



Building on firm foundations

Improving end of life care in care homes:
examples of innovative practice

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Foreword

The End of Life Care Programme, of which this document is an important part, is an integral component of the wider programme of work in developing a national End of Life Care Strategy.

The Strategy will deliver improvements in the care provided to all adults at the end of life. The creation of a separate working group on care homes to support the development of the Strategy emphasises the central role of care homes in providing high quality end of life care.

Care homes play a vital role in providing a home and care for residents, and support for their families and friends. Treating residents with respect for their dignity and is fundamental to all care provided by care homes, but it is especially true for care at the end of life. However, to deliver the standards of care that we would expect for our own families, staff need to have the right skills, knowledge and support.

Respecting people's dignity, and providing them with high quality care at the end of life, means that people should be enabled to have the maximum level of independence, choice and control about their care, with staff listening to what they and their carers want (which might include going home to die or preferring to spend their end of life in a care home).

Residents' spiritual needs, wishes about faith support, and arrangements for funerals in case of death should also be taken on board.

However, whilst progress has been made towards this caring approach, as set out in the various end of life care models included in this document, there is still a lot to do to ensure that all residents in care homes, and their family and friends have access to end of life care which best suits their needs.

This guide which has been produced in collaboration with the National Council for Palliative Care suggests ways that care home staff working in partnership with other organisations have improved the care that the residents now receive, whether in assessing needs support for staff, new roles, education and training. It highlights where organisations have brought a number of these elements together in a creative way to improve care.

I would like to thank all those who have contributed to this guide and hope that it will help others to implement some of the ideas in their own practice.



*Professor Ian Philp,
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Introduction

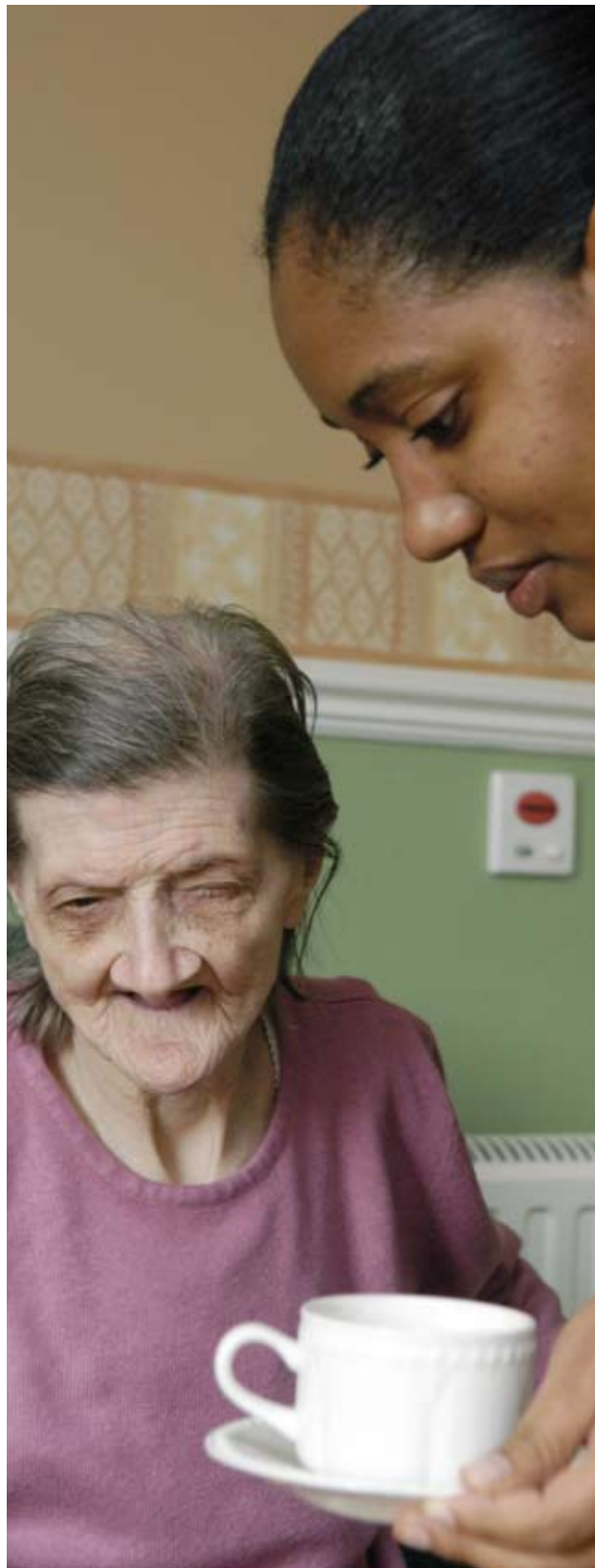
Care homes are the normal place of residence for a large proportion of people as they approach the end of their lives. They also provide shorter-term care for people who can no longer cope independently because of a terminal illness.

Currently there are around 18,500 care homes in England with around 400,000 beds; and around 100,000 deaths each year, or 20% of all deaths of people over the age of 65, happen in these homes.

In April 2006 the End of Life Care (EoLC) Programme and the National Council for Palliative Care (NCPC) published an 'Introductory Guide to End of Life Care in Care Homes'³. As the name suggests, the aim of this publication was to help care home staff consider some of the issues they face in meeting residents' end of life care needs and therefore arrive at potential solutions. The guide also sets out details about the EoLC Programme tools and many other useful resources.

Uptake of end of life care models/tools has been rapid – rising from 0.3% to 5% of care homes in the last two years. Although the numbers are still relatively small this reflects a significant increase and also supports evidence that NCPC's recommendations from its 2005 publication *Focusing on Care Homes, Improving Palliative Care provision for older people in care homes*⁴, have been largely met.

However, there is still much to be done!



3 www.endoflifecare.org.

4 www.ncpc.org.uk

Questions for care home staff to consider

In an 'Introductory Guide to End of Life Care in Care Homes' we asked care homes to consider certain questions about their practice. These remain important points for everyone to consider as a guide for future working:

How many of your residents die each year either in your care home or after transfer to acute care?

Do all your residents have up-to-date care plans including care at the end of life?

Can you identify the residents who are nearing the end of their lives?

Do you talk with your residents about where they would like to live and die?

What are the main disease groups among the residents in your care home?

How many GP practices provide medical care to your residents?

What links do you have with social care or specialist palliative care such as a link Macmillan nurse?

Have any of the EoLC models/tools been implemented in other organisations within your geographical location – for example, GP practices, acute trusts, community hospitals, hospices and other care homes?

Do you know what the priorities of your commissioners are, whether there is an overall palliative care strategy and how care homes fit in?

Common challenges to delivering end of life care in care homes

They also underline the fact there are still a number of challenges to implementing best practice. These include:

- Out of Hours (OOH) access to medical help and drugs
- Anticipatory prescribing – the ability to hold some drugs in stock and have access to the commonly used drugs in palliative care
- Number of GPs/practices involved in each care home. While people in a care home should have a choice of GP, it may be of benefit to limit the number of practices per care home. Some have used locally enhanced services to have one GP practice per care home. Others pay practices directly for personalised care – the most difficult scenario is multiple GPs with no common procedure or protocols
- District nurse and specialist palliative care nurse involvement is variable
- Advance care planning - initiated by some homes as standard but they experienced some difficulties, especially with communication. However, others find that discussing advanced wishes and preferences to inform an advanced care plan can be a natural way to start a conversation around end of life care and any concerns/questions people may have
- Resuscitation issues - local policies need to be developed giving clear guidance
- Verification of death – local protocols need to be developed
- Education of staff, especially at induction and on-going training
- Cultural and language differences of both staff and residents
- Rapid staff turnover
- Residents with co-morbidity - there may be

fewer service users with cancer, for example, but a high incidence of chronic respiratory disease, heart failure and dementia and also additional difficulties with mobility, deafness and incontinence

- Different pattern of dying - most people die over a longer period than in the traditional cancer/palliative care pattern and there can be great difficulty in recognising the end of life phase.

To follow on from this work the EoLC Programme and NCPC asked care homes to provide examples of innovative practice within their area. The response was overwhelming and reflects the importance attached to this issue not only by care homes but also commissioners, other service providers and users and carers. These innovative practice models offer solutions to many of the issues identified in an 'Introductory Guide to End of Life Care in Care Homes'.

What follows are some examples of the innovative practice that is now taking place up and down the country. They show how using different approaches to address end of life care helps to improve the quality of care, cut unnecessary hospital admissions and, most importantly, ensure that more people end their lives in the place and manner of their choosing.

Most of the initiatives we highlight found solutions to these issues. But they remain important challenges. Although these case studies only act as a guide to shape your local practice they have been chosen as ones which may well be replicable and achievable. At the end of each case study contact details are supplied so that further information can be shared, networking can occur and support be given. We hope you find this guidance helpful.

Please let us know your comments at information@eolc.nhs.uk or enquiries@ncpc.org.uk

Definitions

End of life

The 'end of life' phase finishes in death. Definition of its beginning is variable according to the individual and professional perspectives. In some cases it may be the person who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the person. In all cases, subject to individuals consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

Professional judgement may be informed by use of a range of indicators. They include:

1. The surprise question: Would you be surprised if this person were to die in the next 12 months?
2. Choice: The person with advanced disease makes a choice for comfort care only.
3. Need: The person with advanced disease is in special need of supportive/palliative care.
4. Clinical indicators: Specific indicators of advanced disease for each of the three main groups – people with cancer, organ failure, elderly frail/dementia.

End of life does not normally begin earlier than one year before death and for most individuals it may come much later than that. However, in some cases discussions with individuals about end of life may start much earlier – for example, at the point of recognition of incurability.

End of life care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and their family to be identified and met throughout the last phase of life and

into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

End of life care is underpinned by:

- An active and compassionate approach to care that ensures respect for and dignity of the individual and their family
- Partnership in care between the person, family and health and social care professionals
- Regular and systematic assessment of person/carer needs incorporating the individual's consent at all times
- Anticipation and management of deterioration in the individual's state of health and well-being
- Advance care planning in accordance with the individual's preferences
- Individual's choice about place of care and death
- Sensitivity to personal, cultural and spiritual beliefs and practices
- Effective co-ordination of care across all teams and providers of care (in statutory, voluntary and independent sectors) who are involved in the care of patient and family.

(This definition is taken from Operating framework 2007/08: PCT baseline review of services for end of life care April 2007)³

Making change happen

The Gold Standards Framework in Care Homes Programme (GSFCH)

The Gold Standards Framework (GSF) for Community Palliative Care has for more than seven years been helping to improve care for people nearing the end of their lives in the community. It is now being used by about a third of primary health care teams in the UK.

The GSF for Care Homes was developed and modified from the GSF primary care model to optimise the organisation, communication and proactive planning for people in the last years of life in care homes. Its aims are to improve quality of care for residents as they near the end of their lives, to improve the collaboration with GPs and specialist palliative care teams and to reduce crises and hospital admissions.

Based on the principles of GSF to 'identify, assess and plan care' and using modified versions of the same seven key tasks, it now incorporates additional specially developed tools and resources. These include using an identification, needs-based coding and advance care planning processes, assessment tools, educational resources and a minimum protocol for the dying stage, which for many leads on to use of a care pathway for the dying such as Liverpool Care of the Dying Pathway.

The programme has been used by almost 400 care homes, with studies confirming a demonstrable effect in improving the quality of care, restructuring patterns of working and reducing hospital admissions and deaths. It is now being run as a comprehensive three-stage quality assurance programme. An accreditation process is being developed in partnership with Help the Aged.

For more information:

Tel: 0121 465 2029

www.goldstandardsframework.nhs.uk

The Preferred Priorities for Care Plan (formerly Preferred Place of Care)

The Preferred Priorities for Care Plan (PPC) is a document that individuals hold themselves and take with them if they receive care in different places. It has space for the individual's thoughts about their care and the choices they would like to make, including saying where, if possible, they would want to be when they die. Information about choices and who might be involved in their care can also be recorded so any care staff can read about what matters to the individual, thereby ensuring continuity of care. If anything changes, this can be written in the plan so it stays up to date. It is never too early to start a PPC plan particularly for residents in care homes, which for many is their permanent and final place of residence. The PPC provides an opportunity for care home residents and staff to work together to develop advance care plans in accordance with the new Mental Capacity Act. Residents can initiate the PPC at any time and this will help staff follow their wishes and act as an advocate if the resident loses capacity towards the end of their life.

For more information:

Tel: 01772 647041

<http://www.cancerlancashire.org.uk/ppc.html>

The Liverpool Care Pathway for the Dying Patient

The Liverpool Care Pathway for the Dying Patient (LCP) was developed to take the best of hospice care into care for people in hospital and other settings, including care homes. It is used to care for residents in the last days or hours of life once it is known they are dying. The LCP involves promoting good communication with the residents and family, anticipatory planning, including psychosocial and spiritual needs, symptom control (pain, agitation and respiratory

tract secretions) and care after death. The LCP has accompanying symptom control guidelines and information leaflets for relatives.

For more information:

Tel: 0151 706 2273/2274

www.mcpcil.org.uk

Developing an organisational approach to end of life care in Anchor Homes

Anchor Homes instituted a three-day training programme for its care home staff during 2005 and 2006 which has helped remove the taboo surrounding death and encourage staff and residents to deal with the topic more openly.

The home manager from each Anchor home along with three colleagues attended three one-day sessions over an 18-month period aimed at giving them the skills and knowledge to deal with the topic sensitively and professionally.

In all 300 members of staff took part in the training, delivered in conjunction with the International Institute on Health and Aging, with each participant encouraged to complete personal portfolios on end of life care.

Most Anchor Homes residents stay in the homes until they die, explains national care specialist Louise Bulcock 'We felt that although we provide a good service we could improve how we communicated about death to staff, residents and their families. Our aim was to provide the best end of life care in the residential care sector.'

Often it is staff or relatives who find it most difficult to discuss death, she says. 'But by making it difficult to discuss death, we are making it difficult for the person in question to express his or her wishes.'

To try and tackle this, part of the training asked staff to investigate funeral costs at the local funeral directors. This then gave them an opening to discuss wider issues and options.

Staff who took part have shared their learning and helped to implement changes in the way they handle deaths in the home and the way they discuss dying with residents. They have also changed how they announce residents' deaths and try to involve fellow residents in celebrating the life of the person who has died.

There have been some excellent examples of good practice as a result and some homes are now working towards the GSF with their PCTs.

Work is already under way to provide a toolkit in each home on handling end of life care and also to incorporate a section on death and dying in the Anchor Homes induction manual.

Key points:

- 300 Anchor Homes staff took part in end of life care training over 18 months
- As a result staff and residents discuss dying more openly and deaths in the home are handled more positively
- A toolkit is now being developed to embed this within all that Anchor does, including its introduction manual

Contact details

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'The final lap' - improving end of life care in Methodist Home Association Care Group

Staff at Methodist Home Association (MHA) Care Group homes has introduced a number of changes aimed at humanising the process of death and dying following a series of 'Final Lap' training days.

These include - depending on the residents' choice - having flowers and music during

the final days as well as making the room welcoming for relatives after death. Residents are also encouraged to talk about death and discuss how they would like to spend their last days.

In addition MHA has reviewed its policy regarding a death during the night. In most circumstances it is unnecessary to call out an undertaker and remove the deceased there and then. Instead these arrangements are now left until the morning, allowing staff and residents to pay their last respects.

More of those who die are now taken out in a coffin rather than a body bag. Thanksgiving services in the home are more common and many homes have introduced funeral teas and some encourage residents to raise a toast to the deceased resident after the funeral service.

Residents are also remembered through memory books of poem and photos, their names are mentioned at the next service in the home and memorial gardens have been created, and trees planted, to commemorate those who died. Some homes also send bereavement cards to families.

A total of 240 staff have now taken part in the initial training.

Key points:

- Staff at the MHA Care Group have introduced a range of modifications to arrangements during and after a resident's death following training sessions
- These include having flowers and music in the last days and celebrating the resident's life afterwards

Contact details

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An organisational approach to introducing the Liverpool Care Pathway at a BUPA care home (nursing), Bexley

The number of residents who were being transferred to hospital to die in a BUPA nursing home in Bexley dropped sharply following the carefully managed introduction of the Liverpool Care Pathway (LCP).

Before the LCP was introduced, 67% of deaths occurred in the home and 32.5% in hospital. But in the six months following implementation hospital deaths dropped to 21% and in the last six months they fell even further, to just 16%.

The new approach was partly the result of concerns expressed by the local A&E department about the number of residents being transferred from care homes (nursing) who then died within a few hours of admission.

Bexley Care Trust's older people's project team, together with the lead cancer nurse from Queen Mary's Hospital Sidcup, prepared the ground for the change with meetings with the home manager and local GPs. They also ran workshops for staff, produced resource folders for each unit and visited the home regularly to support the implementation.

Staff now feel confident about discussing issues around dying and the preferred place of care with residents. They can also use the pathway to discuss spiritual issues more readily.

They feel able to counter requests by the families for subcutaneous fluids by showing it is unnecessary and often contra-indicated.

At the same time they are better placed to ensure that those hospital admissions that do occur are appropriate.

Moreover, when a resident's condition starts to deteriorate, staff can begin preparations earlier and so anticipate what might need to happen to prevent a hospital admission.

Implementation of the pathway has thrown up some challenges. Staff can find it difficult to recognise when a resident is dying, for instance. Homes will only accept implementation on their own terms and their own pace. So engaging with the care home manager, local GPs and district nurses at an early stage is vital. It is also crucial to identify a 'champion' within the home.

There are now plans to roll out the pathway to another large care home (personal care) in the area. It has already been successfully implemented in a second BUPA home in the area.

Key points:

- Hospital admissions at the end of life have dropped sharply following the introduction of the LCP at a BUPA home in Bexley
- Staff feel more confident about discussing issues around death and dying and can counter requests for unnecessary treatment
- Some staff still find it difficult to recognise when a resident is dying

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Improving symptom control at the end of life in Conwy

Care of the dying in a Conwy care home (nursing and personal care) has improved 'beyond recognition' following the introduction of the community care pathway for the last days of life.

The new pathway has been in place for two years and has led to 90% of residents ending their days in the Cartfey Brynn-Yr-Eglwys care home with good symptom control and their wishes respected. The other 8% died in acute

hospitals following long illnesses and just 2% died suddenly or unexpectedly in the care home.

The decision to introduce the care of the dying element of the Liverpool Care Pathway followed a distressing incident two years ago when an elderly resident died in some pain and discomfort after the out-of-hours GP service failed to attend to alleviate her symptoms.

Before the pathway was introduced, registered nurses received in-house training from the community Macmillan nurse as well as a study afternoon on the use of syringe drivers and good symptom control. Local GPs also agreed to employ the new tool.

The new approach has made a significant difference to the care of the dying, with residents now experiencing a more dignified and peaceful end to their lives. However, some staff still find it difficult to know when to stop striving to keep a person alive and to accept that death is approaching and therefore adapt their care to management of symptoms alone.

Key points:

- A distressing incident where a resident died in discomfort led to the introduction of the end of life community care pathway
- 90% of residents now end their life with good symptom control
- Some staff still find it difficult to know when to stop striving to keep someone alive

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Introduction of end of life care tools to improve care at Risedale Estates

Residents at Risedale Estates care homes in the north west of England say they feel more comfortable and in control of their care following the introduction of the Gold Standards Framework (GSF).

The five homes, which care for 243 residents with a variety of care needs including residential, elderly mentally infirm and continuing care, joined the pilot scheme for the GSF (phase 2) in 2005. A GSF link team - consisting of a facilitator, a Macmillan nurse and five link nurses – then helped introduce the scheme.

They began by implementing a new advanced care plan for all residents, which included issues around end of life and their preferred place of care. A new resuscitation policy was also introduced and all nurses received training in basic life support and how to verify death.

Finally each care home identified a group of residents who would benefit from being on the GSF register and these were then reviewed at two-week intervals.

The homes have also introduced the Liverpool Care Pathway and the Preferred Place of Care document, which help residents to discuss their wishes before any crisis or emergency. The new care pathway allows nurses to discontinue irrelevant procedures in the last 48 hours of life and concentrate on ensuring the last hours are comfortable and peaceful for residents and families.

Staff say they feel more confident and knowledgeable because of the training they have received and better able to communicate effectively with the multidisciplinary team. The GSF link team won the 2006 Allcora Excellence in Care award, together with a £6,000 prize.

Key points:

- All Risedale Estates homes implemented the GSF, LCP and PPC tools
- Residents say they feel more in control; staff are more confident and knowledgeable
- The LCP has enabled nurses to discontinue inappropriate procedures in the last 48 hours of life and therefore concentrate on ensuring the last hours are comfortable and peaceful for residents and families

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Implementing the Liverpool Care Pathway in St Mary's Care Home (nursing)

St Mary's Care Home (nursing) in Hull introduced LCP following a number of referrals of people with very short-term life expectancy. The aim was to improve care of the terminally ill and provide a more multidisciplinary service. One of the big challenges has been persuading GPs to prescribe appropriate medication for end of life care and some remain resistant. But although implementation is not complete, the home has already seen benefits to residents, families and staff. The pathway has also raised the home's profile and increased local and regional recognition.

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Tel: 01482 307590

Improving end of life care for individuals with neurological conditions at Sue Ryder Care

Sue Ryder Care is adapting the Gold Standards Framework, the Preferred Priorities of Care and the Integrated Care of the Dying Pathway – for use with residents in the centre’s six neurological care centres across the country.

The programme, which involves both qualified and non-qualified staff, is being supported by the Sue Ryder Care hospices.

The care centres will work with their local health care providers to deliver co-ordinated care to residents in the last stage of their lives.

The aim is to help more residents die in their chosen care setting and to reduce the number of residents being admitted inappropriately to hospital in the last days of their life.

Following a successful six-month pilot the full programme is now being rolled out to all six Sue Ryder neurological centres in England. It will also help inform education and training programmes in Sue Ryder Care hospices

Key point:

- With slight adaptations Sue Ryder Care has found the end of life care tools highly successful for people with neurological conditions

Contact details

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Improving end of life care for individuals with dementia in the North West

Five pilot sites in Greater Manchester and the North West are implementing the Gold Standard Framework for care homes for people with dementia.

The pilots involve four independent sector care homes and one mental health trust, spread

across four PCTs.

Staff in each pilot site receives extensive training to help residents stay in their preferred place of care. Support is also extended to families, friends and staff themselves.

Each site has set up a working party and has monthly GSF meetings to discuss residents with palliative care needs and consider anticipatory planning and prescribing. There is also an opportunity for reflective practice and education.

NHS Northwest, which is running the pilots, has faced a number of challenges along the way. Some training sessions have been poorly attended, for example, which meant extra training had to be organised. It is also difficult to maintain the momentum when staff face so many other pressures on their time.

It has not always been possible to persuade GPs to prescribe in advance. And the cultural and spiritual differences within teams meant some staff had very different attitudes to death. All now recognise that their beliefs should not affect how they deal with a resident’s death as everyone will have a different path to take.

Key points:

- Five pilot sites in the North West are introducing the GSF for people with dementia
- It has not always been possible to persuade GPs to prescribe in advance.
- Following discussion and the use of the end of life care tools staff have learnt that each person has their own beliefs and wishes and these should be respected even when different from their own

Contact details

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Implementing the PPC in Daken House Care Home (nursing)

A team of three nurses working for Newham PCT is helping to introduce the Preferred Place of Care tool in care homes within the borough to allow residents to remain where they wish and so reduce hospital admissions and ambulance call-outs.

The PPC tool has now been fully implemented in one home, Daken House Care Home (nursing). It was chosen because many residents have in the past indicated their desire to die in their place of care. Families and residents value the tool and have expressed their satisfaction with how it is working.

Introducing the tool has not been easy because everyone's time is so pressured. Engaging staff and raising awareness about palliative care has also proved difficult at times. Newham is also a diverse borough and there were cultural differences between staff – mainly from ethnic minorities - and client groups, most of whom were white. Staff needed to ensure their own emotions and experiences did not interfere with clients' needs and preferences.

But the tool has proved to be successful. It has been helped by good working relationship with GPs who have been very supportive. Newham's Care Homes (Nursing) Project is now developing a database of all clients using the PPC. It also plans to roll out a local end of life care pathway for all care homes in Newham.

Key points:

- Newham PCT is introducing the Preferred Place of Care tool in care homes to support residents to remain in their place of choice and reduce hospital admissions and ambulance call-outs
- Cultural differences between staff and residents proved an initial barrier to

implementation but these were acknowledged and have been successfully overcome

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A network approach to end of life care by the Pan Birmingham Palliative Care Network

The Pan Birmingham Palliative Care Network has launched an ambitious strategy to enable all residents in the area's care homes to end their lives 'in the place and manner of their choosing'.

The Living Well to the End of Life strategy encourages all care homes in South Staffordshire, Birmingham, Solihull and Sandwell to sign up to the new service and nominate a lead member of staff who could be a nurse, health care assistant or even secretary.

They will then be given support to implement the care delivery frameworks, make use of the network's quality assurance tools, and introduce innovative ways of caring for people at the end of their lives.

Care homes often feel excluded from service improvement initiatives as well as public consultation, says the network. But with this initiative they will not be expected to act alone - instead they will be 'part of a healthcare team, working together in your area'.

The network aims to provide baseline data sets for all care homes involved in the project as well as a generic toolkit of resources, including a newsletter, palliative care reference books and syringe driver guidelines. Staff will have access to educational DVDs and onsite training as well

as pharmacological advice and telephone and email assistance. They will also be encouraged to develop a care homes support network.

Participating homes will be expected to set up a register of residents thought to be approaching their last few weeks of life and start them on the supportive care pathway. They should also inform their GPs and enlist their help in ensuring they can die at home.

The result of implementing the strategy, say the organisers, will be a reduction in deaths in hospital as well as staff who are more confident and committed.

Key points:

- Care homes in the Birmingham area are being invited to participate in a palliative care network
- The network will provide education, support and resources to help staff improve end of life care
- The care homes are also being encourage to form a care homes network which has been shown to be effective in other parts of the country

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Assessment

Improving end of life care in Worcestershire

Nine care homes (personal care) run by Heart of England Housing and Care Ltd in Worcestershire have been examining ways of developing services to allow more residents to spend their last few months in familiar surroundings with families and friends.

Director of care John McCarthy explains that their homes already looked after residents who were dying, with the help of primary care services. But they were finding that as they worsened residents would often be moved to hospital or a care home (nursing) where they died.

As a result the group decided to conduct a pilot study in two homes. This involved staff working with local district nurses to examine how the care of those approaching the end of their lives could be improved. The team looked specifically at the next two people in each home who were approaching death.

Following this exercise the district nurses identified good practice in supporting residents with personal and physical care. This involved considering, for example:

- Managing pain relief
- Nutrition and hydration
- Skin and pressure area care
- Oral hygiene
- Management of continence
- Moving and handling and positioning to aid comfort
- Appearance and comfort
- Maintaining good relationships with residents, their families and medical professionals

- Involving families and friends in the resident's life
- Respecting residents' and families' wishes leading up to and at death

District nurses also identified areas for improvement, some of which were relatively simple to implement. For instance, the homes were struggling to address people's spiritual needs fully. But at a National Council for Palliative Care event Mr McCarthy and his assistant director met a hospice chaplain who was able to provide them with spiritual needs guidelines and assessment forms as well as an action plan.

The learning from the pilots is now being spread to the nine other homes within the group. It is also hoping to find funding to appoint a trainer/champion who can develop a training strategy to be used by all the care homes in the county.

Key points:

- A pilot study identified ways in which staff could improve their care of dying residents
- It is hoped this will allow more residents to end their life in familiar surroundings with families and friends
- The need for spiritual guidelines and assessment forms was highlighted and these are now in place

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Implementing a coding system to identify residents nearing the end of life in Sussex

A group of care homes (nursing) in Sussex have adopted a 'traffic light' system to help anticipate when residents are approaching the end of their lives and plan care accordingly.

Residents at Sussex Health Care, a group of homes catering for the elderly mentally infirm and people with learning disability and physical disability, are coded from A-D depending whether their prognosis is in years, months, weeks or days. Those on C and D are reviewed weekly while those on A and B are reviewed monthly at a meeting which then agrees care plans to suit each individual's circumstances.

The new approach was introduced as part of a general attempt to raise awareness of end of life care but also because staff were facing difficulties anticipating some residents' care needs in the last stages of life.

The new arrangements - which have been in operation since last June - encourage more in-depth work with residents and mean that more are now dying where they wish to die. They have also led to better partnership working with GPs and the specialist palliative care service. For instance, there is better coordination with the out-of-hours service as well as more anticipatory prescribing by GPs.

GSF care home facilitator Nikki Sawkins admits even the best laid plans cannot cover all eventualities. For instance, some residents coded A (that is, predicted to survive for years), died suddenly. But staff are now able to recognise that this does happen sometimes. 'It was challenging to do first time round, but it really works and is now part of practice,' said one GSF care home coordinator.

Key points:

- A 'traffic light' system helps to identify residents who are approaching the end of their life
- The system means staff can better anticipate residents' needs and so initiate advance care planning. They are also working in closer partnership with primary care colleagues

Contact details

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Setting up an end of life care register to help plan care at Cedar Court

Cedar Court, a 52-bedded care home (nursing) in Leicester, set up a register of residents to identify, assess and plan for people's future needs using advance care planning. The approach helps involve residents and their family in their own care. It has also improved communication between staff and encouraged greater teamwork. This has in turn improved the quality of care and co-ordination with the GP practice and led to fewer hospital admissions in the last stages of life.

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Reducing hospital admissions at the end of life using the Gold Standards Framework and Liverpool Care Pathway in Rambla Care Home (Nursing)

Introducing modified versions of the Liverpool Care Pathway and Gold Standard Framework has reduced admissions to hospital and helped empower the registered nurses at Rambla Nursing Home in Scarborough.

Before implementation registered nursing staff received in-house syringe driver training from the local hospice. Together with residents and carers they took part in in-house training on the new documentation. They then implemented the new approach with three residents requiring end of life care.

The result has been better communication and fewer hospital admissions because residents are able to identify their preferred place of care at an earlier stage. Nurses also report feeling more empowered to act as the residents' advocates.

The intention is to review all residents' care plans after six months and then again after 12 months in order to identify any further changes that need to be introduced. 'Working in the independent sector can be both educationally and professionally isolating for nurses,' says nurse manager June Nockels. 'The benefits to nurses and residents are that the care tools increase knowledge and confidence which cannot be under-estimated.'

Key points:

- Introducing the LCP has reduced the number of residents admitted to hospital to die
- Using and adapting the LCP and GSF has helped staff to feel empowered to deliver end of life care

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Developing roles

Specialist palliative care nurse for care homes in Bassetlaw

Care homes (nursing and personal care) in Bassetlaw are now receiving end of life care training as a result of the appointment of a specialist palliative care nurse for the area.

The post, which has been funded by end of life care monies for three years, is now in its second year and means the local primary care trust has been able to offer training and education within the care homes, which is much more practical than holding centralised meetings.

As a result over 60% of homes have so far taken part in the end of life care training programme, which aims to promote a more coordinated approach to care management as well as fewer admissions to hospital. At the end of the first year there had been a reduction in hospital admissions.

A palliative care link nurse group has also been set up to encourage liaison between community and care home staff. Initially this applied only to care homes (nursing) staff but it is hoped it will soon be extended to care homes (personal care) as well.

Key points:

- Formalised links to specialist palliative care staff can help care homes improve end of life care
- Setting up palliative care link nurses within each care home can help maintain improvements in end of life care and up-to-date information sharing
- Together these initiatives can help staff feel competent in maintaining residents in care homes while they are dying, so reducing the need for hospital admissions

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Specialist palliative care nurse support for care homes in Sunderland

Sunderland Teaching PCT has appointed a specialist palliative care nurse to provide training and support for staff in care homes across the city.

The appointment follows a similar initiative by the Northern Cancer Network for district nurses in the area. It was felt that if district nurses were receiving this training, then nurses in care homes should too.

The specialist nurse will aim to:

- Be a specialist resource for residents, families and staff
- Provide pain and symptom management
- Offer emotional support to residents and their families
- Influence palliative care management at all levels
- Provide palliative care and end of life care training to staff

There have been some challenges along the way, including shortages of equipment, a constrained training budget and a lack of commitment from some private homes.

Key points:

- A specialist palliative care nurse will provide training and support to care home staff
- Challenges include shortages of equipment and limited funds for training

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Supportive palliative care nurse for care homes in Brighton

Lesley Oates' works as a supportive care nurse with staff in a group of care homes (nursing) in Brighton and Hove is helping to improve the care of dying residents.

Lesley, who has been seconded to her current role for the last six months by South Downs Trust, spends three days a week visiting care homes (nursing) that are undertaking the Gold Standards Framework (GSF) as well as two elderly mentally infirm (EMI) care homes.

During the time she has worked in the role no residents have had to be admitted to hospital to die and everyone has spent their last days in their preferred place of care.

Lesley's work involves acting as a role model and helping nurses and carers put the GSF theory into practice. Uniquely for the south east coast, she also holds a small caseload of patients to whom she can offer practical advice on symptom control in end of life care. In addition she offers staff critical incident debriefing and reflection sessions.

'I try to tailor education to the home's individual needs, whether it is one to one or group,' says Lesley. 'I have been involved in monthly syringe driver training sessions encouraging nurses to maintain their syringe driver skills. This does not replace their formal training, but it allows them to look at some scenarios I have prepared and creates discussion around what they would do. I am also looking at starting training using the Macmillan foundation pack in one of the EMI homes.

'One of the challenges in this post is that diagnosis of death remains difficult. Residents often have complex, multiple pathology. This makes it difficult to differentiate between a natural deterioration and the beginning of the dying process. Experience and education should

help us empower staff to pick up on these subtle changes. This has prompted me to run recognising dying training sessions for staff.'

Lesley is now looking at piloting the pain management tool for people with dementia as well as rolling out the Liverpool Care Pathway in all the GSF homes in conjunction with Rachel Reed, End of Life Care Facilitator /Liverpool Care Pathway Lead.

Key points:

- A supportive care nurse is helping to implement the Gold Standard Framework by visiting all care homes (nursing) in Brighton and Hove
- Since she began every resident has died in their preferred place of care
- Staff can struggle to identify when someone is dying – possibly because they care for them every day

Contact details

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Working with palliative care to assess and develop training at Princes Court

A four month-pilot study, which involved placing a Marie Curie registered nurse in a dual registered care home (nursing and personal care) to work alongside staff as a role model, has led to significant improvements in end of life care.

The Princes Court initiative, which built upon earlier advances in palliative care within the 22-bed care home in North Tyneside, involved the nurses observing current practice, identifying training needs and implementing change. Staff also completed a learning portfolio.

The result has been increased use of end of

life pathways, implementation of a training plan, greater use of syringe drivers and the introduction of a new handover sheet. There has also been 'an increase in compliments and a reduction in complaints'.

The challenge now is securing funding to appoint a two-day a week outreach worker on a permanent basis with the hope of cascading the learning to other care homes in North Tyneside PCT. A number of other PCTs have already expressed interest in developing a similar role in their patch.

Key points:

- A Marie Curie nurse worked for four months alongside staff in a dual registered care home (nursing and personal care)
- The pilot led to greater use of end of life pathways as well as a new training plan and handover sheet

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Working with ambulance staff in the North West

North West Ambulance Service (NWAS) is taking part in a pilot study designed to ensure that patients' wishes not to be resuscitated are respected wherever possible in GP practices.

A Do Not Attempt to Resuscitate (DNAR) order has to be agreed in consultation with the patient and family as well as the multidisciplinary team caring for the individual.

The reasons for a DNAR may include:

- Where competent patients express a desire not to be resuscitated
- Where cardiopulmonary arrest is the end result of a disease process where appropriate treatment options have been exhausted.
- Where resuscitation would be followed

by a duration or quality of life that would be unacceptable to the patient.

The pilot study guidance – which may eventually form the basis of a new policy for the whole of Oldham PCT indicates that any agreed DNAR must be communicated to relevant healthcare professionals such as the ambulance crew.

The guidance stresses that patients should be aware that the primary role of the ambulance service is to save life and prevent further deterioration. They should therefore only call an ambulance as a last resort when other clinicians are unable to respond.

A copy of any DNAR order – which has to be reviewed every four days – will be sent to the NWAS so that ambulance crews are aware of the situation before responding to specific calls. But if a DNAR is not valid and the wishes of the patient cannot be verified, then resuscitation should go ahead.

Everyone involved in the pilot will be invited to share their views and to provide comments and feedback, both good and bad, about their experiences of the process. The plan is to roll this out to care homes

Key points:

- A pilot study in Oldham attempts to ensure that the wishes are respected of patients who do not wish to be resuscitated
- Ambulance crew will receive copies of DNAR orders and will only be called out as a last resort

Contact details

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Head of Clinical Governance, NWAS

North West Ambulance Service NHS Trust

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Developing a network of palliative care link workers in care homes and domiciliary care in Morecambe Bay

A network of 'palliative care link workers' has been established in care homes and domiciliary care agencies across Lancaster. The aim is to share information about best practice in end of life care with generic staff and to develop closer links between these care workers and the local palliative care team. This initiative has been led by Lancashire County Council Adult and Community Services Directorate and the St John's Hospice in Lancaster.

Contact details:

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Tutor - Palliative and Supportive Care

Morecambe Bay Cancer Network

St Johns Hospice

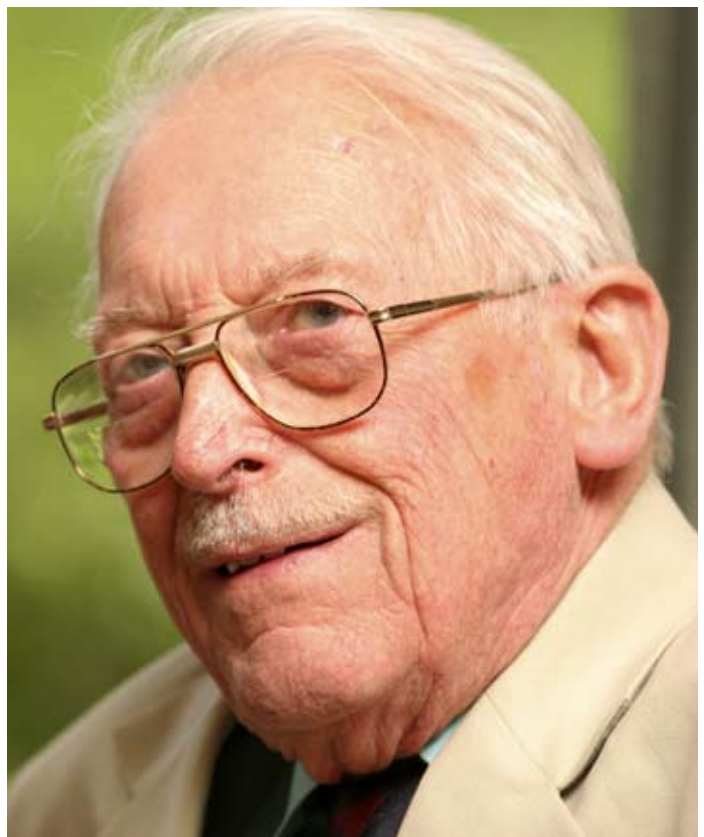
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Workforce development

Implementing a support and training programme in care homes in Avon, Gloucestershire and Wiltshire NHS South West

A six-month training and mentoring pilot project in care homes in Avon, Gloucestershire and Wiltshire has helped improve the care of those who are dying as well as combating the sense of isolation many care home staff feel.

The project involved staff at 12 care homes who received five education sessions and six mentorship sessions. The aim was to increase staff awareness and knowledge about the needs of dying people, identify and make sustained changes and encourage a consistency of approach.

The results have been encouraging. Staff say they have a greater understanding of the needs of dying people. Some say they feel more confident in dealing with colleagues in primary and secondary care – something that has often posed a problem in the past.

The project has also helped improve their own self-esteem. This, the authors of the evaluation report believe, is largely the result of the mentoring, which allowed people to express their doubts and recognise their worth in a safe environment.

Although it is early days, it seems the training programme has led to improved care, with a number of procedures and policies being revised to reflect the new learning.

The authors say the secret of the programme's success is the combination of education and mentorship. They also recommend that future educational activities adopt an experiential rather than theoretical approach and that managers' leadership training needs are identified.

Key points:

- Joint training programmes can help to combat the sense of isolation among many care home staff
- A combination of education and mentoring can have a big impact

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Implementing a cluster training programme in Sheffield care homes (nursing)

Forty four care homes (nursing) across Sheffield are helping to spread best practice in end of life care by offering training sessions to clusters of six or seven homes at a time.

Many staff found it difficult to attend courses in the past because of transport problems and the time and cost implications of attending training some distance from where they worked. The new scheme aims to overcome that by bringing the training to the staff.

The sessions, provided by Elaine Bird, a community specialist palliative care nurse at St Luke's Hospice in Sheffield, are hosted by individual homes within each cluster and focused initially on three topics – end of life care pathway, syringe drivers and verification of death.

The clinical aims of the programme are to help share best practice and improve forward planning, so preventing crises and inappropriate hospital admissions. But it is also hoped it will strengthen relationships between care homes

and reduce the isolation felt by staff working in the independent sector.

So far the turnout at all sessions has been excellent - the only problem being fitting everyone into often-limited space! Everyone involved completes an evaluation form at the end of the session and is encouraged to suggest new topics. Managers will also report each year on the impact of the training on practice.

Future sessions are likely to include breaking bad news, bereavement care, communication and care of the dying.

Key points:

- Education sessions within care homes are proving successful and save time and money
- The cluster approach has improved relationships between homes and reduced staff's sense of isolation

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Support

Setting up a staff support group at Waltham Hall

Waltham Hall Nursing Home in Leicestershire has set up a weekly support group to help staff improve their skills in relation to end of life care.

The 'Butterfly Group' is open to all staff who have completed the Macmillan Foundations of Palliative Care course. Staff meet up for 1-2 hours each week for training in palliative care and to exchange ideas.

Those involved say they feel more confident as a result and are able to communicate better with residents and families during end of life care. They can also recognise when someone's life is drawing to a close, which has led to better care and avoiding being overtaken by events.

Key point:

- A weekly support group improved staff confidence, communication skills and care

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Hartlepool Care Home Managers' Forum

Following requests from care homes for up-to-date palliative care training, the Macmillan Nurses and PCT in Hartlepool organised some training sessions. As a result the Care Home Managers' Forum was formed and after an initial meeting organised a regional conference in the North East of England to raise awareness of end of life issues in care homes.

The conference, entitled Passionate about Care,

was attended by 300 delegates from care homes (nursing and personal care) across the North of England. It increased interest in provision of palliative/end of life care in care homes and resulted in more demand for training.

To date 50 health care assistants have completed a level-one work book and 16 qualified staff have completed the university-run palliative care course. In addition these key workers are planning to meet every six weeks for an update and journal club. The key worker meetings will be facilitated by the Macmillan Nursing Team and will be used to identify best practice and new avenues for palliative care training in the care homes sector.

Organisers now hope to extend the scope of training for registered nurses to issues such as verification of expected deaths, syringe drivers, symptom relief and bereavement.

Key points:

- A Care Homes Managers' Forum has helped to direct training in palliative and end of life care
- A regional conference has led to increased take-up of university courses

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Project Manager – End of Life Care

NHS North East

c/o Hartlepool and District Hospice

Alice House

Regular liaison to support care homes

Improved liaison with primary care trust services is enabling patients with Huntington's disease in Strood, Kent to remain in care homes (personal care) until they die.

Staff now hold a monthly meeting with dieticians, speech and language therapists and palliative care clinical nurse specialists as well as bimonthly patient reviews with GPs and palliative medical consultants. In addition a regular multidisciplinary review of all patients is planned at least once a year.

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Education and training

Developing a LINK Nurse scheme to improve end of life care

A system of LINK Nurses in 27 care homes (nursing) in West Lancashire, Southport & Formby has been developed.

The aim of the scheme is to develop closer working links with care homes (nursing) by providing regular education, a named community palliative care nurse specialist (CPCNS) attached to each home, and increased use of the Vigil Care Pathway for the Dying Document (adapted from the LCP) for all expected deaths.

Audit results demonstrated that many care homes (nursing) could not afford to send staff to palliative care education courses because of the cost of travel to the education centre and the backfill costs of releasing staff.

The Terence Burgess Education Centre (TBEC) at Queenscourt Hospice organised free 'in house' education on the Vigil Care of the Dying Pathway and use of syringe drivers. The number of care home staff receiving palliative care education increased by 400% over an 18-month period.

The LINK Nurse system evolved from this initiative. LINK Nurses receive training, information and support. Each care home (nursing) has a named CPCNS attached who gives advice and acts as a resource. Each LINK Nurse is offered a free place on the three-day care homes palliative care course.

In return LINK Nurses are expected to disseminate information to their colleagues, maintain a training register, keep a record of all expected deaths using agreed documentation and join in teaching sessions with their named CPCNS.

The scheme has yet to be evaluated, but it is hoped it will increase confidence among care home staff, enable provision of good end of life care for all care home residents and increase the use of the Vigil Pathway for the Dying Document for all expected deaths.

Key points:

- A LINK Nurse system was developed for 27 care homes (nursing) in West Lancashire, Southport & Formby
- The aim is to develop closer links with care homes (nursing), increase staff confidence and extend the use of the care pathway for the dying to all expected deaths.

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Implementing an end of life care pathway in Durham Dales

Nine care homes (nursing) in Durham Dales have now implemented the end of life care pathway as a result of a range of training initiatives introduced by Durham's End of Life Care Project.

The initiative followed a scoping exercise in January 2006 that showed that no care homes (nursing) or hospitals were using the End of

life care pathway. As a result palliative care specialists visited care homes in the area to run a range of in-house training sessions on such things as pain management, drug sliding scales and the Liverpool Care Pathway.

In addition it meant care home staff were able to identify professionals from the team who might be able to offer advice when needed.

The team have so far visited 11 care homes, of which nine have now implemented the pathway. The care home managers' report increased job satisfaction and improved management of residents' final days as well as relatives witnessing a peaceful, controlled death for their loved ones.

Staff have left more empowered following the training, which has helped to prevent some emergency hospital admissions. The pathway is also being used for a range of diagnoses, including dementia. It is planned to roll out the programme to every care home in the area.

Key points:

- Nine care homes (nursing) have introduced the end of life care pathway following a new training initiative
- The pathway is being used for a range of diagnoses and some emergency admissions have been prevented

Contact details

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Implementing an education and training programme at Teesside University

Teesside University in Middlesborough has helped improve palliative care skills and knowledge among care home staff by taking its courses into the community rather than running them at the university.

Working with specialist palliative care teams and other NHS colleagues, a group of cancer specialists from the local Cancer Care Alliance delivered palliative care training to all care homes in the area.

The initiative followed calls from care home staff for more training and reports from both the Macmillan Nursing Service and the community district nursing service about gaps in staff's knowledge and skills.

The courses, which were tailored to staff needs, proved very popular and quickly became over-subscribed. They have helped raise aspirations, encourage self-directed learning and given staff the skills and knowledge they previously lacked.

Key point:

- Tailored palliative care courses in the community proved popular with care home staff and quickly became over-subscribed

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Lancashire and South Cumbria educational approach to care homes (nursing)

Care homes (nursing) staff in Lancashire and South Cumbria are getting the chance to go on a free 2.5-day course designed to improve their communication skills when discussing end of life issues with residents.

The enhanced communication skills course – financed by the Big Lottery Fund – is part of

the Lancashire and South Cumbria Preferred Place of Care Project, which began in 2005 and aims to ensure people die where they wish to by encouraging end of life discussions and an advance care plan between residents, carers and professionals.

The need for the course became apparent after a survey showed that around 70% of district nurses deliberately changed or avoided the subject when conversations turned to dying. Although the survey was of district nurses, the results were felt to be relevant to care home staff

As a result Lancashire and South Cumbria Cancer Network arranged to put on interactive workshops for staff to learn specific communication skills and strategies as well as exploring why they often feel uncomfortable about tackling these issues.

So far 10 courses, provided by Cancer Help, Preston and the University of Central Lancashire, have taken place with another 25 planned during 2007.

Student evaluations have been very positive with most saying the course has boosted their self-confidence. As one senior nurse said: 'Following the course I had more confidence in the skills I realised I already had, as well as the ones I had learnt.'

Meanwhile North Lancashire and Blackpool PCTs have organised free courses for nursing home care staff on palliative and end of life care topics. The sessions used to cost £60 each. They also appointed an educational care facilitator to work exclusively with nursing homes for at least a year.

Key points:

- Many district nurses blocked difficult conversations with dying patients.
- A free interactive workshop is giving staff new skills and greater confidence

Contact details

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The implementation of the Gold Standards Framework at Arboretum Care Home (nursing)

Arboretum Care Home (nursing) in Walsall is implementing the GSF with the aim of giving residents control of care at the end of their life. All staff received in-house training both before and during implementation and progress is monitored through weekly meetings and action planning. The home is now negotiating with social services and the local PCT about the possibility of having contracted beds, which would allow residents to be admitted as required rather than when death is imminent.

Contact details

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Conclusions

Probably one of the most important aspects of any sustainable and successful model is that they involve all key partners working together and sharing expertise. An important message to take home, therefore, is the need to meet your local partners, establish communication and information-sharing links and to develop practice which meets your local population's and individuals' need.

To help care homes achieve this and so this way of practicing becomes embedded in local service planning and delivery the Department of Health is at present developing an End of Life Care Strategy led by Professor Mike Richards, the National Cancer Director, who is being supported by Professor Ian Philp, the National Director for Older People, supported by all the other national clinical directors. The strategy will provide guidance to commissioners and providers on how to bring about improvements in end of life care at a local level and has a specific group concentrating on care homes.

It will set out in more detail the rationale for the new developments on end of life care, which were heralded in the White Paper Our health, our care, our say - 2006. These were:

- establishing end of life care networks
- investing in rapid response teams and hospice-at-home services
- expanding existing highly successful training programmes

The overall aim will be to deliver more choice for the vast majority of people on where they die with much better coordination between health, social services and the voluntary sector. It will enable them to respond quickly and effectively to people at the end of life.

Both the End of Life Care Programme and National Council for Palliative Care are involved in the End of Life Care strategy development and the care homes subgroup, we are committed to supporting care homes, so please do visit our dedicated website page at www.endoflifecare.nhs.uk or www.ncpc.org.uk and look out for future events and publications.





Useful contacts and web addresses

The following list cannot be exhaustive but is offered as suggestions:

The NCPC

(Tel: 020 7697 1520) is the umbrella body all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions NCPC promotes palliative care in health and social care settings across all sectors to government, national and local policy makers. It has an interest in improving the palliative care provided to older people. For more information about their work and about palliative care, see www.ncpc.org.uk

The NHS EoLC Programme

(Tel: 0116 222 5103) was set up to improve the quality of care for people at the end of life. In particular, it aims to help more people to live and die in the place of their choice. It also aims to reduce the number of people who live in care homes being moved unnecessarily to hospital in the last weeks of their life. For further information, see www.endoflifecare.nhs.uk

The Alzheimer's Society

(Tel: 0207 306 0606) is committed to maintaining, improving and promoting its unique knowledge and understanding of dementia. www.alzheimers.org.uk

Mencap

is the UK's leading learning disability charity working with people with a learning disability and their families and carers. www.mencap.org.uk

British Heart Foundation

(BHF) (Tel: 08450 708070) is a charity, which aims to play a leading role in the fight against diseases of the heart and circulation so that it is no longer a major cause of disability and premature death. www.bhf.org.uk

Marie Curie Cancer Care

(Tel: 0207 599 7777) is a national charity working with people with cancer and other life limiting conditions. www.mariecurie.org.uk

Macmillan training pack - Foundations in Palliative Care

(Tel: 0808 808 2020) This is a programme of facilitated learning for care-home staff, which enables staff at all levels to improve their knowledge and understanding of palliative care. It is a self-contained educational resource which uses a work based case study approach.

Help the Aged

(Tel: 0207 278 1114) is a charity working with older people to ensure they have enough to live on, feel more involved, get equality in all areas of their lives and receive high quality care when and where they need it. www.helptheaged.org.uk

Age Concern

(Tel: 0208 765 7200)— supports and promotes the well-being of all older people and to help make later life a fulfilling and enjoyable experience. www.ageconcern.org.uk

The Citizens Advice service

helps people resolve their legal, money and other problems by providing free information and advice from nearly 3,000 locations, and by influencing policymakers. www.citizensadvice.org.uk

Counsel and Care

(Tel: 0207 241 8555): advice and help for older people – Counsel and Care’s advice work team works over the telephone and by letter backed up by a range of well researched and regularly updated fact sheets. They are able to advise on a wide range of subjects such as welfare benefits, accommodation, residential care, community care and hospital discharge.

www.counselandcare.org.uk

The British Red Cross

(Tel: 0870 170 7000) – short-term support for independent living: Thousands of people every year benefit from the caring assistance that these services provide.

www.redcross.org.uk

Carers UK

(Tel: 0207 490 8818) - the voice of carers: Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. Carers UK is the voice of carers and is the only care-led organisation working for all carers.

www.carersuk.org

Princess Royal Trust for Carers

(Tel: 0207 480 7788) is a provider of comprehensive carers support services in the UK. Through its network of independently managed Carers’ Centres and interactive websites the Trust provides quality information, advice and support services for all including young carers.

www.carers.org

Help the Hospices

(Tel: 0207 520 8200) is the national charity providing support to hospices. Hth support hospices in their vital work on the frontline of caring for people who face the end of life and caring for those who love them

www.helpthehospices.org.uk

Hospice Information

(Tel: 0207 520 8232) is an information service for anyone with a professional or personal interest in hospice and palliative care both in

the UK and worldwide. Services include a wide range of publications, electronic news resources, training database, quarterly journal and enquiry line. Hospice Information is provided by Help the Hospices and St. Christopher’s Hospice.

www.hospiceinformation.info

Heart Improvement Programme

(Tel: 0116 222 5184) (formerly Coronary Heart Disease (CHD) Collaborative) draws upon the National Service Framework (NSF) for CHD aiming to fundamentally redesign the systems for prevention, diagnosis, treatment and care of patients with coronary heart disease. They published a framework, “A Framework for Supportive and Palliative Care for Advanced Heart Failure” (Dec 2004).

www.heart.nhs.uk

National Institute for Health and Clinical Excellence

(Tel: 0207 067 5800) works on behalf of the NHS and the people who use it by making recommendations for treatment and care using the best available evidence.

www.nice.org.uk

Healthcare Commission

(Tel: 0207 448 9200) – Its full name is the Commission for Healthcare Audit and Inspection (CHAI); it was launched in April 2004 to promote improvement in the quality of healthcare in England and Wales. It covers the independent sector in England only.

www.healthcarecommission.org.uk

Commission for Social Care Inspection

(CSCI) (Tel: 0207 979 2000, 0191 233 3323) is the single independent inspectorate for all social care services in England. It promotes improvements in social care for the benefit of all. It incorporates work formerly done by the Social Services Inspectorate (SSI), the SSI/Audit commission joint review team and the National Care Standards Commission.

www.csci.org.uk

Mental Health Foundation

(Tel: 0207 803 1100) website. Copies of 'Dying Matters A workbook for people with learning disabilities,' is available from this site:

www.mentalhealth.org.uk

Foundation for people with learning disabilities

(Tel: 0207 803 1100) A leading UK charity that provides information, carries out research, campaigns and works to improve services for anyone affected by mental health problems, whatever their age and wherever they live.

www.learningdisabilities.org.uk

The English Community Care Association

(Tel: 0207 220 9595) is the largest representative body for community care in England. Working on behalf of care homes, it speaks with a single unified voice on behalf of its members and the sector, and seeks to create an environment for providers to continue to deliver and develop high quality care.

www.ecca.org.uk

Registered Nursing Home Association

(Tel: 0121 451 1088) gives information for nursing home owners and staff; for people seeking a nursing home place; and for members of the public with an interest in the care of older people and those with disabilities.

www.rnha.co.uk

The National Care Forum

(NCF) (Tel: 0247 624 3619) has a primary purpose of promoting quality outcomes for people receiving care and support through the not-for-profit sector. NCF supports not-for-profit providers through information and guidance, research and development, partnerships and networking opportunities.

www.nationalcareforum.org.uk

National Care Association

(Tel: 0207 831 7090). This website is intended for members, care professionals and members of the public, to provide easy access to information about the independent care sector and issues that affect us.

www.nca.gb.com

NB: information correct at time of printing

Useful documents

Various sites/documents on topics you may find useful and can download.

Documents below can be accessed from the Department of Health website: type in the title of the document in the search box at www.dh.gov.uk

Our health, our care, our say: a new direction for community services - 2006

Supporting people with Long Term Conditions - 2005

A New Ambition for Old Age - Next Steps in Implementing the National Service Framework for Older People - 2006

Building on the Best: Choice, responsiveness and equity in the NHS: summary documents – 2004

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Supporting organisations

English Community Care Association



National Care Forum



Registered Nursing Homes Association





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