

IN THIS ISSUE:

1 **National Update**

2 **News**

Features

QIPP

- 4 Projects that offer quality and productivity
- 5 Alternatives to emergency admission at the end of life
- 6 Family Liaison Nurse Co-ordinator Service, Birmingham E & N
- 7 Fast Track Service, Bradford and Airedale
- 8 Midhurst Macmillan Specialist Palliative Care Service
- 9 St Benedict's Hospice OOH Specialist Palliative Care Service
- 10 Meeting people's spiritual needs at the end of life

11 **News in Brief**

National Update

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

New study shows rise in home deaths



New research from the Cicely Saunders Institute at King's College, London suggests that the downward trend in deaths at home has been reversed in the last few years.

The analysis reveals that the proportion of deaths at home rose from 18.3% in 2004 to 20.8% in 2010. Absolute numbers of home deaths increased by 9.1%, while overall numbers of deaths decreased by 3.8%.

The rise in home deaths was more pronounced in cancer and was the case for both genders and across most age groups. Home deaths increased for the first time since 1974 among people aged 85 and over.

The rise was more evident when ageing was accounted for (age-gender standardised proportions of home deaths increased from 20.6% to 23.5%).

National Clinical Director for End of Life Care Professor Sir Mike Richards (pictured) said the findings were very encouraging. "However, there is still a very long way to go to ensure that people approaching the end of life are cared for in the setting of their choice," he warned.

Consultation response

NICE has now published the response to the end of life care for adults quality standard consultation. For more information see the [website](#).

Commissioners' guide

NICE has produced a new [guide](#) for commissioners on end of life care for adults. The guide is divided into eight sections, including sections on how to assess local service levels and establish contract specifications as well as explaining the cost impact of service redesign and signposting to further information.

This guide includes the mapped areas of care for the NICE [quality standard](#) for end of life care for adults and covers settings in which care is provided by health and social care staff to adults approaching the end of life and adults who die suddenly or after a very brief illness. It also includes support for the families and carers of people in these groups.

Click [here](#) for the commissioning and benchmarking tool.

Dignity Action Day



This is a final reminder that the second Dignity Action Day will be taking place on 1 February. The day, which is organised by the Dignity Care Network, aims to ensure people in care are treated as individuals, are given choice, control and a sense of purpose in their daily lives and provide stimulating activities.

All health and social care workers are being urged to take some form of action in their place of work to promote dignity on the day. The network's website contains [resource packs](#) with ideas for

staff and members of the public on how to take part in the day.

E-learning resource pack

Working with e-Learning for Healthcare (e-LFH) we have developed a starter pack for our e-learning programme (e-ELCA) which will be launched by the end of February.

A hard copy pack will include a DVD containing information for facilitators and trainers and a demonstration of some of the sessions. Also included will be information on how to register to use e-ELCA, which has been simplified, as well as where to get help and a section giving answers to frequently asked questions. Packs will be available from the Programme office and there will be more information on our website in March.

QIPP changes

This month's focus on how end of life care is meeting the Quality Innovation Productivity and Prevention (QIPP) agenda is particularly topical since the QIPP end of life care work-stream has been amalgamated into the NEoLCP. It is now jointly led by myself and Tessa Ing, Head of End of Life Care with the Department of Health Policy Team. Amalgamation into the NEoLCP enables the work-stream's activities to be better aligned with the wider NEoLCP and DH Policy Team's end of life care objectives. Work is under way to refresh the workstream's programme plan.

Claire Henry
National Programme
Director
January 2012



News

Audit highlights failings in hospital dementia care

Significant improvements need to be made in hospital ward environments, staff training and the overall approach to care delivery for patients with dementia, according to the first [National Audit](#) of Dementia in England and Wales.

Although most wards meet basic safety requirements, it shows that many have not addressed simple measures that could lessen the distress caused to dementia patients by an unfamiliar and confusing hospital environment. It also reveals deficiencies in staff training.

The report by the Royal College of Psychiatrists' Centre for Quality Improvement highlights issues such as poor communication with families and a lack of personal care for patients. Under half of hospitals had a process in place for sharing information with families.

It says that too little is being done to prepare for patients' discharge by liaising with community services.

There are also wide variations on key standards such as nutritional assessment. Although 70% of patients across the country receive an assess-

ment, this ranges between 3% and 100% depending on the hospital. Many staff said they felt they lacked the skills to deal with dementia patients, with under a third saying they had had sufficient training.

But the failings are also related to a lack of quite simple but effective measures, such as placing family photographs or cards where the patient can see them, or displaying larger signs.

The report accepts that many hospitals have started improving their practices in light of the interim findings, which have already been passed on to them.

Care Services Minister Paul Burstow said the government would introduce a financial incentive to encourage hospitals in England to screen patients for dementia when they were admitted for other conditions. See also the NCoLCP's [dementia resource guide](#).



Commission calls for change in assisted dying law

An independent commission on assisted dying, organised by the think tank Demos, has called for a change in the law to allow people to be helped to die within clearly defined rules.

The [Commission on Assisted Dying](#), which was launched in November 2010 and chaired by former justice secretary Lord Falconer, concludes that the current system is "inadequate, incoherent and should not continue".

The present arrangements are not only distressing for the people affected and their families, it says, they are also unclear for health and social care staff and pose difficulties for police and prosecutors.

It proposes that assisted suicide should be allowed if an individual is over 18, has less than 12 months to live, is making a voluntary choice and is not impaired mentally. They would also need to be independently assessed by two doctors.

At the same time "substantial improvements" would need to be made to end of life care to protect potentially vulnerable people from any form of social pressure to end their lives. If all these conditions were met, there is a "strong case" for a change that would give people "greater choice and control regarding how and when they die".

The commission was set up and funded by people campaigning for a change in the law but the government indicated earlier this month that there were no immediate plans to legislate.

A spokeswoman for the British Medical Association, which declined to give evidence to the commission, said: "While, there is a spectrum of views on assisted dying within the medical profession, the BMA believes that the majority of doctors do not want to legalise assisted dying."

Extra care housing 'is cost effective alternative to care homes'



A detailed [study](#) of 19 extra care housing schemes suggests that residents tend to have better outcomes in terms of both mental and physical functioning than in comparable care home accommodation.

The study by the Personal Social Services Research Unit (PSSRU) together with Housing LIN also indicates that fewer people died in the first 30 months than would have been expected when compared with deaths in care homes.

By the end of the 30-month period of the study around a quarter of the sample had died, usually in hospital, although 37% were able to remain in their extra care home. For those who died the average survival time after moving in was 18 months. Of those still alive over 90% remained in the scheme.

The Department of Health-funded study examined the experiences of residents in 19 extra care housing schemes between April 2006 and November 2008. It found that after 18 months most residents' physical and cognitive functioning had either improved or was stable. Even after 30 months more than half had improved or stable physical functioning while more people's cognitive functioning had improved than deteriorated.

The report concludes that extra care housing has better outcomes and similar or lower costs to residential care and appears to be "a cost effective alternative for people with the same characteristics who currently move into residential care".

One major barrier, it says, is the limited supply of extra care housing. At the moment there are 43,300 extra care housing places compared with over 450,000 in care homes. "Increasing provision requires improved strategic planning by social services departments and planning, health and housing partners," it adds.

Spiritual needs must not be ignored, conference told



Spiritual care is fundamental to good end of life care – yet all too often nurses and other professionals shy away from offering it, a recent conference heard.

Professor Stephen Wright, from the Sacred Space Foundation, a spiritual retreat in Cumbria, was speaking at the Buckinghamshire Healthcare NHS Trust end of life care conference in November which attracted a capacity audience of nurses, doctors and volunteers.

Spiritual care was different from religious care, he stressed, and could not simply be left to the hospital chaplain. In fact it was as important for those giving care as for patients since being clear about your own values underpinned good care.

Jeanette Tebbutt, the trust's newly appointed Nurse Consultant in Cancer Care, explained that concerns about spiritual care had been the trigger for

the event. "As a cancer information and education team we wondered how we could raise the profile and show the importance of spiritual care. The conference was the result!"

The one-day conference covered a range of topics including the End of Life Care Strategy, local community initiatives, the Liverpool Care Pathway, tissue donation and compassionate administration. Other speakers included Maureen Gambles, Operational Lead for the Service Innovation Division at the Marie Curie Palliative Care Institute, Liverpool.

Buckinghamshire's Cancer Education, Information and Support Team is pictured above. From left to right: Penny Boon, Sandy Barnett, Jeanette Tebbutt, Judith Simmons.

The trust is considering staging a similar conference next year. For more information contact Jeanette Tebbutt on 01296 315101.

Hospice helper Joan wins top volunteering award

Joan Hallock, a volunteer with Greenwich & Bexley Community Hospice, has been selected as one of the winners of the annual Health and Social Care Volunteering Award.

Joan, who is pictured (left) receiving her award from Chief Executive Kate Heaps, was one of eight winners across four categories linked to delivering and supporting health and social care services. The award recognises her outstanding contribution to the delivery of health and social care services at the hospice.

Joan joined the hospice in 1995 as a volunteer fundraiser and five years later helped set up a drop-in service called *Stepping stones* to support patients, their carers, families and the bereaved.

Within this service she set up a *Helping Hands* team to provide benefits support and guidance to in- and

outpatients, families and carers. The service has helped hundreds of patients, families, carers and bereaved people over the past 10 years.

Commenting on her win, Joan said, "I'm overwhelmed with the news. I'd encourage anyone to volunteer here. There are plenty of things to do and it's so satisfying and rewarding. I'm really privileged to have had a chance to do this."



Cut elderly stays in hospital, urges report

A new report by the King's Fund says that hospitals need to do more to help older people who have had a stroke, pneumonia or a broken hip to return home more quickly.

Latest figures show that 10% of patients account for more than half of all emergency bed days. A disproportionate number of those who stay for at least a fortnight, at a cost of £200 a night, are elderly and many could be discharged long before they are.

The NHS must discharge some of these patients earlier if it is going to be able to meet the government target of making £20 billion in efficiency savings by 2015, says the report. "Reducing unnecessary use of hospitals offers a key opportunity for significant savings."

NHS figures show that the number of patients being admitted as emergencies, the amount of bed days they occupy and the total staying for at least two days have risen since 2007.

Four out of five longer-stay patients are 65 or over and more than 30% are over 85. "Typical diagnoses among older patients with very long length of stay include stroke, hip fracture, pneumonia and urinary disorders, dementia and delirium," the report says.

Patients accounting for as many as 42% to 55% of bed days would be better treated at home, with or without medical support, or in a nursing home rather than in hospital, the study's authors add. But to achieve this other services, including social and community care, must be in place.

The government has announced a further £170 million funding for councils to help them improve care and support for elderly people coming out of hospital. Most of this amount will be divided among councils with social care responsibilities and will be allocated through PCTs.

Care Services Minister Paul Burstow said it was crucial the NHS and local authorities worked together to help people leave hospital when they were ready.

See also the NEoLCP route to success booklet on [acute care](#) and QIPP case studies, pages 5-9.



Good end of life care lies at the heart of the QIPP programme because it is not only beneficial for the individual and their family, it makes the best use of resources. Here we describe how that can be achieved and on the following pages highlight some examples of good practice in care delivery

Projects that offer quality *and* productivity

It has often been said that high quality care which places the individual at the heart of everything is also the most cost-effective. And nowhere is that more so than in end of life care.

Quality and supporting an individual's choice are of course central to all end of life care. But delivering the right care in the right place at the right time also makes the best use of NHS resources and is in turn likely to increase overall productivity.

End of life care is one of the 12 workstreams within the national QIPP (Quality Innovation Productivity and Prevention) programme which seeks to align the quality and productivity agenda. And in this issue we describe five examples of local end of life care projects that are helping to improve the individual's experience while also making best use of resources.

They were chosen because they demonstrate community service interventions and models of care which have improved patients' end of life care experience while also being innovative and cost effective.

At the moment it is estimated that more than 50% of people in their last year of life experience two or less unplanned hospital admissions while 20% have five or more admissions. Each admission costs an average of £3,000. At any one time 20% of beds are occupied by someone who is in the last phase of life but has no medical reason to be there, according to a recent National Audit Office [report](#).

At the same time many people nearing the end of life are on complex ,multiple medications, only some of

WHAT IS QIPP?

The current economic climate has presented the NHS with an enormous challenge. That is to continue to improve the quality of care and services to individuals with a budget that is forecast to be held constant for a number of years from 2011. Alongside this is an ever-increasing demand for new technologies and care and above average inflation in the healthcare sector.

The QIPP initiative seeks to identify how services can be redesigned to achieve the twin aims of improved quality and efficiency. It aims to involve NHS staff, users, carers and the voluntary sector in delivering excellence of care while making the best use of financial resources.

Local and regional initiatives are supported by national QIPP workstreams, one focusing on end of life care.

which may still be relevant to their needs. They may also experience futile and often painful interventions.

All of this is not only a waste of valuable and increasingly limited resources, it causes needless suffering, inconvenience and intrusion to the dying person and their family.

At the moment 40.8% of deaths across England occur in people's usual place of residence – normally the home or care home – although there is a big variation between trusts. Given that up to 70% of people say they want to die at home, it seems clear the present proportion is too low.

If we could prevent just one unnecessary hospital admission for only 10% of those who die each year, this could save £132 million on the tariff. Most importantly, it could enable up to 44,000 people to have a better death.

The end of life care pathway sets out how this can be achieved. It includes identifying more people in the last year of life, having honest conversations about their condition, offering the opportunity for advance care planning and ensuring that we can respond with the right care services across social care and health.

That in turn requires robust partnership working, good communication with individuals and their carers and better co-ordination across all the agencies that may need to be involved in their care.

The new NICE [quality standard](#) for end of life care together with commissioning guidance provide helpful advice on how to make local plans for improving end of life care. Meanwhile the following pages, outlining how other projects set about the task, show what can be done.

RESOURCES

Useful websites for more information:

- [Map of information for QIPP](#)
- [NHS Improvement, eQIPP](#)
- [NHS Institute, cost and quality](#)
- [DH, QIPP case study films](#)

These resources are available from the End of Life Care Quality Assessment Tool (ELQUA) website:

- [End of life care objectives](#)
- [Commissioners ELCQuA infosheet](#) (requires Publisher)
- [Providers ELCQuA infosheet](#) (requires Publisher)
- [What is ELQUA? Q&A guide](#)
- [NEoLCIN ELQUA presentation](#)
- [ELQUA numerical indicators guidance](#)
- [Latest version of the Quickstart Guide and Test Script](#)
- [National End of Life Care Intelligence Network website](#)
- [National Cancer Peer Review Programme \(CQuINS website\)](#)

1 Alternatives to emergency admission at the end of life

NHS Oxfordshire and Allied Healthcare

A rapid intervention service in Oxfordshire has helped prevent over 250 emergency admissions and made savings of nearly £350,000. One of the keys to success has been close co-ordination with other services

BACKGROUND

NHS Oxfordshire serves a population of 670,000 - 185,000 in the city and 485,000 in the surrounding county. In 2010 there were 5,094 deaths and 2,529 hospital admissions within the last year of life. Of these 1,000 were discharged within two days of admission. The total cost of these emergency admissions to the trust is estimated to be over £10 million.

RISE - the Rapid Intervention Service for End of Life Care - was set up in NHS Oxfordshire by Allied Healthcare as a six-month pilot scheme to establish whether providing crisis care in the community could cut the number of unnecessary emergency admissions in the last year of life. A subsidiary objective was to compare rapid access to care home beds with rapid access to care at home.

Over the course of a year the team prevented 258 emergency admissions while admitting just 26 and made a gross saving of nearly £350,000.

The main objectives of the service included:

- Improving patient and family satisfaction
- Offering an alternative to the trauma of emergency admissions
- Providing patients with the option of dying at home
- Making contact within 20 minutes at times of crisis
- Giving patients the choice to be cared for and die in their preferred place of care
- Allowing rapid discharge to die at home when that is preferred and the service can support their needs
- Providing a flexible and timely response to unscheduled demand.

co-ordination with others services such as the GP Fast Track Team and key worker.

A total of 344 patients were referred to the team between July 2010 and June 2011. Of these 267 had a malignant condition and 77 did not. Most (64%) were referred by a district nurse, 10% by GPs, 9% by the PCT and 6% by the hospice.

A total of 25% of the patients were referred to another agency, 9% were admitted to hospital and 40% died, mostly in their own home or care home.

As a result of the project the RISE team prevented 258 hospital admissions, saving a total of £774,000. Taking into account the cost of the service (£350,000) and the fact that 26 patients still had to be admitted to hospital (at a cost of £78,000) this results in a gross saving of £346,000.

Patient and family satisfaction with the service was extremely high with 87% saying it was good value for money and 83% rating it good or excellent.

"We felt the situation was out of control and RISE very much took it under control," commented one respondent. "It was reassuring to see this support available when we have nowhere else to turn," wrote another. And another expressed their hope that "many residents of this county will have similar outcomes."

The service has now been funded on a three-year contract and it is expected to increase the number of referrals to 600 in the coming year. It is also hoped to expand the service to include night cover, to extend the concept to other service provision and to establish closer links with local hospitals. The organisers are also looking to develop joint training pathways.



Patient and family satisfaction with the service was extremely high

The service is staffed by an RGN, who did the initial assessment of needs and care plan, together with a team of trained support workers. Another trained nurse acts as co-ordinator and staffed a dedicated telephone helpline.

Patients can self refer or be referred through their GP, district nurse, hospital or hospice and receive the service for a maximum of six days – although they are able to access the service as often as required. The team aims to refer each patient on to the appropriate service or to support the patient and family until the time of death. A big emphasis is placed on close

KEY MESSAGES

- Establish key relationships between multiple stakeholders from the start
- All stakeholders need to attend regular forum meetings to ensure good networking and engagement with the service
- There should be a clear referral pathway on to additional services once the six days are completed
- Avoid duplication of assessments by sharing information across services.

CONTACT DETAILS

Aileen Turner, Community Services Lead Allied Healthcare Group

- aileenturner@alliedhealthcare.com
- 07814 463406

Laura Carter QIPP and Transition Project Manager, NHS Oxfordshire and Buckinghamshire

- laura.carter@oxfordshirepct.nhs.uk
- 01865 334621

2 Family Liaison Nurse Co-ordinator Service, Birmingham E & N

Healthcare at Home

Starting from small beginnings, the BEN family liaison service has expanded to cover the whole of the trust and is helping to improve patient choice at the end of life as well as cutting hospital admissions and length of stay

BACKGROUND

The population of Birmingham East and North is 400,000. Birmingham North, the original pilot site, has a predominantly affluent white elderly population with pockets of deprivation. Birmingham East has a predominantly black and Asian population, with higher than national average deaths from respiratory and heart disease.

The Birmingham East and North (BEN) Family Liaison Nurse Co-ordinator Service was set up as a 12-month pilot in November 2009 with the aim of making links with existing end of life care services and ensuring patients in their last 12 months of life had choice about where they were cared for and died.

The project – staffed by three co-ordinators which later rose to six – has succeeded in cutting the number of hospital admissions and reducing the length of stay, making net savings of nearly £800,000 in the process. In addition 86% died in their place of choice.

The service was commissioned for a further three years in November 2010. It now has a caseload capacity of 975 patients, managed by 15 co-ordinators.

The pilot was launched following feedback that patients' choices were not being supported because of a lack of 24-hour co-ordination of end of life care services.



The aim is to optimise end of life care for patients, regardless of diagnosis

The principal aims were to:

- Deliver an innovative service to optimise end of life care for patients in the last 12 months of life, regardless of diagnosis
- Enable patient choices at the end of life and facilitate those discussions around care provision and place of death
- Avoid unnecessary hospital admissions
- Signpost, support, promote and navigate patients and their families to existing services
- Provide continuity of care through one named person – the family liaison nurse (FLN) co-ordinator
- Offer equality to all people in all care settings and enhance the patient and family experience.

All those who were taken on by the service were allocated their own FLN co-ordinator and were contacted within 48 hours of being referred. They received monthly visits after their first assessment and had access at any time of day or night to a nurse adviser (known as the Care Bureau). The team tried to identify patient concerns early and then refer them on to

the most appropriate service. And all reporting was in real time to help inform triage decisions as well as KPI reporting to commissioners.

Over the course of its first year the service handled 604 patients all of whom were estimated to be in the last year of life and were on the GSF register. In May 2010 the service was extended to cover more localities.

Of the patients seen by the service 38% had cancer, 18% dementia, 13% were frail elderly, 9% had a respiratory condition, 7% cardiovascular problems and 4% neurological conditions. For those who died the average length of time with the service was 83 days.

At the end of the pilot 61 patients had died. Of these 86% died in their place of choice – with only 21% dying in hospital (compared to 67% before). And while the average number of hospital admissions for patients in the last year of life was previously three, it fell to 0.74 in the project group.

This has led to a 12% reduction in hospital admissions and a 40% drop in the length of stay. The costs of hospital admissions have also been cut by 40%, resulting in a net saving of £798,412.

All patients and their families were surveyed after three visits and more than 90% expressed their satisfaction with the standard of the service. One respondent said the service was "excellent, very supportive and kind, checking my needs are seen to and things that are available to me".

The service now covers all parts of East and North Birmingham and is staffed by 15 co-ordinators. A total of 1,264 patients have accessed the service and 871 are currently on its books. The service has added specialist co-ordinators for mental health and dementia and has also extended its dementia services beyond the last year of life. In addition its close partnership working with the emergency services means that patients' DNAR decisions are now respected, which has helped to prevent hospital admissions.

KEY MESSAGES

- Ongoing clinical and commissioner engagement is essential
- There needs to be constant communication with other provider services
- It is important to employ experienced nurses with skills to deliver the service
- A 24-hour phone line for patients and families is vital.

CONTACT DETAILS

- Jill Doyle, Service Delivery Manager
- jill.doyle@hah.co.uk
 - 07771374062
 - www.healthcareathome.co.uk

3 Fast Track Service, Bradford and Airedale

Bradford District Care Trust

Bradford's Fast Track Service is helping to co-ordinate services for patients at the end of life and cut duplication. In the process it has increased the number dying where they wanted and reduced costs

BACKGROUND

Bradford is the most deprived area in West Yorkshire and is within the top 10% of deprived red areas in the country – although there are significant variations in levels of deprivation across the Bradford and Airedale district. Nearly a quarter (23%) of the population is from black and minority ethnic groups compared to 13% nationally.

The current population of the district is 502,000 but by 2030 this is expected to rise to 650,000. In 2010 there were 5,000 deaths, 1,200 relating to cancer and 550 to long-term conditions.

In 2009 Bradford Palliative Care Services were asked to set up a fast track service to co-ordinate services for those in their last weeks of life and to ensure that wherever possible they died in their preferred place of care.

The Fast Track Service, which was piloted in December 2009, replaced a system run by the Continuing Health Care Team that was based on want rather than need and had led to an overspend on its budget.

80% of patients have been cared for within provider services while services for the remaining 20% have been specially commissioned.

The service works closely with the Hospice at Home Team as well as the Marie Curie Night Service, district nurses and accredited local care services. It also liaises with the area's hospitals and hospices to enable patients to be rapidly discharged when they express a wish to die at home.

Between December 2009 and August 2011 688 people were accepted on to the Fast Track Service of which 670 have since died. On average 36 new patients are referred each month. The service has helped to reduce duplication and has also increased the number of people achieving their preferred place of care. Seventy six per cent are now dying where they wish compared to 60% previously.

Of those seen by the service 447 (65%) had cancer while 241 (35%) had non-malignant conditions such as COPD, dementia and heart failure. Of the 500 who indicated a preferred place of care, 303 opted for home, 99 hospice, 54 nursing home, 39 hospital and 5 community hospital.

At the same time costs have been significantly reduced. The package of care is now centrally co-ordinated by the fast track team which has led to a reduction in agency costs. The average spend per patient per week is now £169.70 and the average total spend per patient is £480. Under the old system the average cost per patient was £1,093.

The team has also introduced an end of life care template across the Bradford and Airedale district, which addresses issues such as preferred place of care, DNACPR, the Liverpool Care Pathway, anticipatory medicines and out of hours forms.

The service is now looking at the possibility of extending the scheme to cover all those in the last year of life. It is also planning focus groups to help improve the support offered to carers.

The main aims of the new service are:

- To co-ordinate services for patients in the terminal phase of their condition
- To identify people's preferred place of death
- To adopt a multidisciplinary team approach
- To set up individual care packages to meet the needs of patients and carers
- To make use of provider services
- To review patient services on a regular basis
- To ensure the quality and equity of the service.



Packages of care are now centrally co-ordinated by the fast track team

The fast track team consists of two Continuing Health Care nurses and operates 8am-5pm, Monday to Friday. The service has a single point of access for professionals to refer patients who are in the terminal phase of their condition, are rapidly deteriorating and have increased needs.

The team will arrange a visit to make an assessment from one of its team within four hours of receiving the first referral. It will then hold a multidisciplinary team meeting, on the same day if necessary, to determine who needs to be involved in meeting the patient's needs.

The resulting package of care will be centrally co-ordinated by the fast track team. So far an average of

KEY MESSAGES

- We used existing resources and services to provide a quality service that is cost-effective and has good outcomes
- Build on existing partnership working where possible
- It is important to ensure communication at all levels when changing and adapting the process.

CONTACT DETAILS

- Belinda Marks**, Clinical Lead Palliative Care Services, Bradford District Care Trust
- belinda.marks@bdct.nhs.uk
 - 01274 323513

4 Midhurst Macmillan Specialist Palliative Care Service

Sussex Community NHS Trust and Macmillan Cancer Support

The watchword of the Midhurst Macmillan Service is 'not replicating but enhancing'. That philosophy has helped the team reduce hospital admissions and ensure four in five of its patients die where they wish to

BACKGROUND

The Midhurst Macmillan Service covers a rural area of 400 square miles which includes several small towns such as Midhurst, Haslemere and Petersfield. The population of around 200,000 is an aging one with pockets of rural deprivation.

As a result the disease profile is changing with increases in dementia and co-morbidities. The area also has higher than national average rates of breast and prostate cancer in all age groups. The service receives referrals from 19 GP practices and, as with other local specialist palliative care providers, sees a relatively large number of referrals of people under 60.

The Midhurst Macmillan Specialist Palliative Care Service was set up in 2006 when the King Edward VII Hospital's inpatient palliative care unit closed. It has helped to increase choice for those at the end of life and ensure that nearly four in five of its patients die in their place of choice.

The main aims of the service are to maximise patient choice by providing as much treatment and support in the home or community as possible through a consultant-led multidisciplinary community-based team. It seeks to reduce hospital interventions and inpatient stays and ensure

close co-ordination between all the agencies involved with people at the end of life. Its watchword is: "not replicating but enhancing".

Commissioned by three local PCTs and Macmillan, the service consists of specialist professionals as well as a large voluntary team providing active palliative care following early referral from either the hospital or GP. The service, which provides a range of interventions undertaken either at home or in the community, offers access to care at all times as well as after care and bereavement support.



The service consists of specialist professionals and a large voluntary team

In 2010/11 the service received 409 new referrals, 365 of which involved people with cancer. During the same period there were 283 deaths and 63 discharges – a similar proportion to when the service was provided at the King Edward VII Hospital. The majority of referrals (291) were from GPs with 98 coming from hospitals.

Of the 283 deaths 224 (79%) died in their preferred place of care/death and 46 (16 %) in an acute hospital. For seven hospital patients this was where they wished to die while 12 others had not made their wishes known. Some patients died in hospital as a

result of unexpected treatment complications. A total of 139 deaths were at home, 60 in a nursing home, 21 in a community hospital and 17 in a hospice.

The palliative care team was able to avoid hospital admissions through a range of interventions in the home or community, including 70 IV injections, 40 subcutaneous fluids, 40 IV fluids, 20 blood transfusions, 14 paracenteses and two patients who received intrathecal pain control.

An evaluation of the scheme indicates that significant cost savings can be made if patients are referred at an early stage before any hospital admissions have occurred. It is also clear that preventive care over the last year improves patients' quality of life. Moreover, integrated support, including practical and bereavement help, relieves the suffering of both the patient and their family.

In the last year the service, which has a total budget of £1.2 million, has helped to improve choice and reduce inpatient stays. It has also seen an increase in people with non-malignant diseases and has offered support to younger people. And it has been able to offer support for carers and bereavement services.

It works closely with all members of the primary healthcare teams, community services, social services, care agencies and voluntary organisations. It has also seen the introduction of a community-based volunteer service and is able to signpost people to financial support and advice.

Over the coming year the team will be working with acute hospitals and palliative care and discharge teams to reduce the number of hospital deaths. It plans to increase the use of advance care planning and work with local teenage and young people's transition groups.

It also hopes to become a one-to-one cancer site by working with primary care, secondary care and community services. This will include models of early palliation and self-monitoring for other diseases.

KEY MESSAGES

- Aim to avoid duplicating existing services
- Work closely with primary care and community services
- Increase the range of interventions which can be undertaken in the community
- Increase the range of education sessions.

CONTACT DETAILS

Sue Dewar and Joanna Stuttford,
Midhurst Macmillan Service

- sue.dewar2@nhs.net
- joanna.stuttford@nhs.net
- 01730 811121

5 St Benedict's Hospice OOH Specialist Palliative Care Service

South Tyneside NHS Trust

Over the last 14 years the St Benedict's OOH service has helped prevent unnecessary hospital admissions and enabled patients to die at home when they wished. It has also reduced the stresses for patients and their carers

BACKGROUND

Sunderland has a proud industrial and mining heritage which has left a legacy of urban deprivation and high disease. There are high levels of cancer, heart failure, alcohol consumption, smoking and obesity, unemployment and social deprivation. The average life expectancy is seven years lower than the UK average.

St Benedict's Hospice OOH Specialist Palliative Care Service was the first service of its kind when it was set up in 1998 with the aim of enabling people to be cared for and die in the place of their choice.

It now makes over 1,600 crisis visits and 1,400 planned visits a year as well as offering telephone support and advice on over 1,600

occasions. In the last six months 90% of those on the scheme who died were in their own home, 93% were in their preferred place of death – and only 3% of deaths were in hospital.

The principal aims of the service are to prevent inappropriate admissions, facilitate rapid discharge from both hospital and hospice, make a planned visit following discharge and provide a co-ordinated, flexible and seamless patient/carer-centred service.

Demand for the service continues to increase. In the year from April 2010 to March 2011 the service saw an average of 40 new patients a month while an average of 37 died each month. Of these 87% were at home and 92% in their preferred place of death. The average number on the caseload each month was 84.

In the last six months (April to October 2011) the monthly caseload has risen to 93.5 with 45 new patients each month. Of the 33 deaths per month, 90.5% were in their home and 93.5% in their preferred place of death. The average percentage of hospital deaths throughout this 18-month period has remained at 3%.

The service is consistently highly rated by patients and their families with only one complaint in the last 14 years. Meanwhile the team's low sickness rates, low staff turnover and ease of recruitment testify to its success. The service also enjoys excellent working relationships with the OOH deputising doctor service, GPs and district nurses.

Over its 14 years the St Benedict's OOH palliative care service has helped to prevent unnecessary hospital admissions and readmissions as well as cutting the lengths of stay and reducing ambulance and deputy doctor call-outs.

Just as importantly, it has helped to keep dying patients at home when that is their wish and vastly reduced the stresses for patients and their carers. An audit of its work shows that for every £1 spent, £1.65 is saved in terms of reduced hospital admissions and the facilitation of rapid discharge.



The service aims to be in attendance following a crisis call within an hour

The nurse-led service operates from 4pm to 9.15am every day of the year. During that time a team of two nurses are on duty providing direct planned care in patients' homes or care homes as well as responding to crisis calls and providing triage, advice and support over the phone. The team also offers advice and support to staff and patients in the hospice and nearby hospital.

The service, which is open to anyone with a life-limiting condition in any care setting, responds immediately to crisis calls by phone and aims to be in attendance within an hour. In the last six months it achieved this latter target in 85% of cases. Meanwhile 96% of planned visits took place within half an hour of the appointment time. Over the last 18 months 99% of those who have received a crisis visit have remained at home and not required hospitalisation afterwards.

KEY MESSAGES

- Always keep the patient at the centre of everything you do
- Ask patients and carers what they need
- Listen to your patients and carers and be led by their agenda
- Give staff running the service the flexibility to develop it around the patients' and carers' agenda. Frontline staff know what needs to be achieved
- There is no one size fits all. Always be prepared to adjust to fit the patients' and carers' needs
- Audit performance and standards continuously - it's very powerful to prove your worth and help to influence investment and growth
- Network, influence and raise the profile of the service as widely as possible.

CONTACT DETAILS

Julie Newby, Palliative Care Team Manager,
St. Benedict's Hospice
 • julie.newby@sotw.nhs.uk
 • 0191 5410055
 • 07876654083

Meeting people's spiritual needs at the end of life

There is little documented evidence that patients' spiritual needs are being met at the end of life. Lead Chaplain Paul Salter (pictured) describes an initiative in North Tees & Hartlepool that is seeking to redress the balance

The National Council for Palliative Care has referred to spiritual care as "the missing piece" in end of life care¹. And it is easy to see why.

Under the Liverpool Care Pathway (LCP)², for example, it is expected that all the patient's needs – physical, psychological, emotional and *spiritual* – should be assessed and met as far as is practical. However, in an (unpublished) survey undertaken at North Tees & Hartlepool NHS Trust in 2008, it was found that in only 4% of patients placed on the LCP (about 40% of the average 1600 deaths a year) was there any documented evidence to suggest there had been an attempt to assess patients' spiritual needs. This situation may not be untypical of other acute hospital trusts in England and Wales.

45 to 50 patients each month on the LCP. And more than 97% of patients on the LCP accept spiritual and pastoral support in those last few hours and days before they die. There is anecdotal evidence that complaints around care at the time of death are declining. Staff feel better supported and they know that dying patients on their wards are receiving regular supportive input. They are also more likely to refer other patients for support and spiritual care than they were previously.

I am convinced this model is transferable and would be happy to advise colleagues from other trusts. But certain preconditions have to be met to make it work effectively:

1. *Support of the palliative care MDT, especially the consultants.* The consultant is key and can help make things happen
2. *Support of the trust board.* Again, the influence of the consultant is critical to having chaplains accepted as part of the MDT
3. *Support of the staff on the wards.* Staff took a little time to be convinced but the successful pilot ensured the model was accepted
4. *Support of the chaplains.* Unless we were all committed to this role in the trust, it would be ineffective. There was some concern that this work would overwhelm our workload but this has not proved to be the case and in fact greatly enriches what we do.



More than 97% of patients on the LCP accept spiritual and pastoral support in their last few hours and days

In an attempt to ensure that the spiritual needs of patients on the LCP are addressed within our trust, the palliative care multidisciplinary team, in partnership with the chaplains, developed a new model.

This model proposed that when a patient is placed on the LCP, the chaplaincy team would be informed as a matter of course. One of the chaplains would visit the patient and/or carers to ascertain what, if any, spiritual needs there might be and, if required, address that need. The chaplain would leave a contact card and make further visits if requested. The outcome would be recorded in the LCP documentation, which is kept on the ward.

Over the seven months of the pilot, which began in July 2009, the chaplains visited 223 patients on the LCP - on average 37 each month. Fewer than 8% of those visited declined the support of the chaplain and 63% received more than one visit³. No complaints were received from patients or carers but there were many compliments. Any misgivings professionals might have had about the involvement of chaplains had dissipated. Indeed, staff recognised that the support offered by chaplains was not only beneficial to patients but also to staff.

The model is now firmly rooted in practice in the trust. In the first two years, up to July 2011, we visited well over 1,000 patients - on average, we see

REFERENCES

1. National Council for Palliative Care. *The missing piece*, NCP, 2010
2. Marie Curie Palliative Care Institute. *What is the Liverpool Care Pathway for the Dying Patient?* Marie Curie, 2010.
3. Pugh E, Smith S, Salter P. *Offering spiritual support to dying patients and their families through a chaplaincy service.* Nursing Times, Vol. 106, No. 28, pp.18-20, 2010. .

ABOUT THE AUTHOR

Paul Salter is Lead Chaplain at North Tees & Hartlepool NHS Foundation Trust, Stockton-on-Tees and Hartlepool, Teesside..

CASE STUDY

When the chaplain visited Charles*, who had been placed on the end of life care pathway, he found him conscious and his wife sitting with him. The couple explained they were humanists and had already made arrangements for a non-religious funeral service. However, they were happy for the chaplain to make occasional supportive visits.

Within 24 hours Charles became unconscious but his wife stayed at his bedside. At one time the chaplain met her in the corridor and she asked to speak to him away from her husband. She became tearful and said she didn't want to cry when she was with her husband but was naturally upset at the thought of his impending death. The chaplain saw her at least once more when she was not with her husband where she again shed tears.

Although there were no religious needs for this couple the chaplain was able to offer support and emotional care which otherwise might not have been readily available.

*Not his real name

CONTACT DETAILS

- paul.salter@nth.nhs.uk

News in Brief

Registration consultation

The Health Professionals Council has launched a [consultation](#) inviting stakeholders for their views on the proposed registration cycle for social workers in England as part of their preparatory work before opening the register for the profession. The deadline for responses is 29 February.

New e-bulletin



The latest edition of the Lung Improvement e-bulletin is now available. For more details click [here](#).

Cancer progress

The first [annual report](#) following the publication of *Improving outcomes: a strategy for cancer* has been published, outlining the progress made this year on implementation of the strategy and improving cancer outcomes.

Organ donation

In a new clinical [guideline](#) on organ donation for transplantation NICE recommends that organ donation should be considered as a usual part of end-of-life care planning. It also proposes that each hospital should have a policy and protocol, consistent with these recommendations, for identifying potential donors and managing the consent process.

Commissioning toolkit

The [Cancer Commissioning Toolkit](#) December 2011 includes a wide range of high level indicators and profiles across the patient journey. Regular chart updates include incidence 2009, mortality 2010, cancer waits Q2 2011-2012, and place of death 2010-2011. If you have comments or queries please contact kathyates1@nhs.net or neil.hughes@ncin.org.uk or servicedesk@concentra.co.uk.

Cancer information

The Department of Health has published an [intelligence framework for cancer](#), setting out plans to tackle deficiencies in cancer intelligence. The framework sets out an action plan to ensure that high quality, timely intelligence is available to all those who need it to improve cancer outcomes.

Bereavement benefits

The Department for Work and Pensions has launched a [public consultation](#) on bereavement benefits, which support people after the loss of a spouse or civil partner. The consultation, which applies to England, Wales and Scotland, ends on 5 March.

HealthWatch delay

The [deadline](#) for setting up local HealthWatch bodies, which will replace local involvement networks, has been extended to April 2013 following consultation. An additional £3.2 million will also be made available to local authorities for this purpose.

Cancer consultation

[Draft versions](#) of the cancer of unknown primary measures and the community skin cancer measures, for inclusion in the Manual for cancer services, have been issued for consultation. The consultation deadline is 14 March.

Message in a bottle



The Northern Ireland Executive has launched its [message in a bottle](#) scheme, run by the Armagh Lions Club, to enable quick identification of pre-existing medical conditions and prescribed medications in the event of an emergency call-out. The scheme is supported by the ambulance, police and fire and rescue services.

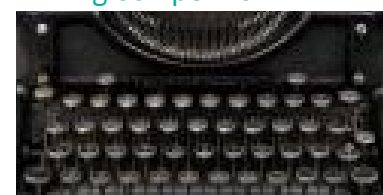
Dignity newsletter

The latest copy of the newsletter of the organisation *A Dignified Revolution* is now available to subscribers on its [website](#).

Dementia inquiry

The All Party Parliamentary Group on Dementia has launched an [inquiry](#) into how to improve dementia diagnosis rates across the UK. The deadline for written submissions is 2 March.

Writing competition



The Dying Matters Coalition is running a new creative writing competition, entitled [Final Chapters](#), about dying, death and bereavement. The deadline for entries is 31 March.

COMING EVENTS

NICE conference

The NICE annual conference takes place in Birmingham on 15-16 May. For more details click [here](#)

Marie Curie conference

This year's Marie Curie Annual Palliative Care Research Conference takes place on 23 March at the RSM, London and will focus on the challenge of symptom control in advanced progressive disease. The deadline for registration is February 24 and can be done via the Royal Society of Medicine [website](#).

New week-long course

St Christopher's Hospice will be running Multi-Professional Plus, an intensive week's study for advanced end of life care practitioners, from 21 to 25 May. The cost is £750. For more information visit the [website](#).



NATIONAL END OF LIFE CARE PROGRAMME
PHONE: 0116 222 5103
EMAIL: information@eolc.nhs.uk
TWITTER: @NEoLCP

3rd Floor
St John's House
East Street
Leicester LE1 6NB

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