

Care To Learn

**NCPC's introductory
end of life care
training programme
revised and updated**



NCPC's
new report:
Getting
Serious
About
Prevention

The role
of family
members in
interpreting at
the end of life

Ambitions for
Palliative and
End of Life
Care

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Welcome



Firstly, thank you and farewell to Professor Mayur Lakhani who stood down as NCPCC's Chair of Trustees in September after seven years of dedication and service. A warm welcome to Baroness Iora Finlay who has taken over the position.

I'm delighted that NCPCC was nominated for a Laing Buisson Award in their Excellence in Training category. The nomination was for our training on end of life care communications skills, delivered in partnership with Kent Surrey Sussex Academic Health Science Network, which is now into its second year. I'm thrilled to see yet more recognition for our training which goes from strength to strength.

Finally, in September I was pleased to open the Holly Road Supportive Care Centre in Uttroxteter

(pictured above), a partnership project between St Giles Hospice, Katharine House Hospice and the Hermitage Charity Care Trust. It aims to provide the local community with support and information on issues around end of life care, such as advance care planning. Community initiatives like this are so important, and there are a range of examples from hospices and NHS organisations throughout this issue.

Claire Henry
Chief Executive

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Ambitions for Palliative and End of Life Care

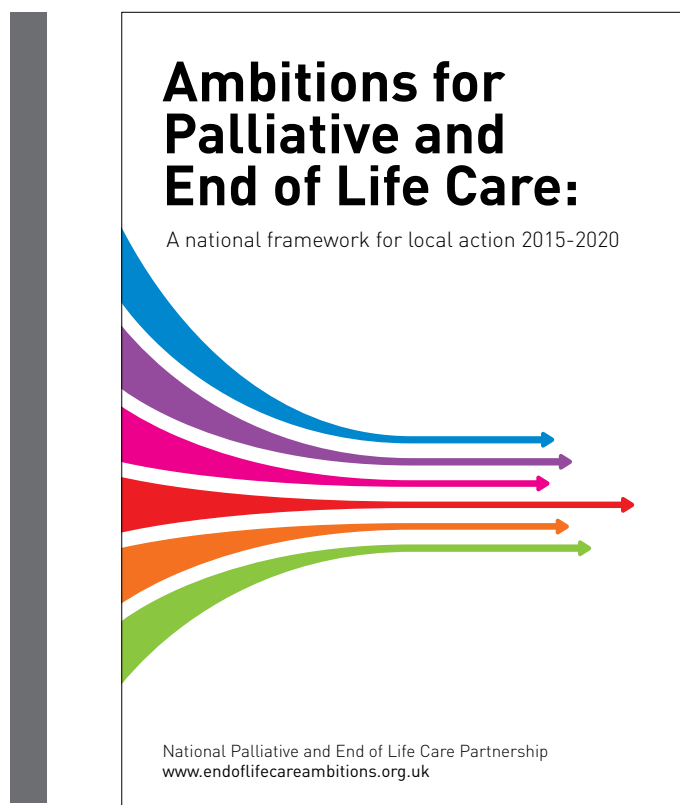
A national framework for local action 2015-2020

In September, the National Palliative and End of Life Care Partnership, which consists of 25 national organisations including NCPC, published a major report, *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*.

The partnership has come together to create this shared vision for what needs to happen next to improve end of life care. The vision, which is based on six key ambitions, will only be made to happen if local organisations agree to work in partnership to improve end of life care for the people they serve, with a common determination to ensure that everybody has the care and support we would want for ourselves and our families. We are asking organisations in every locality to come together to do this, and to designate a local lead, whether this is the Health and Wellbeing Board, the Clinical Commissioning Group, the Local Authority or some other organisation.

As ever we encourage you to use this document to build local partnerships, designate the lead, and work together to do a stock-take of where you are and agree a common plan to achieve these ambitions in your area.

We look forward to hearing how you are getting on.



We'll be sending a hard copy of the report to all our subscribers during November.

You can find more information about the National Palliative and End of Life Care Partnership, and a slide-set based on the report at

www.endoflifecareambitions.org.uk

Policy Roundup



New Minister Ben Gummer MP affirms Government intention to get end of life care right and work with NCPC

Government Minister gives first public speech at NCPC conference

Ben Gummer MP, Parliamentary Under Secretary of State for Health, gave his first public speech at NCPC's Making Choice Happen conference on 15th October 2015.

In his speech the Minister, whose priorities include end of life care and maternity care, emphasised that the Government has the ambition to "get end of life care right". He praised the work of the end of life care sector in identifying the changes necessary to improve end of life care, and in raising the profile of the issue in recent years.

Mr Gummer stated that his two priorities for end of life care were ensuring quality across all care settings, and enabling people to choose to die at home. He committed to working with NCPC and the End of Life Care Coalition (of which we are a member along with six other charities) to develop his policy.

At the end of his speech, Mr Gummer emphasised the importance of good end of life

care, affirming that there is only "one chance to get it right" for people who are dying. He confirmed that improving end of life care was a core part of the Government's mandate.

National survey of bereaved people (VOICES) published

The latest National Survey of Bereaved People, VOICES (Views of Informal Carers - Evaluation of Services) has been published by the Office of National Statistics. The survey findings include:

- 75% of bereaved people rated the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
- 69% of bereaved people whose relative or friend died in a hospital, rated care as outstanding, excellent or good - compared to 83% for those who died in a hospice; 82% for those who died in a care home; and 79% for those who died at home.
- Ratings of fair or poor quality of care were significantly higher for those living in the most deprived areas (30%) compared to the least deprived areas (21%).

House of Lords debates on access and quality in palliative care

Two recent discussions on palliative care took place in the House of Lords.

On 22nd October, there was a short debate on palliative and social care at end of life.

On 23rd October, Baroness Ilora Finlay's Private Members' Bill on Access to Palliative Care, passed its second reading. However, Lord Prior of Brampton (Parliamentary Under Secretary of State for NHS Productivity), stated at the end of the debate that the Government did not support the Bill, as the proposals within it are deemed to be inconsistent with the Government's reforms to give more autonomy to local organisations.

NCPC publishes statement on Assisted Dying Bill

Prior to the second reading of the Assisted Dying (No. 2) Bill in the House of Commons on Friday 11th September, NCPC published a joint statement on the Bill with the Association of Palliative Medicine and the National Palliative Care Nurse Consultants Group.

Following the second reading of the Bill, a majority of MPs voted against it, with 330 votes against the Bill compared to 118 in favour.

Read our statement at www.ncpc.org.uk/news

Independent Cancer Taskforce publishes national cancer strategy

The Independent Cancer Taskforce has published a new cancer strategy for England.

The recommendations in 'Achieving world-class cancer outcomes: A Strategy for England 2015-2020' have been developed in consultation with people with experience of cancer treatment and care, cancer charities, and professional groups.

The recommendations include that CCGs should commission appropriate end of life care, in accordance with the NICE quality standard, and taking into account the Review of Choice in End of Life Care and the new document setting out Ambitions for End of Life Care (see page 3).

Government responds to Health Select Committee report on end of life care

The UK Government has responded to the Health Select Committee's report on end of life care. The report from the Health Committee was published in March 2015, and was based on its Inquiry into end of life care, to which NCPC contributed both written and oral evidence.

The response summarises the current work underway to address the issues raised in the committee's report. It affirms the importance of improving end of life care, and states that the Government is exploring how 24/7 care could be implemented, and is considering a number of options to ensure rapid access to social care, of which free social care is one.

UK ranked top out of 80 countries for end of life care

The UK has been ranked first in the 2015 Quality of Death Index, a measure of the quality of palliative care in 80 countries around the world released in October by The Economist Intelligence Unit (EIU).

The index is based on an assessment of infrastructure, and does not measure outcomes or people's experiences. According to the index, the UK's ranking is due to comprehensive national policies, the extensive integration of palliative care into the National Health Service, a strong hospice movement, and deep community engagement.

Law Commission opens consultation on Deprivation of Liberty

The Law Commission has recently held a consultation on mental capacity and the Deprivation of Liberty Safeguards (DoLS). NCPC and Hospice UK are making a joint submission. The Commission expects to publish a final report with its recommendations and a draft Bill in 2016.

Getting serious about prevention

NCPC's new report on enabling people to stay out of hospital at the end of life



THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE



Care and support
through terminal illness



NCPC's latest report, *Getting Serious About Prevention: enabling people to stay out of hospital at the end of life*, has been produced in partnership with Hospice UK and Marie Curie, the report calls for action to prevent unnecessary and costly hospital stays at the end of life. It is intended to help commissioners as well as providers and contains key recommendations on how they can enable people to stay out of hospital at the end of life when they neither need nor want to be in hospital.

The report also contains examples of good practice where good planning and co-ordination enable people to be cared for out of hospital at the end of life, and examples from people with personal experience of end of life care.

We would encourage you to share this

report with local commissioners in your area, and encourage them to take note of the recommendations and insights it contains. In particular please give it to anyone involved in developing local integration work or system resilience – as groups working on winter pressures are now known.

As ever we welcome your feedback, so please send any comments on Getting Serious About Prevention by email to enquiries@ncpc.org.uk or write to us at the address on page 23.

NCPC subscribers received their copy of Getting Serious About Prevention in October. Additional copies can be purchased at <http://shop.ncpc.org.uk>

Care To Learn

NCPC's introductory end of life care training programme revised and updated for 2015

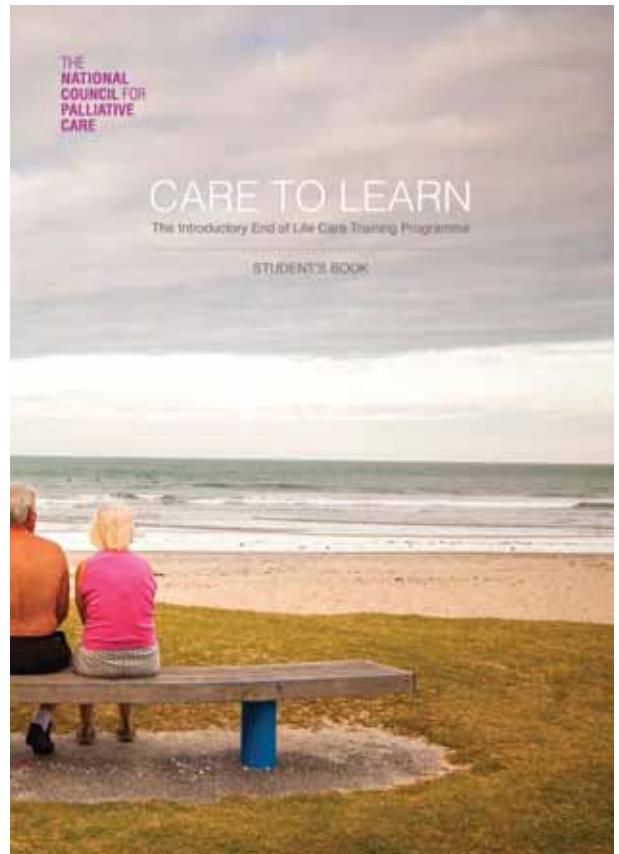
NCPC's *Care to Learn* training programme was first launched five years ago and has been a popular resource for training people who are new to the sector.

Following significant recent changes within palliative and end of life care (and in the wider health and social care landscape), and in response to feedback from those who have used *Care To Learn*, the programme has been subject to a thorough process of revision and updates. The format has also been changed so that it is now presented in two A4 booklets - one for students and one for mentors.

Care To Learn is designed to help staff improve end of life care. It provides an introduction to good practice, and is flexible so that it can be tailored to each individual learner, organisation or locality.

It is aimed at Health Care Assistants and direct care staff across all settings including hospitals, hospices, care homes, the individual's home or in housing schemes. Qualified nursing staff moving into end of life care for the first time will also benefit from using the programme. Other qualified direct care staff and managers of services may also find it useful for induction or refresher training as each module can be used as a standalone resource, although the main benefit of the programme comes from working through each of the modules.

The accompanying Mentor's Guide provides guidance for the mentor by highlighting what they should be looking for when having discussions with the learner and how they can offer on-going support. Support throughout the modules from a mentor who is either a line manager or a more experienced colleague will be key in embedding the learning, changing attitudes and improving the quality of end of life services.



If a number of learners are in the same setting and are working together as a learning set NCPC can arrange topic focussed workshops delivered by experts to explore subjects in more depth, provide opportunities to learn from colleagues and consolidate learning.

NCPC is grateful to the Shaw Foundation whose financial support has made the updated Care to Learn possible.

NCPC subscribers will receive their copy of Care to Learn in October. Additional copies will be available to purchase at <http://shop.ncpc.org.uk> with discounts for bulk orders.

What role should family members play in interpreting at the end of life?

NCPC's Senior Policy & Public Affairs Officer Andrew Grey explores this complex area

Sensitive and honest communication is central to good end of life care, and underpins all five of the priorities for care set out in One Chance to Get it Right. Yet language differences can be significant barriers to this, and are enhanced by the lack of funding for professional interpreters in NHS settings.

For this and other reasons family members often become involved in interpreting. There are advantages and disadvantages to this option, but often family members are more available than professional interpreters.

However, there are several issues to consider if family members are to be involved in interpretation.

What do the person dying and their family members want?

Firstly, it is important to ask whether the person dying wants their family members to act as interpreters and whether the family members actually want to adopt the role of interpreter. Some may be uncomfortable with this and it would be inappropriate to pressure them into doing so, yet other family members might feel excluded if they were not given the opportunity.

Staff responsibilities

Health and social care staff need to remember that a family member acting as an interpreter is there to aid the person being cared for,

rather than the member of staff. When working across languages, with an informal or a formal interpreter, it is very easy for staff to fear that the person's safety may be compromised. By attending to basic issues, such as those below, health and social care staff can make their own judgements on when it is appropriate or not for a family member to interpret, to help ensure the person's safety.

Sensitive information

There are also questions about the nature of the conversations that family members might be interpreting. Discussions about the person's care are likely to affect their family members, too – is it appropriate for them therefore to be interpreting at the same time as they themselves are trying to make sense of the information? Equally, as a family member, they may not wish to know some aspects of the information – is it fair to expect them to interpret when there is a risk of them finding out what they would have preferred not to know?

The sensitivity of the information also means that confidentiality is a very important principle, and it is vital that the person acting as interpreter is able and willing to keep this confidentiality, in order to maintain the trust of both health and care staff and the person at the end of life.

It is also important that the interpreter conveys the information impartially. This may be difficult as they might struggle with a desire to protect the person.



Involving the person being cared for

When these conversations are taking place, it is crucial that they do not become simply dialogues between two people – the interpreter and the member of staff. They must always involve the person themselves. There are also issues of confidentiality: health and social care staff ought not to communicate significant news about the person's condition to their family members before communicating with the person themselves. If communication is taking place via the family member, is there an effective way to avoid this?

Accurate information

It is also crucial that any information is not misinterpreted. There are sometimes practical reasons for this being a risk, such as differences in vocabulary: for instance, in many Asian languages there is no direct translation for 'dementia'. Equally, there is a risk of family members deliberately not interpreting exactly what is being communicated to them – they may be reluctant to pass on the full extent of any bad news. Even if this is not deliberate, there are still questions of how to ensure that family members have the level of language proficiency necessary to act as interpreters.

Having the skill to speak two languages does not, by default, mean someone is an effective interpreter. It is important to be able to switch seamlessly between languages to assist communication, and to have strong memory skills, as well as understanding intricacies and idioms of each language.

Whilst there may be a number of benefits to

A family member acting as an interpreter is there to aid the person being cared for, rather than the member of staff.

family members adopting the role of interpreter at the end of life, the considerations in this article demonstrate that this is a complex issue involving communication skills which are at the heart of palliative care. Using family members as interpreters always needs to be given a lot of thought.

Further information

- NHS England is carrying out a review to improve the quality of interpreting in primary care. More information is available on the NHS England website:
www.england.nhs.uk/commissioning/primary-care-comm/interpreting/
- NHS England has published an 'Accessible Information Standard'. The standard applies to health and social care organisations and identifies their obligations regarding provision of communication support and information in accessible formats:
www.england.nhs.uk/ourwork/patients/accessibleinfo-2/
- The Five Priorities for Care are set out in One Chance to Get it Right, which was produced by the Leadership Alliance for the Care of Dying People. It can be downloaded from the UK government website at:
www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations

NPCPC is grateful to the following organisations for their input to this article: Carers Trust, Everyday Language Solutions, Faith Action, Hospice UK, Mothertongue, Race Equality Foundation, Sense and Sue Ryder.

Update on NCPC's Community Involvement work

NCPC's Community Involvement Manager Louise Palmer on our work with people with personal experience of end of life care



NCPC's 'Speak Out' training will help people with personal experience of end of life care to be confident to talk about their stories in public

People in Partnership

Our latest People in Partnership (PIP) meeting took place in September. This was a full meeting with guest speaker Wendy Gray who came to talk about the Electronic Palliative Care Co-ordination Systems Programme (EPaCCS). EPaCCS enable the recording and sharing of people's care preferences and key details about their care at the end of life. Wendy came to ask people from the group to share their experiences about using the system, in line with work being done with family members, carers and people with life limiting conditions.

Feedback from Dying Matters Awareness Week was presented by our Communications Director Joe Levenson which was extremely positive. We had over 630 events this year,

over 700 separate pieces of media coverage and 10,000 volunteer hours contributed. We know that many of those holding and participating in Dying Matters Awareness Week events are people with personal experience of end of life care. A big well done and thank you to all who participated in making it such a great campaign this year.

Training to 'Speak Out'

We are very pleased to have a date set for our first pilot session of this training in November, to be held at St Giles Hospice in Lichfield, Staffordshire. Two of our People in Partnership members Tony Bonser and Ian Leech will be delivering the course which focusses on developing public speaking skills and confidence in talking about dying, death and bereavement. We're also very excited

to have now secured funding to roll this out across four more regions next year, thanks to NHS England. We look forward to feeding back after our pilot and will update details on which areas we will be running the rest of the training.

Call for feedback Care Quality Commission: Review into inequalities and variation in End of Life Care

We are still busily consulting with people across the country about the variations in end of life care experienced by different population groups. One of the big challenges we have established is that people are still very reluctant to talk about the subject. We know that it can be very distressing, however the CQC want to hear good and bad examples of care in order to improve services in the long term. We all know how vitally important it is and we are still looking for people to come forward with their experiences in the following areas:

Bassetlaw, West Surrey, Solihull, Newham, Oldham, Crawley, Great Yarmouth & Waveney, North Staffordshire, Southwark, Hull, Tyneside, West Kent, Basildon & Brentwood, Greenwich.

If you are or have been a carer of someone who has had end of life care in the last 12-

18 months, or know someone currently experiencing this who has a non-cancer specific condition and is over 75 years, please do get in touch with me via the details below. These include life limiting illnesses such as heart failure, motor neurone disease, dementia, alzheimer's, stroke and COPD. Any feedback given will be strictly confidential and a 'thank you' voucher worth £15 to spend in a variety of high street stores will be given to those who can contribute. The CQC are also looking for people to interview about their experiences. For further information about this, please contact me directly.

Big Conversation heads to Leeds

I'm delighted to announce that we are now making plans for our next Big Conversation event in March 2016 to celebrate our involvement work and all who help influence good practice in end of life care. For the first time the event will take place outside London, at St Gemma's Hospice in Leeds, with a special focus on bereavement. One theme we are particularly interested in is grief in the digital world and also how this links in with children and young people. Watch this space for further developments and details of how to book your place!

You can contact Louise on 020 7697 1520 or email l.palmer@ncpc.org.uk

What to expect when someone important to you is dying

Shaped by people who have experienced the death of someone they were close to, and with support from NHS England, Marie Curie, Sue Ryder and Hospice UK, *What to expect when someone important to you is dying* is intended to make the last hours and days of someone's life less distressing for all concerned, including friends, family members and carers.

What to expect when someone important to you is dying is available to download free of charge at www.ncpc.org.uk/freedownloads

Hard copies are available to purchase for £2.50 or just £1.25 for subscribers at <http://shop.ncpc.org.uk>



Everything in place

Developing a service to help communities with advance care planning



As more of us choose a home death, with less medical intervention, with our families around us and in our own environment, the need increases for emotional and physical support for families. The significant fact is that we no longer have extended families to support long term care of each other. We are also less likely to have been exposed to death. Death happens behind closed doors, at arm's length, we have lost our familiarity with the dying process – meaning that when it does happen individuals are left unprepared, unable to know what to expect and in very many cases, unable to cope. Death is often seen as a medical failure not the natural progression that it is.

In January 2015 St Cuthbert's Hospice, Durham, appointed Louise Johnson as Community Liaison Officer in a role supporting communities to understand the impact of an increased demand for palliative care. As the number of home deaths are expected to rise, St. Cuthbert's wants to work with local communities (or communities of interest) to create community led innovative solutions to tackle this shift.

“How amazing if we could help individuals and their families to plan for future care and end of life. Encourage them to consider the things that might be important to them whilst they are fit and well. The project creates a space to process thoughts and conversations around end of life, promote philosophical and practical discussion, help provide solutions and put

plans into place. All whilst free of the burden of illness or invasive treatment.”

The real question of course is how do we engage with people about death? How can we change perceptions and ultimately culture? In fact the first barrier to engagement for Louise was the use of the words “death” or “dying”. After many deliberations the title of “Everything in Place” was agreed by a steering group that had been brought together to support the development and delivery of the project. The group set about delivering a series of community sessions, not only looking at wills, powers of attorney and advance care needs but also posing such questions as “Would you realise or think of these issue if you were not managing at home, if you were having too many falls, or not eating properly?” Do you have spiritual needs to address? Is it time to go back to a place of worship, or is there a need to meditate, listen to music or enjoy nature. It may be a walk in the park or sitting by an open window listening to the birds, whatever it is that soothes the soul.

In scoping the sessions discussions were held with undertakers, solicitors, social workers and church ministers, asking them all the same question.

“When someone comes to see you what are the most common questions you are asked?”

We wanted to de-mystify the information from the professionals, present information in layman's terms and design sessions that would be informative, conversational, relaxed and stimulate thinking. Ultimately the project is about planting those seeds of thought and encouraging positive actions, providing one to one help and support where necessary. The Hospice is looking to develop a team of



Mr and Mrs Hall benefited from the hospice's advice and support around forms and paperwork to make their end of life plans

community volunteers and identify gaps in provision or points of concern for families. This would be the evidence base for a range of community led creative solutions to ease the pressure on families supporting a loved one with a life limiting illness or complex medical needs.

Lisa Coverdale of partner organisation Cestria Community Housing says:

"The whole ethos of the project is to help people think about the choices they have, if plans are not made in advance choice becomes limited, situations are managed re-actively. Many family fall outs occur at the time of a death. It may be because someone's opinion was not considered or someone feels isolated, often unintentionally, purely circumstantial and as a result of people managing their own grief. The degeneration of the relationship can often remain unresolved and lead to a divisive rift that never heals."

Mr and Mrs Hall of Sacriston, Durham attended their Community Centre for local sessions, wanting to make sure that they had everything in place to remove the burden of dealing with formalities for their only daughter. They found the sessions informative and liked the relaxed approach, meaning they could ask as many questions as they needed and get help with forms and paperwork.

The project was launched during Dying Matters Awareness Week, when several

methods of engagement were tested. Direct presentations to community groups were the most effective, coffee morning and drop in sessions were the least, leading to a conclusion that people do realise what they don't know, and without 'knowing' they did not see the relevance of the topic. Louise says,

"It was not always easy to get the message across, but once the message was understood tangible changes could be felt within a room – not of sadness, but of acceptance and easing the burden for families. The journey of mortality is not an easy one to engage with – in reality any small steps are fairly huge!"

The Dying Matters event collated 108 questionnaires, the first information sessions started with 6 participants and by the third session we were up to 21. Hospice staff believe that word of mouth is the best recommendation and look forward to securing the project as a cornerstone of the community.

For more information visit
www.stcuthbertshospice.com
or contact Louise on
Louise.Johnson@stcuthbertshospice.com

Medical Examiners Pilot

Sheffield Teaching Hospitals Leading the Way



The loss of a relative is a particularly difficult time and families need to have confidence in the medical and nursing care given to their loved ones. The Medical Examiner system provides an independent safeguard.

For most families their experience of the process surrounding the death of a family member is satisfactory, at least given the circumstances, but there is a possibility of things going wrong at some point during someone's final illness. This may be a delay in diagnosis, a fall resulting in injury, incorrect medication being administered or failure on the part of the medical or nursing staff to provide adequate care.

People of all ages can feel upset, angry or frustrated if they feel that their loved one has been mistreated throughout their illness, whether it was at diagnosis, treatment options, at a follow up or at the time of death. But who can the family of the deceased turn to when they have concerns about the medical care? Some feel they cannot raise the nursing concern with the care home manager or ward sister as they feel they will not be listened to, that their 'complaining' may worsen the situation for their relative or others. Some have lost all faith in the GP or Hospital system and feel they the concerns will not be answered honestly. Others may have questions relating to the final illness or events when the death was natural, but sudden or unexpected, and they have not had chance to discuss the diagnoses.

The Shipman inquiry examined the current process, and concluded that existing arrangements do not provide adequate safeguards for the deceased or their

families. In response to this the Department of Health propose to establish a Medical Examiner system throughout England and Wales. This will require every death not investigated by the coroner to be scrutinised by a suitably trained independent medical examiner to ensure appropriate medical care has been given during someone's illness as well as ensuring accuracy of the certified cause of death. This will increase safeguarding of the public and provide a better service for the bereaved without causing undue delay to families who require a fast release of the body and the certificate.

Crucially, in every case, the circumstances and cause of death are discussed with the bereaved family before the death is registered, to ensure there are no concerns. If the family do have concerns or questions regarding the diagnoses or medical care these are carefully considered to establish if the event or concern has played a part in their relative's death. If there is concern that this is the case, the medical examiners can pass the concern to the coroner to allow appropriate investigations into the events and circumstances, taking into consideration the views of the family.

Since 2008, we have an established Medical Examiner system including the community and acute hospitals. To date, over 15,000 deaths have been reviewed. Feedback from relatives and staff has been extremely positive;

"It is so difficult to take it all in at the time, thank you for going over the certificate with me; it makes so much more sense now I know how it all fits



New scheme will see every death that is not investigated by a coroner scrutinised by an independent medical examiner over quality of care and cause of death

together”

“I think it is smashing what you do, I’m pleased someone is keeping a check on things, I mean, I’m not medical and I just take what I’m told by the doctors, so it is really good that someone is checking it all out for us lay people”

“Thank you so much for your help with things, I was in the dark about what happened as mum died so suddenly, but now you have gone through it with me I am much more settled.... It’s is good to know that another doctor hasn’t got any concerns about what happened

“What an excellent system, it is reassuring to know that things are being checked”

“It enables the deceased relatives to ask any questions they may have

to the right people in the right place and to discuss any concerns with an independent person removed from the unit.”

We hope that an announcement on the national introduction of this valuable system will be made by the Department of Health soon.

Further information on the medical examiner system can be obtained from the Department of Health’s web site www.dh.gov.uk/deathcertification

The Sheffield team are happy to respond to any queries and can be contacted on 0114 271 5354 or at sht-tr.medicalexaminersoffice@nhs.net

Tackling the ‘terrifying’

How a community education project is taking the fear out of talking about dying



An innovative training project launched by St Catherine's Hospice in Lancashire is educating community practitioners in how to deliver effective end of life care which meets the wishes of patients.

The Community Transform project is based on the Transforming End of Life Care in Acute Hospitals programme. The two-year programme, funded by Greater Preston CCG and Chorley & South Ribble CCGs, was launched in March 2015 with an End of Life Care Master Class, followed by the roll out of training in April.

It targets community professionals including GPs, district nurses and ambulance personnel and aims to:

- Promote conversations about Advance Care Planning (ACP) and ensure they are recorded.
- Encourage GPs to find 'your 1%' – relating to research that indicates 1% of patients registered to a GP surgery are in their last 12 months of life and should therefore be included on the Supportive Care Register (SCR).
- Support staff in enabling patients to achieve their wishes and preferences at the end of life.

Topics covered on the course include ACP, Do Not Attempt CPR (DNACPR), priorities

of care for the dying person, communication skills and the Gold Standards Framework (GSF) – a model that enables good practice to be available to all people nearing the end of their lives, irrespective of diagnosis. As the programme has evolved, the team has begun to support the planned implementation of Electronic Palliative Care Co-ordination Systems (EPaCCS) – an electronic system which enables the recording and sharing of people's care preferences and key details about their care at the end of life by raising awareness and promoting data entry in GP surgeries.

The Community Transform team adopt a variety of approaches – interactive presentations, attending GSFs and meeting with administration staff to facilitate system change.

The impact of the training is being measured in several ways including: the number of people on the SCR; number of ACP/CPR/Preferred Priorities of Care discussions taking place; and the number of people dying in their preferred place. Survey results from professionals have also been positive – with increased confidence amongst staff who are no longer 'terrified' of having conversations about dying.

Among the delegates at the programme launch were paramedics from North West Ambulance Service (NWAS). Following this, the Community Transform team was invited to deliver a session at their South Lancs Summer CPD Event. The service was keen to empower paramedics with information and training to help them with decision-making related to ACPs and DNACPR, as well as end of life issues such



Clinical Educators Sue Clayton, Anthony Walsh and Fiona Tucker who are part of the St Catherine's Hospice Community Transform Team, which is working to improve end of life care

as anticipatory medication. EPaCCS was also discussed as presently NWAS has no access on scene to IT information around ACP and DNACPR.

Guest speaker at the NWAS session was NCPC and St Catherine's Hospice Trustee Tony Bonser, who provided a patient/family perspective. Although he strongly advocates the wonderful care his son received at the end of his life, he also highlights shortfalls in one of the most important areas of end of life care – communication. He said:

As a minimum I expect people to be asked 'what do you want?' People need to be given choice; to understand and be understood; to be involved about decisions about their care and to receive person-centred, goal orientated care."

Fiona Tucker, Clinical Educator at St Catherine's Hospice, said:

"Early results are looking promising in relation to numbers on the SCR. We wait to see if this project alongside other local and national projects will impact on preventing unnecessary admissions and increasing DiUPR – ensuring that people's wishes are met at the end of life."

For more information contact Fiona Tucker, Clinical Educator, St Catherine's Hospice via email on fiona.tucker@stcatherines.co.uk

Taking the right approach to advance care planning



Wakefield Clinical Commissioning Group

The Mid Yorkshire Hospitals 
NHS Trust



By providing a whole system approach to Advance Care Planning (ACP) with a dedicated programme and trainers, the number of patients supported to think about and have their choices recorded, through ACP, has increased across a Yorkshire district.

Health Education Yorkshire & Humber identified that the region required ACP training; this opportunity was grasped by Mid Yorkshire Palliative Care Education Forum who had already identified ACP as a priority in their Strategy 2011-2015.

Two, End of Life Care Education Facilitators were employed for 18 months. They were supported by a, Macmillan Consultant in Palliative Medicine and a GP, End of Life Care Lead.

The remit was to provide practice based training in ACP for clinical teams within Mid Yorkshire Hospitals, Wakefield District Community and Wakefield GP Practices.

The overall aim of this project was to improve care/experience (choices) for patients by giving staff the knowledge, skills and confidence to talk to patients and those important to them about their future wishes thereby:

- Increasing the percentage of patients who die in their preferred place of care / death (PPC/PPD)
- Improving anticipatory prescribing for symptom control

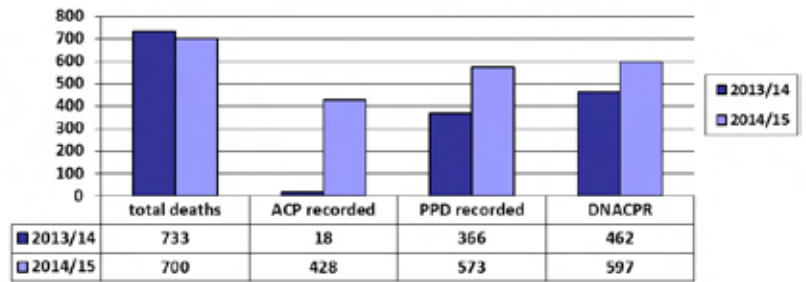
- Reduce bereavement associated problems (Voices survey 2014)
- Increasing the number of patients with an Advance Care Plan (ACP)
- Reducing inappropriate investigations & treatments
- Reducing inappropriate hospital admissions

It was essential to network and advertise in bulletins and newsletters via the Clinical Commissioning Group (CCG) and the Trust. Training packages were devised that could be delivered in any setting, i.e. on the wards, GP practices, lecture theatres and opportunities were utilised to train groups and specialist teams as they arose.

For a two month period delegates completed a pre training survey. This identified that 65% of respondents had received ACP training previously but only 18% implemented this in practice.

This project was undertaken at a time when there were huge demands on service delivery, especially staffing shortages within the acute setting which appears evident in the numbers trained compared with community services.

It was important to engage staff, at all levels and help them identify what skills they have or may need to implement this in practice. A pub quiz was devised, a game was played



Evidence shows more people are documenting their wishes

and patient scenarios were used to explore the issues and this also supported communication skills training.

Working independently from the Specialist Palliative Care (SPC) team was advantageous allowing the facilitators to network freely, explore different ways of training and be flexible to venues and audiences requirements. Having no patient care responsibilities allowed them to commit to the project 100%.

Evaluating training and collecting data continually proved invaluable, and it was soon established that for the sessions to be effective a minimum of an hour was required. Also that ACP was appropriate to their roles and patients. Staff of all levels was equally challenging and enthusiastic regarding ACP. Currently just over 1000 staff have been trained with further sessions arranged. Staff feedback has been continuously positive:

"I found this a valuable session, I now feel much more comfortable speaking to patients and family/carers"

"Very informative course delivered in a relaxed manner that allows for explanations and discussion"

Relatives have also responded well.

One daughter said her mother had an ACP and *"she made it really easy for me"*

Another person said because they had an ACP their teenage granddaughter was able to be involved in the funeral

"because she knew it was what her grandmother had wanted"

There is evidence of changes in practice; a clinical nurse specialist team now incorporate ACP in their assessment process in the outpatient department. A community pharmacist was able to facilitate this for patients in the community with positive outcomes. This project worked in conjunction with the introduction of the Electronic Palliative Care Coordination System (EPaCCS) across the Wakefield district.

The above pre and post data collection graph clearly demonstrates the improvements made and that ACP is now being implemented in practice, suggesting that an increasing number of patients have had the chance to think about and have their wishes for future care formally documented.

It is important to remember each number represents an individual person, their experience and that of those who matter to them

The figures above suggest the training has led to a positive change in practice which benefits patients and those who are important to them.

While this project and its funding are time limited, there is good evidence to support a further future and sustainable programme of training.

The team's substantial draft report at June 2015 to evidence success and achievements includes a recommendation for an on-going programme of training, which will be discussed with local commissioners.

For more information email Marian Oakhill End of Life Care Education Facilitator marian.oakhill@midyorks.nhs.uk or Jan Walker, End of Life Care Education Facilitator jan.walker@barnsleyhospice.org

Hope for Home

Delivering Namaste Care to people at home



SUPPORTING DEMENTIA CARE AT HOME



St Joseph's
Hospice

Registered charity no. 1113125

Something rather wonderful is happening in East London. It's happening in the homes of people with dementia and it's happening very slowly. You see that's the key. A truly person-centred dementia project is having a very positive effect on service users and their family carers in Newham, one of the most culturally diverse and the third most deprived local authority in London.

Namaste Care was first developed by Professor Joyce Simard in Vermont, USA. She says:

"Dementia is rarely recognised as a terminal illness. We've been medicating rather than thinking about quality of life. That's why I came up with Namaste Care – to honour the spirit within. It started in care homes – and now I'm really excited that it's happening in people's homes. It's all about loving touch, it's so easy, but we all tend to go too fast."

UK registered charity Hope for Home, dedicated to supporting people caring for loved ones with dementia at home, is responsible for introducing this life-changing, programme into the homes of people with advanced dementia in Newham, with volunteers trained and managed by St Joseph's Hospice.

Namaste Care is a non-medical approach so volunteers create a peaceful and loving

environment, offering meaningful activities using music, massage and touch, pleasing scents and appetising food and drinks.

"It's about honouring people with advanced dementia who can no longer tell us who they are or who they were and are unable to care for themselves without assistance," says Prof Simard.

Lourdes Colclough manages the programme for Hope for Home and St Joseph's. A year into the project and the results are really striking. She says she was inspired by the statistic from the Alzheimer's Society that only 41% of relatives of people with dementia feel their loved one has a good quality of life and this is what she wanted to address. She added:

"The social context of dementia resonated with me – people not knowing how to talk about it and deal with it – it's dehumanising. I knew we had to build a bridge with the people with dementia and their families. This is the community approach to working with people with advanced dementia."

Lourdes is candid about the challenges of setting up and running such a project. Finding the volunteers was the first major test. After an intensive recruitment drive as well as advertising

Home visits under the programme by Geraldine, a volunteer, have had a positive impact on Mrs Hackett, who has lived with dementia for five years



in local media, a team of 35 volunteers was recruited and then trained.

Lourdes' next task was to match the newly trained volunteers with the people with dementia. In some cases this was dictated by simple geography, in others cultural factors played a big part.

Judith Richards helps care for her mother Elna Hackett, 92, who lives in the same house she and her husband bought in 1960. Mrs Hackett taught at a primary school for 40 years and was diagnosed with dementia five years ago. She started to decline more rapidly in late 2013. Judith says that the visits of volunteer Geraldine Corcho have had a hugely positive effect on her mother. She says:

"It's been fantastic. Geraldine hit it off with my mother immediately, they really made a connection. She drew out a lot of my reminiscences and by giving her one to one attention and really focussing on her made her feel very special."

Geraldine concentrated on giving Mrs Hackett hand massages and manicures.

"My mother really enjoyed the tactileness of it. It felt like a very special treat and really affected her mood for the better,"

said Judith.

The positive impact isn't limited to Mrs Hackett and her daughter. Geraldine says:

"Every time I go there I feel like I am making a difference. When I said it was finished Mrs Hackett was very sad so I have continued. I would go every day if I could."

After a year, Lourdes says it's possible to reflect on the 100 sessions delivered and look at the key findings. In formal terms, these were that service users demonstrated increased communication and mobility with reduced agitation and anxiety.

Lourdes' gut feeling is that the project has exceeded expectations and says this is mainly down to the quality and commitment of the volunteers. Families have reported huge appreciation of the service.

Building on the success of the project in Newham, Hope for Home is planning to work with more providers in other parts of the country – helping dementia sufferers and their carers enjoy a better quality of life at home.

For more information visit www.hopeforhome.org.uk

Through our eyes



New project and report explore black and minority ethnic people's experiences of end of life care in the north west.



Greater Manchester, Lancashire and South Cumbria
Strategic Clinical Networks

Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks (GMLSC SCNs) have worked in partnership with Stories To Change on a new project to raise awareness of some of the end of life care issues and needs in black and minority ethnic communities in the North West. There was a particular focus on those happening between families and care professionals, commissioners and providers and within communities to enable a more holistic palliative and end of life care to be delivered.

The project involved filming interviews with volunteers from some of the different communities in the North West who talked about their own experiences of end of life care. It culminated in a stakeholder summit which explored increasing knowledge and awareness, access and utilisation of services available, managing communication and language barriers, utilising the voluntary and third sector more in local engagement, enhanced service provision and delivery and community engagement.



Stories to Change

Maqsood Ahmad, Network Manager for the GMLSC SCNs said:

"I would like to thank all those who shared their very personal experiences on film. Minority groups are often called, 'hard to reach'. I don't believe they are hard to reach. I believe the NHS can be hard to reach and we can do better. The people in the film have highlighted areas where I and my NHS colleagues can make a difference. I look forward to working in partnership with NHS colleagues and our communities to ensure the experiences (good and bad) of those that took part in the film are shared with the decision makers and implementers of care."

For more information and to download the Through Our Eyes report visit www.gmlscscn.nhs.uk

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About NCPC

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters coalition in England and Wales which aims to change public attitudes and behaviours around dying, death and bereavement.

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Contact us

The National Council for Palliative Care
The Fitzpatrick Building
188-194 York Way
London
N7 9AS

Tel: 020 7697 1520
Fax: 020 7697 1530
Email: enquiries@ncpc.org.uk
Web: www.ncpc.org.uk
Twitter: @NCPC_tweets

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Get more details and book online at www.ncpc.org.uk/events

Keynote Address

Day 1 Dame Julie Mellor DBE, Parliamentary and Health Service Ombudsman

Day 2 Sir Keith Pearson, Chair, Health Education England

Speakers include

Baroness Ilora Finlay, Chairman, NCPC, Claire Henry, Chief Executive, NCPC, Dr Jane Collins, Chief Executive, Marie Curie, Roy Lilley, Health Commentator, Professor Sir Mike Richards, Chief Inspector of Hospitals, Care Quality Commission, Dr Bee Wee National Clinical Director for End of Life Care, NHS England and many more...

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