals across Oxfordshire all received a copy of the Department of Health Dementia Strategy and are now planning to pilot a pain tool specifically for patients with dementia.

The End of Life Reference Group for Oxfordshire also discusses dementia issues at its regular monthly meetings. This strategic meeting, which is supported by the commissioner for end of life care, involves stakeholders from all areas including social services, the four hospices across Oxfordshire, Age UK, continuing care, primary and secondary care and the county council and has really helped to link dementia with palliative and end of life care.

The results have been dramatic. By the end of 2010, just four months after the initiative began, the number of patients on end of life registers within Oxfordshire had increased to 19 and this figure is only from the third of practices who responded to the original request.

But this is just the beginning. We want to continue to add more people to the registers and so enable them to receive the support the GSF offers. But we also recognise that sustaining this will probably be the hardest part.

## CONTACT DETAILS

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# Why paramedics are a vital part of the team

Ambulance staff can play a vital part in good end of life care. Here Tracy Reed tells Andrew Cole how a training programme run especially for paramedic staff is already helping to cut unnecessary hospitalisation

The important role of ambulance staff in good, co-ordinated end of life care can sometimes be taken for granted. But that is not a mistake that is being made in West Essex.

The trust does not have 24-hour nursing cover for those at the end of life so the ambulance service – and specifically emergency care practitioners – will often be the first people on the scene when the patient or their relative dials 999. If they aren't aware of people's wishes or needs, this can often result in needless hospitalisation.

For the past six months St Francis Hospice, Romford – in conjunction with local community services – has been running a training programme especially for paramedic staff and the benefits are already beginning to be felt.

Tracy Reed, who is Education Facilitator for End of Life Care with South Essex Partnership University NHS Foundation Trust (formerly NHS West Essex Community Health Services) and has been closely involved in the scheme since it started last November, explains that as first responders paramedics' understanding of the individual's needs can be critical.



Paramedics say they now feel more part of the team "and not just a transport system"

She knows this all too well from personal experience. In her previous job she came across two incidents where staff attempted to resuscitate dying patients despite the fact that their DNACPR documents were lying close by in the same room.

"Sometimes doing nothing can be more beneficial than acting precipitously," she says. "But of course if you don't know what to look for, you're not going to realise this."

So far 60 paramedics in south east England have gone through the one-day end of life care training, which covers such things as just in case boxes, medication, syringe drivers, GSF, LCP, PPC and general trouble-shooting.

And, says Tracy, it is already having an impact. Because most emergency care staff now have the training, palliative care patients have been advised to ring the emergency care number rather than 999 in

the event of a crisis. This has already led to at least eight cases within West Essex where hospitalisation was avoided because paramedics were either able to provide help themselves or call in the necessary support to maintain the patient at home.

This has improved partnership working with the community teams and strengthened links with the hospice palliative care and integrated teams. The paramedics now use the local hospice 24-hour advice line and link with the integrated teams.

In addition the palliative care leads for ECP have been able to challenge some over-rigid care protocols. For instance, says Tracy, one protocol used to stipulate that paramedics could not administer the first catheterisation, which would have probably meant the patient being admitted to hospital. "But when a patient is on the Liverpool Care Pathway it would be absolutely ludicrous to take them to hospital for this and we have managed to change it."

Another innovation has been the development of an end of life care booklet – produced by two members of the emergency care team – that is now carried by all paramedics. This contains examples of best practice as well as helpful advice on a number of end of life care scenarios. The East of England SHA is currently considering adopting this for paramedics across the whole of the south east.

For the paramedics themselves, the training has been something of an eye-opener, says Tracy. "It's helped them realise what they don't know and pointed up simple things like looking for documents such as the patient's PPC that previously they didn't know about. They say they now feel more part of the team and not just a transport system."

This sense of being part of a team with a common goal is critical to good end of life care. "Partnership working is key to fulfilling what the patient wants," she observes. "If you're not all singing from the same hymn sheet, then that's never going to happen."

Emergency care practitioner Amanda Lee, one of the authors of the end of life care booklet, agrees. The training has given her a lot more confidence in dealing with people who are dying, she says. It's also helped to make other professionals such as district nurses more aware of the team's role.

Most importantly, it is helping to avoid unnecessary hospitalisation. "Since we had the training we have been able to keep people where they want to be, which is generally at home, 99% of the time. And that's very rewarding."

## CONTACT DETAILS

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# Finding the words: communications at the end of life

A group of users who came together to discuss their experience of end of life have helped produce a powerful booklet and DVD on the dos and don'ts of good communication. Andrew Cole talked to some of them

Time and time again, it seems, the difference between a good and bad end of life care experience comes down to how we communicate. The right information at the right time can be so important – as can the way in which it is conveyed.

Tony Bonser knows that only too well. His son Neil died two years ago after a five-year struggle with cancer. He says he wouldn't want anyone else to have to go through the experience he and his wife suffered while their son was dying.

For instance, he says, they were never told about the seriousness of Neil's condition until almost the end. "We weren't told his life was likely to be short. It was never suggested we might best spend our time together as a family - and as a result we went around chasing cures."

They were also startled to be told by the consultant at the bedside that the medical team had decided they wouldn't attempt resuscitation in the event of a heart attack. "We didn't even know that a heart attack was on the cards until that moment. Nor did we know whether Neil was awake and could hear what was being said."

Yet in contrast Tony recalls how the day before Neil's death the Macmillan nurse started by asking Neil what he wanted. "That was the first time in the whole process anyone had asked him what he wanted."

"He said he wanted to be at home and that's what happened. I know that if he had been in hospital he would have been angry and scared – he hated hospitals. But in the event he died peacefully where he wanted to be."



**“It was the first time in the whole process anyone had asked Neil what he wanted”**

Tony Bonser

Tony is now “on a mission” to ensure that others involved in end of life care learn from what his family went through. “It's the only way I can make sense of, and validate, Neil's life as well as trying to make it better for other people,” he explains.

So when late last year the NEoLCP and Connected decided to invite users to be involved in their Communication Skills Pilot Project, Tony was only too happy to sign up.

The group, which first came together in London in October 2010, consisted of people who had experienced bereavement or had life-limiting conditions. The members met again in February this year to work with the film company Rosetta Life to make a DVD about their experiences and their priorities around end of life care conversations and communication.

The result was a training workbook and accompanying DVD about communicating in end of life care, entitled *Finding the Words*. The package, which is aimed at all health and social care staff working in end of life care, was published in July and is already proving popular.

So how was this achieved? Independent consultant Ann Macfarlane, who chaired the meetings, says that one of the secrets was encouraging the users to set the agenda from the start.

It also helped that they shared a common experience. “You can't measure the support that people get from telling their story. To bring somebody from isolation to a group and to have that space and opportunity, knowing you're not going to be put down or criticised, is so important.”

An indication was that initial introductions continued almost all the way to lunch on that first day – much to Ann's initial concern since she had only allotted it 15 minutes! But, she says, she soon realised the benefits.

“It was amazing. People were so respectful and wanted so much to hear others' experiences. And they had the space and time to do it. I realised that it was not only therapeutic but also useful for the end product.”

That is a feeling fully shared by the participants. Mandy Paine, for instance, has end stage COPD. “I felt comfortable opening up and sharing what I was feeling almost from the start,” she says. “We all bonded really well as a group. Everyone was so understanding and the whole thing was so beautifully done.”

One of Mandy's main motivations for taking part was to ensure others avoided the “nightmare” she has sometimes experienced, including having the news that she was now at end stage broken to her over the phone “because you'll be getting a letter from your social worker anyway”.

It is so important that professionals understand what the patient is going through, she says. It's one thing for a doctor to read up about a condition “but it's another thing living with that condition and at the end of the day the real expert is the person living with it.”

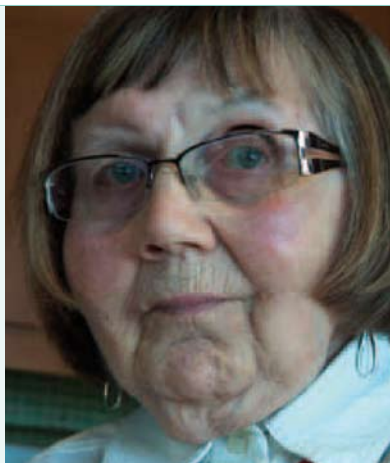
She feels privileged to have worked with the group, she says, and proud of what it has achieved. “It's helped me make something positive out of some-

thing very negative and that's so important. It makes you feel your life hasn't been a waste."

One problem in Tony's view is that professionals tend to think information-giving is a one-way transaction. "Sometimes there's a place for saying, 'How are you feeling about that at the moment? I know what I've said to you but I don't know how you're responding to that.' Sometimes people need to listen, not just talk."

**"People are not good at listening. We always want to put our own point of view across first"**

Ann Macfarlane



Timing is also critical. "I think an awful lot of problems that occur with people after death could be lessened appreciably if more time was given earlier on."

After Neil's death, for instance, the GP contacted them to say they could have as much time as they wanted if they would like to talk. It was much appreciated. "But perhaps we actually needed it before Neil died rather than afterwards."

Being involved with the group has been both rewarding and therapeutic, he says. "At the end of the first session I knew I would be comfortable talking about things that were quite emotional and highly charged. It moved me along and helped me to come to terms with my loss."

He describes feeling completely emotionally drained after the five-hour filming session that was ultimately distilled into a 10-minute DVD. Yet despite this "I almost felt light of foot because a huge burden had been lifted. I'd been able to talk honestly with people who had been through similar experiences. My immediate reaction was: this has been good for me."

His more considered reaction came when he started hearing reports about how valuable the workbook and DVD were proving. "I have a sense now that all the emotional energy and the very considerable honesty that went in from everybody has been worthwhile if it's going to impact and make things better for other people."

He still feels a strong connection with the other members of the group. "In the early stages of bereavement you can feel very isolated. In some senses it was quite a relief to know that other people felt the way you did but were able to express it as well. There is a common bond in talking about grief."

He is full of praise for the way the group was facilitated and how its discussions were turned into something of use to others. And, he adds, if the chance to work with its members cropped up again, "I would jump at it".

That is certainly a possibility. In the meantime the focus is on spreading the messages within the workbook and DVD.

Ann Macfarlane says the package has a wide potential and hopes it will be used in end of life training courses and e-learning as well as within nursing and other degree courses.

"It will also be very useful for users of services. Sometimes you need to hear people express the things that you may find difficult to articulate."

For her one of the principal messages is the importance of listening. "Listening is a huge skill and you do hope people will really listen and, where appropriate, act on what they hear. But the difficulty is people are not good at listening. We are always wanting to put our own point of view across first and we're often in a rush."

The secret is to carve out enough time not only to impart information but also to respond to people's reactions to that information. "So often people are left with a series of unanswered questions and there is no-one to listen to all these concerns."

She is immensely proud of what the group has achieved. "It has been a great privilege to work with people who have had such a hugely tough experience, who have come through as best they can to be the people they are and to support others. I believe this is a really important piece of work."



**"It's helped me make something positive out of something very negative"**

Mandy Paine

Anita Hayes, NEoLCP Deputy Director, says the project has been a very humbling experience for her and other managers involved. "It was developed with heartfelt honesty and I hope it will help all of us to have a greater awareness and understanding of how we can better listen, communicate and support each other to deliver compassionate end of life care."

#### MORE INFORMATION

A copy of the workbook plus DVD is available by emailing [information@eolc.nhs.uk](mailto:information@eolc.nhs.uk). The workbook can be downloaded from the programme [website](#).

# A new set of standards for end of life care in prisons

As the new *route to success* guide to end of life care in prisons is published, Gill Scott explains how a new set of standards developed by Macmillan Cancer Support and local staff is helping to change practice and attitudes

Macmillan Cancer Support has worked with the HMP Durham cluster of prisons to develop a series of prison standards and associated tools which should mean more people can die in prison where this is their choice and fewer will be admitted to hospital unnecessarily.

It is also hoped to reduce hospital and hospice lengths of stay, to increase the number of key staff with accredited end of life care and to raise the profile of palliative and end of life care within the prison community.

There are seven prisons in the North East with a population of more than 5,000. The prisons include one high security prison - HMP Frankland - one category C prison, HMP Acklington and Castington, and one resettlement prison, HMP Kirklevington Grange.

All these establishments have a growing number of older prisoners who may be serving lengthy sentences and potentially will require palliative and end of life care. There are also four prisons which primarily serve the courts - HMP Durham and Holme House, which are large, busy local prisons, HMP/Young Offenders Institute Low Newton, which is a female prison, and HMP Deerbolt juvenile and YOI. Even these latter prisons occasionally need the support of palliative care services.

offender healthcare pathway for palliative and end of life care from arrival to release or dying in prison. End of life care tools have been adapted to encompass the end of life issues within the prison setting.

The team has also produced a DVD, filmed in HMP Frankland, entitled *End of Life Care in the Prison Service*. The DVD will not only be used for patients and families but also as a training resource by Tees-side University and in local training for prison staff.

In addition it is delivering work-based accredited education in palliative and end of life care to staff across the Durham cluster. Twenty four staff, including prison officers, have now gained accreditation. Syringe pump training has also been delivered in three prisons and key trainers identified. Three clinical leads have begun a key worker/end of life care course at degree level. Finally, four palliative care champions have been identified in three prisons, including one healthcare governor in HMP Frankland.

Delivering high quality end of life care in prison is complicated by its nature and culture. Not only is there a tension between care, security and discipline but the nature of prison facilities, the regime and the resources available can also impact on care.

Developing a collaborative approach has been essential as has multidisciplinary working and ensuring all stakeholders are represented on work groups. It has also been important to establish clear lines of communication and reporting within each prison – while recognising that different prisons may have different requirements.

There are many competing priorities within prisons. Ensuring the project does not lose momentum is a challenge and part of the solution is making sure staff feel they have ownership. Establishing a prison champion system has made a difference and will help with sustainability.

We remain confident that by the end of the project more prisoners will be able to die within the prison setting, hospital and hospice admissions and lengths of stay will be reduced and we will have saved money. We also hope the Macmillan Adopted Prison Standards (MAPS) and adapted end of life care tools will become embedded in the prison setting.

Among our other aims are increasing the number of palliative care champions, identifying prisoners with end of life care needs at an early stage, increasing the use of advance care planning, developing prison palliative care registers and ensuring every patient on the register has an allocated prison key worker.



Gill Scott (left) is pictured with end of life care prison champions at the IJPN awards earlier this year

In 2010 funding was secured for one year from Macmillan Cancer Support, the North East Strategic Health Authority and County Durham and Darlington Foundation Trust to deliver the current project. Macmillan has now teamed up with The North East Offender Commissioning Unit, supported by County Durham and Darlington Foundation Trust, to provide funding for a second year and extend the project across all seven prisons in the regional cluster.

Users were not involved in setting up the project but have been consulted through prisoner working groups and questionnaires.

The project team has already developed prison standards for practice (Macmillan Adopted Prison Standards) as well as prison-specific patient information, including a key worker leaflet. The 28 standards reflect the

## ABOUT THE AUTHOR

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# How Newark and Sherwood are caring for the carers

A pilot scheme in the East Midlands has been providing support to carers of people with dementia and at the end of their lives. We report on the positive impact it is having - on carers and on staff

It is well established that without the UK's army of informal carers, this country's health and social services would effectively grind to a halt. Their unpaid work is estimated to save the country £119 billion a year.

Much has been done in the past decade to help carers, underpinned by the National Carers Strategy that was first launched in 1999. But many are still not even identified and those that are do not always get the support they need.

In Newark and Sherwood, for example, a recent survey showed that 60% of carers were still unregistered and only 34% had received a formal assessment. Meanwhile two in five have a long-term condition of their own and 71% spend more than 50 hours a week caring for their loved one.

Tellingly, more than half disagreed with the statement: "The help I received came at the time it was most needed."

Over the past year two practices in the area – Barnbygate Surgery and Fountain Medical Centre – have been involved in a pilot to help raise awareness among potential carers about the support available and among the practices about what carers' needs are.

The pilot, which was funded by NHS East Midlands, focused especially on those looking after people with dementia and at the end of their lives – where a particular gap in support had been identified.

help and advice for carers on their website. The team, consisting of the Carer Co-ordinator and patient participation group members with support from the practice-based commissioning cluster, also produced an information sheet on improving carer awareness for other practices and a special A-Z handbook providing carer support information. A survey of carers was carried out between September and December 2010.

In addition, practices held a series of training sessions for their own staff about carers' needs. This was complemented by training by the local Alzheimer's Society for carers. Practice staff also began identifying all unpaid carers on their books with a halo symbol.

Finally, the Alzheimer's Society set up two additional dementia cafes in Newark providing a forum for carers and clients to undertake joint activities. At the start of the project only one cafe existed, serving a clientele of about 20. By the end the number of regular participants had swelled to 60 and a dementia café carers group had also been established.

So what did the pilot achieve? First and foremost, the practices were able to identify a number of carers who had not previously been known to statutory services. Barnbygate identified a total of 20 between 2009 and 2011 while Fountain Medical Centre located an additional 51. A further 14 carers were identified from outside the two GP practices, making a grand total 85.

The feedback from carers themselves also indicated that they now knew where to access unbiased advice and information about their work as well as their loved one's condition.

As a result they felt less stressed and had an increased sense of well-being. This in turn meant they felt better able to carry out their caring role.

And because they were now able to discuss concerns with the Care Co-ordinator, they made fewer GP visits. In the past, they said, they had sometimes been using GP appointments to gain support and information.

The aim now is to roll out the project across the remaining practices within Newark and Sherwood. Sue Cox, Pathway Development Manager for Newark and Sherwood Health says the team is working in partnership with the local hospice information centre, which is using the information packs and practice contacts to support carers. "We are also ensuring that information is available within practices, patient participation groups and local libraries."



Carers felt less stressed and had an increased sense of well-being as a result of the pilot

Over the course of the project, which ran from May 2010 to May 2011, there were a number of significant improvements. To start with, a Carer Co-ordinator was appointed who worked three days a week both within the practices and in community voluntary services. All identified carers were sent a letter inviting them to drop in for a chat, book an appointment or simply talk on the phone.

The project also encouraged practices to include

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# News in Brief

## Dying in hospital

The August 2011 *British Journal of Hospital Medicine* features a paper on *Improving the care of dying patients in hospital*, written by Professor John Ellershaw, Director of the Marie Curie Palliative Care Institute Liverpool, and Anita Hayes, Deputy Director of the National End of Life Care Programme.

## New conversations

The government has asked the NHS Future Forum to carry out a new phase of *conversations* with patients, service users and professionals, following the recent listening exercise. The Forum will provide independent advice on the following four themes: information, education and training, integrated care and the public's health.

## Commissioning intelligence

Primary Care Commissioning has teamed up with NHS Library and Knowledge Services and South East Coast Quality Observatory to offer commissioners free access to a one-stop shop for commissioning intelligence. The *Ask an Expert* service brings together expertise in commissioning, evidence searches, data analysis and health intelligence in an easy-to-access format online.

## Marie Curie awards



The Marie Curie Cancer Care Research Programme has awarded over £1m funding for six palliative care research projects. The Dimpleby Marie Curie Cancer Care Research Fund has awarded a total of £440,000 for three research projects which focus on the role of volunteers in improving end of life care. More information can be found on the Marie Curie [website](#).

## Early death risk

Parents who lose their child during the first 12 months after birth are at significantly increased risk of an early death and the effect can last for up to 25 years, according to new [research](#) led by University of York academic Dr Mairi Harper.

## RCGP commissioning guide



The Royal College of General Practitioners has produced *Guidance for commissioning integrated urgent and emergency care: a whole system approach*. It aims to provide clear, practical advice and information for commissioners of urgent and emergency care services.

## COMING EVENTS

### BASS Conference

A call for abstracts is now open for the second international conference of the British Association for the Study of Spirituality (BASS), *Spirituality in a Fragmented World*, which takes place between 15 to 17 May 2012. Abstracts should be submitted by 30 September to [c.gregory@hull.ac.uk](mailto:c.gregory@hull.ac.uk)

### End of life care conference

The Royal Surrey County Hospital NHS Trust in partnership with St Luke's Cancer Centre will be holding a one day conference in London on 9 December entitled *End of life care in 2011: art or science?* This event aims to review the evidence base for various aspects of end of life care, including symptom control, spiritual care and bereavement.

### Long-term conditions

St Christopher's Hospice is holding a study day on 29 September entitled

*Living longer, dying slower – where does palliative care fit in?* and costing £100. For more information visit the [website](#).

## International symposium

Dove House in Hull will host the 4<sup>th</sup> International Symposium, entitled *What's new in palliative care? – Explaining difficult things in an easy way*, from 17-18 November. For more information contact [education@dovehouse.org.uk](mailto:education@dovehouse.org.uk).

## Advanced dementia

St Christopher's Hospice is holding a study day on 24 November on advanced dementia and feeding, costing £90. For more information visit the [website](#).

## Bereavement course

The Laura Centre in Leicester will be running a bereavement course accredited with Leicester University School of Education next year. The course runs over three weekends - 15-16 January, 18-19 February and 18-19 March. For further information email [cpdinfo@le.ac.uk](mailto:cpdinfo@le.ac.uk) or contact Alison Beck on 0116 2544341, email [alison@thelauracentre.org.uk](mailto:alison@thelauracentre.org.uk).

## NAHH annual conference

The National Association for Hospice at Home's annual conference, *Adapting Hospice at Home in the new Health Market – developing quality value and cost effectiveness in services*, takes place in Liverpool from 10-11 November. For more information contact [conference@helpthehospices.org.uk](mailto:conference@helpthehospices.org.uk), phone 0207 520 8200 or visit [www.helpthehospices.org.uk/hweb/courses.aspx](http://www.helpthehospices.org.uk/hweb/courses.aspx)

## Palliative Care Congress

The 9th Palliative Care Congress will be held at The Sage Gateshead in Newcastle from 14-16 March 2012. For more information visit the 9th Palliative Care Congress [website](#).