End of Life in residential care for people with Dementia

A Good Practice Learning Toolkit

For
Individual Care Homes
Groups of Care Homes
Local authorities
Other health and social care organisations
Acknowledgements

The contribution of the following Residential Care Homes in Derby City to the project is also acknowledged:

- Chestnut View Residential Home
- Coleridge House
- Douglas Court
- Elvaston Lodge Residential Home
- Holly Tree Lodge Residential Home
- Manorfields Residential Care Home
- The Yews Residential Care Home

Thanks are extended to the three Carer Ambassadors who undertook the work to gather the views of other carers on provision of care at End of Life.

- Vita Snowden
- Margot Keats
- Moira Findlay

This Project was funded by
The National End of Life Care Programme
End of life Care Toolkit for people with dementia in residential care

This toolkit is designed to support residential care homes in the delivery of high quality End of Life Care for people with dementia. It is the product of a project that was funded by the National End of Life Care programme (NEoLCP)

The project brought together senior staff from local residential care homes, training staff from Derby City Council and Southern Derbyshire Clinical Commissioning Group, family and friends of residents (Carers) and other stakeholders to design, deliver, undertake, evaluate and inform a programme of learning for good practice in End of Life Care for people with dementia.

Senior residential care home staff took part in training and action learning, sharing their knowledge and putting what they learned into practice in their Homes. The learning programme was continuously evaluated and evolved to meet the needs of the participants, residents and their Carers.

Health and social care staff, participants, Carers and other stakeholders co-produced this toolkit, which provides guidance and resources to enable others who wish to improve staff skills and confidence in providing End of Life care. The toolkit can be used by individual care homes who self-assess their own progress or by larger groups of homes who have access to facilitators.

The toolkit:
- Describes the learning method
- Provides information and resources to support training
- Provides or references materials to support the delivery of training and the creation of a care homes End of Life Care resource kit
- Offers additional information about the project that produced the toolkit

Objectives of the NEoLCP funded project

- Improve confidence and understanding of End of Life (EoL) and specifically issues relating to dementia
- Improve EOL planning for individuals and likelihood that residents will die in their place of choice
- Improve communication between residential homes to share best practice
- Improve communication with and understanding of carers and family members re EOL
- Facilitate learning within other areas via EOL action learning set toolkit
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For information about this toolkit contact IntegratedCommissioning@derby.gov.uk
For information about the Derbyshire End of Life Quality Award contact kathy.gorman@nhs.net
1. Understanding the Wider Agenda

1a. Introduction to End of Life Care

End of Life Care ‘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 patient and 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’.

The National Council for Palliative Care 2006

There has been much confusion about terminology and the interpretation of what “End of Life” means. Some people may interpret it as the last few days, others as the last few years.

People nearing end of life may be identified by using a variety of prognostic indicators which highlight general issues e.g. weight loss, increased dependence or disease specific indicators e.g. increase in difficulty in breathing in heart failure.

The use of the Gold Standards Framework surprise question “Would you be surprised if this person died in the next year?” supports identification. This question demonstrates the uncertainty about the patient’s chances of recovery or deterioration. Where clinicians would not be surprised if a person died in the next year they should consider starting the end of life pathway.

The prime aim of End of Life care is to provide the best possible quality of care for patients and their Carers and to enable that care to take place in the patient’s preferred place of care.

The Department of Health (DH) document ‘End of Life Care Strategy: promoting high quality care for all adults at the end of life’ (July 2008) identified a comprehensive framework aimed at promoting high quality care across the country for all adults as they approach the end of life. It was acknowledged within this document that whilst some people receive excellent care at the end of their life, a number do not. Issues surrounding this primarily relate to the breakdown in communications and services that are not as well coordinated as they should have been.

As outlined in the DH strategy for many a ‘good death’ would involve:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings and
- being in the company of close family and/or friends
The strategy challenges providers and commissioners to ensure the care pathway for those people at the end of their life should follow a number of key steps:

1. Identification of people approaching the end of life and initiating discussions about preferences for end of life care
2. Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly
3. Co-ordination of care
4. Delivery of high quality services in all locations
5. Management of the last days of life
6. Care after death.

They should also address the need for excellent communication, spiritual support and support for carers during a person’s illness and after their death throughout the 6 steps.

1b. Introduction to Dementia

Dementia is one of the biggest health and social care challenges. It may be caused by a number of illnesses that affect the brain. Dementia typically leads to memory loss, inability to do everyday things, difficulty in communication, confusion, frustration, as well as personality and behaviour changes. People with dementia may also develop behavioural and psychological symptoms such as depression, aggression and wandering.

Diagnosis is made by an assessment of symptoms and the use of brief questionnaires that test ability to remember facts, or draw simple diagrams.

Most types of dementia progress slowly. People may live with the condition for ten years or more, requiring increasing levels of support as they become less independent. By working alongside the person with dementia to identify their needs, carefully planning the person’s environment, and identifying supportive activities, it may be possible to reduce the impact and enable people to ‘live well’ with dementia. Symptoms may progress towards end of life, making high quality care essential.

In September 2010 the Department of Health published a revised implementation plan for ‘Living Well with Dementia - A National Dementia Strategy’. One of four priority areas identified is ‘Living well with dementia in care homes’ A number of statements have been developed to capture what people with dementia should expect in terms of their health and social care, one of these statements is: “I am confident my end of life wishes will be respected. I can expect a good death”

In March 2012 Prime Minister David Cameron launched The Prime Ministers Challenge on Dementia. Building on achievements made through the National Dementia Strategy this aims to deliver major improvements in dementia care and research by 2015. Objectives include high quality treatment in care homes and improving end of life care.
1c. Views of Family Carers

As part of the project that created this toolkit, the views of family carers on end of life issues were gathered. Three local Carer Ambassadors, all current or former family carers, were recruited to help with this work. Together with the project manager the Ambassadors designed a meeting format and developed a series of lead-in questions to encourage family carers to express their views.

Engagement meetings were held in participating residential homes and in the local Carers Centre. These were facilitated by the Ambassadors as it was felt that as carers themselves they would have the understanding and empathy necessary to encourage and support participants to discuss their experiences and views. Following this a workshop event was held and family Carers, training participants, home managers and other stakeholders came along to discuss the views that had been collected and identify priorities for action.

What Carers said about End of Life Care.

Carers want information about the way dementia affects people as it progresses

Carers want information about what to expect at End of Life, what plans they might make and what to do after a death

Carers want information on where to go for support

Carers want staff to be the ones who start End of Life conversations

Some Carers want to be included in providing support to at a level that they choose

How Carers views influenced the training model and toolkit

Carers’ views in respect of training have been incorporated in the core elements of this training model.

Carers were given the opportunity to identify specific skills that would help care home staff to support Carers. Complementary training to develop these skills was included in the programme.

At the workshop event carers, care home staff and other professionals had a direct opportunity to meet and speak with Carers.

The Carers we spoke with suggested that Carers should be included as guest presenters to the Action Learning Set and relevant complementary training. This has been included in our training programme.

A report of the views expressed by Carers is included as appendix 2.
2. Sustainability

Embedding the learning

Making sure that learning goes beyond the classroom and maintaining improvements are key issues for any programme of improvement. The skills learned by a small number of champions need to be cascaded, understood and embedded fully into the culture of the Home if change is to be sustained. Skill levels need to be maintained at all levels within the home by providing new or refresher training to overcome problems posed by staff turnover. The ALS could be retained indefinitely as a means of on-going support and sharing of skills.

In Derby progress during the ALS period was supported by The Macmillan End of Life Care Education Facilitator who visited homes to provide guidance and encouragement. This role could also be undertaken by a trainer or senior manager.

At a practical level, the End of Life Resource Kit is a key tool for bringing the learning into practice.

I needed to let go, the hardest part was to hand over responsibility. Now our staff group are more confident talking about death and dying.

Debra (member of the action learning set)

Managing change

One of the more difficult aspects of the programme is managing change outside of the immediate activity and influence of the participants. Within the care home environment this is addressed by engaging the full co-operation and commitment of owners and managers so that they provide all necessary support to the participants in their role as End of Life Care Champions. This is crucial if the key outcome of creating a change of culture around End of Life is to be achieved.

Outside of the care home environment it is important to manage changing expectations within the wider health and social care field, so that involved professionals understand and respect the increased levels of skill that the home can offer. The ALS is the ideal forum to share concerns and discuss ways of liaising with key contacts in health and social care.

There were things I wanted to change but it was hard because the owners of our home didn’t understand what a difference we could make. Now they are as interested as I am, but it would have saved a lot of effort from me if they had been more included from the start

Home Manager
What the ALS members told us that helped us design this toolkit:

When you first attended, what were your expectations about the training?
Learners were not sure what to expect and felt home owners / managers did not understand the full extent of the project when they started it. They thought that an induction meeting would help owners/ managers understand the implications for individuals attending and reduce likelihood of non-attendance or changes in participants. They also thought that an induction would encourage managers / owners to support their EoL champions to implement change. They didn’t favour the idea of a signed agreement in advance of the training.

What do you see as the most useful elements of the programme?
Learners said that all the elements were important, including the carers engagement – like a jigsaw puzzle. Without any part the rest would not have worked because the whole picture would not have been available. The support and visits from the facilitator outside of the meetings were really useful.

What are your views on the length, content and method of learning?
Learners said that 7 sessions, including an induction, would be best. Originally 10 meetings were planned but our learners thought this was too much for this programme.

Learners appreciated their own active role and the opportunity to bring their own ideas forward. They liked the opportunity to take learning away and develop it without being rushed. They liked to bring learning back, share it and get feedback.

The continuity of the content across the Foundations in Palliative Care course and the Action Learning Set and the way these worked with the NEoLCP pathway worked well for our learners. They felt this was really helpful and should be emphasised.

What impact has the programme had in your care home?
All homes involved said that the programme had a considerable effect. The biggest impacts were increased awareness throughout the home and increased confidence levels. Families feel better because staff have the skills and confidence to make them feel better. Staff are less likely to pass EoL queries and issues on to management as they are more confident.

New knowledge and confidence has helped care home staff to engage more effectively with other professionals. Some GPs have overcome initial concerns about this new activity from re homes and are now much more comfortable with this and respond more quickly to requests for DNA CPR.

What did ‘Foundations’ and the ALS do for you as an individual?
Learners feel that they are able to give better information to families, especially around issues such as the Liverpool Care Pathway LCP which they now have some factual knowledge of, not just what the press have said. They can help people more in respect of dementia because they have a better understanding of the stages and how it progresses.

What difference did the engagement with carers make in the home?
It is now easier to connect with Carers and everyone feels more comfortable with this as they understand their needs better. In the homes where engagement meetings were held these were good starting points for carers and staff to open the whole EoL conversation up.

What are your views on how the culture of your home has changed?
The EoL culture of the homes has changed considerably. EoL is less of a taboo subject, it is more openly addressed and people are not afraid to engage. There is a positive difference.

What problems were thrown up?
It is difficult for learners to ‘manage’ their own management in implementing real change. Closer engagement with families increases potential for attachment problems from family carers.
3. The Learning Model

The programme is designed for senior staff that can influence and implement change and development of best practice in End of Life care in their workplace. It is assumed that they will have experience of providing care at end of life and care and care to people with dementia.

Two senior staff members, including either the Manager or Deputy Manager should attend from each establishment. They will develop a high level of skill and knowledge, and with the essential support of Senior Managers and owners will become End of Life Care Champions and provide leadership in developing a culture of quality care at EoL throughout the home. This should be reinforced by introductory level End of Life Care training for a wide group of staff within the home.

The training is aligned to The Route to Success in End of Life Care: achieving quality in care homes (NEoLCP 2010) and cross referenced to reinforce learning. The strength of the model is the combination of the different elements into a cohesive learning programme. The cross mapping is illustrated in Appendix 1

a) Induction meeting

In order to embed and sustain quality care, it is important that home owners and wider management fully understand and support the aims of the programme. Owners / Managers of homes that plan to undertake the training should attend an induction meeting so that content of training, aims, intended outcomes, commitment and responsibilities can be discussed. The sustained commitment of managers is crucial to success and their expectations should be accurate and realistic.

**Induction Session**

**Target group:** Owners and Managers of involved care homes

**Suggested agenda**

1. Purpose of training and EoL Standards for care homes
2. Outline of local training programme
3. Nominating your EoL champions
4. Establishing the EoL care philosophy within the home
5. Supporting your champions to achieve change
6. Developing your EoL resource kit
7. Building capacity in EoL Skills
8. Managing change in the wider pathway
b) **Level 2 Palliative Care training**

The first training element in the model is a level 2 course to provide essential knowledge about end of life care. This underpinning knowledge will prepare senior staff to influence and implement change. The shared learning experience also provides an opportunity for the participants to bond as a learning group.

Our chosen level 2 training was **Foundations in Palliative Care**. In the Derby model the course was run over 4 weeks with staff attending 1 day [9.30 - 3pm] each week for a total of 20 hours training. Participants are expected to attend all 4 days. The course encourages participants to share and reflect on their experiences in their care homes. Participants use the information from each session before they attend the next.

**Foundations in Palliative Care.**

Foundations in Palliative Care is an interactive course designed by Macmillan and the Open University especially for Care Home staff.

There are 4 modules:
- First Principles of Palliative care
- Communication
- Pain and Symptom Control
- Bereavement

The resources to run the course can be obtained free of charge from [www.be.macmillan.org.uk](http://www.be.macmillan.org.uk). There is a series of booklets for the course facilitator and a set of workbooks for each participant.

c) **Supplementary Training**

Some aspects of End of Life Care are not covered by the Foundations in Palliative Care course. These are listed below. In the Derby model all of these other than training on the Mental Capacity Act were woven into the 4 days of the Foundations Course. If this is not done, staff should access the following training separately:

- Mental Capacity Act (essential)
- Advance Care Planning
- Best Interest End of Life Care Planning
- Liverpool Care Pathway
- Gold Standards Framework
- Local documentation and details of local Out of Hours Services
d) **Action learning set**

The fourth element in the programme uses action learning with people working in groups called Action Learning Sets (ALS). Participants attend a number of facilitated sessions of shared learning and discussion. Between sessions they take the learning from these sessions back to the homes to implement. The following meeting provides an opportunity to review successes and problems that arise and reflect on what has been learned.

This learning method is dependent on the development of a relationship of trust and shared understanding between those who are involved. If a member leaves it would be unusual to send a replacement without the agreement of other members and facilitator unless the learning is at an early stage.

The Derby model aligns learning to The NEoLCP Route to Success for Care Homes and recommends that 6 sessions are held over a period of six months. Our sessions were facilitated by a professional trainer but this is not essential as the ALS members can facilitate themselves or a Home Manager can take on the role.

### Action learning

- Agree which issues your Action Learning Set wants to explore
- Discuss the issues as a group, perhaps with input from an external facilitator, and decide what actions you will take before you meet again
- In your working environment implement the ideas, reflect on how they work and learn from what you do
- Meet again to question and explore what you have learned
Session 1: Discussions as the end of life approaches

Aims:

- Understanding the training programme
- Recognising when residents are approaching end of life
- Understanding when and how to approach end of life conversations

Suggested content:

- Developing clear expectations of the intended outcomes of the action learning and the content of your portfolio
- The Route To Success
- Planning your care homes’ End of Life Care resource pack and contents
- The importance of working with the staff team to establish the EoL philosophy and promote cultural change within the home
- Identifying the approach of end of life for people with dementia
- Implementing a supportive care register
- Exploring communication issues for families and carers as EoL approaches

Suggested Guest participants

- EoL education facilitator
- Family Carer

Portfolio elements to complete before next session:

- Identify residents with dementia who may be in the end stage of their life using the Supportive Care Register
- Engage with GPs and the wider team to improve communication, information sharing.

Suggested materials/resources to use in session:

- Alzheimer’s Society DVD re: approaching EOL with dementia

I’ve found working on the course has helped me gain knowledge to give our residents a better quality of life

Mel (member of the action learning set)
Session 2: Assessment care planning and review

Aims:
- Develop skills in holistic assessment
- Understanding and responding to the needs of residents and carers
- Develop skills in recording and communicating wishes
- Introducing self-assessment of provision of end of life and dementia care

Suggested content:
- Feedback and discussion of learning and follow on actions from session 1
- Exploring the meaning of holistic assessment including physical, emotional, social, cultural and psychological needs
- Discovering the person behind the dementia
- Behavioural changes in dementia
- Understanding advocacy
- Advance decisions to refuse treatment
- Balancing the wishes and needs of residents and their relative
- Monitoring your care homes progress in providing end of life care for people with dementia

Suggested Guest participants
- Dementia trainer
- Dementia support worker

Portfolio elements to complete before next session:
- Continue to identify residents with dementia who may be in the last year of life using the Supportive Care Register
- Review of current documentation to ensure an holistic assessment is completed and clearly documented
- Awareness raising of EOL sessions within your home for relatives, residents and staff

Suggested materials/resources to use in session:
- Social Care Institute for Excellence free resources on Holistic Assessment Practice www.scie.org.uk
- Self-assessment tool to measure care homes performance

The resident’s opinion was always valued before, but now those wishes are written down they are going to have their wishes met. It gives the family confidence that we give the right care

Cathy (member of the action learning set)
Session 3: Co-ordination of care

Aims:

- Knowing the key contacts in health, social care and voluntary sector
- Know how to overcome the barriers to effective partnerships with health and social care professionals
- Recognising when to request anticipatory prescribing of end of life care medication and equipment

Suggested content:

- Feedback and discussion of learning and follow on actions from session 3
- Understanding the needs of other service providers in order to establish stronger partnerships
- The benefits of having a keyworker for people nearing end of life and their carers
- Recognising changes on the end of life pathway
- Dementia behaviours as end of life approaches
- The effect on behaviour of reducing anti-psychotics
- Anticipating needs and working with partner organisations to meet needs for drugs, equipment and other support
- Managing transfer of care to hospital

Suggested Guest participants

- GP
- District Nurse
- PROACT-SCIPr-(UK) Instructor

Portfolio elements to complete before next session:

- Continue to identify residents with dementia who may be in the last year of life using the Supportive Care Register
- Review your current practice /documentation to ensure effective co-ordination of EOL care within your establishment.

Since starting this course I am much more aware of the individual person and how to meet their needs.

Bev (member of the action learning set)
Session 4: Delivery of high quality care in care homes

Aims:
- Developing good internal processes and protocols for end of life care
- To understand the needs of Carers as their loved one nears the end of life
- Knowledge of services to support Carers
- To understand your own needs in providing end of life care

Suggested content:
- Feedback and discussion of learning and follow on actions from session 3
- Examine the processes and communication in place to co-ordinate and manage care within your care home
- Progress in self-assessment of end of life care provision
- Team working to provide high quality care
- Understanding and providing for the needs of family Carers
- Looking after your own needs
- Developing staff training

Suggested Guest participants
- Family Carer
- Macmillan Education Facilitator

Portfolio elements to complete before next session
- Review current practice /documentation to ensure effective delivery of high quality EOL care in the home
- Review available options for accessing end of life care training locally and implement a training plan

It was always going to be hard because although I wanted to know I didn’t want to listen. I needed the staff to be able to help me talk about things but they never did, so when my Mum died there were no plans and I really wasn’t ready. I never said goodbye.

Family Carer.
Session 5: Care in the last days of life

Aims:
- High quality patient and Carer lead care.
- Recognising the approach of end of life
- Understanding the Liverpool Care Pathway
- Offering clear communication to families

Suggested content:
- Feedback and discussion of learning and follow on actions from session 4
- Maintaining the Supportive Care register
- Recognising when residents enters the dying phase
- Recognising the dying phase for people with dementia
- Respecting wishes; supporting people to die in their place of choice
- Supporting families to be involved at the level of their choice
- Developing the skills to support people in the late stages of dementia and their families to the very end of their life
- Liverpool Care Pathway
- Dignity and independence at end of life

Suggested Guest participants
- Liverpool Care Pathway Co-Ordinator
- Palliative care consultant

Portfolio elements to complete before next session
- Review current practice/documentation to ensure effective delivery of care in the last days of life
- Review approach to caring for relatives, significant others, staff and other residents with dignity when a resident enters the dying phase.

Suggested materials/resources to use in session:
- Social Care Institute for Excellence (SCIE) DVD re: EOL in Dementia Care
- SCIE DVD re: supporting Staff to deal with death in the care environment

We cannot change the fact that they are dying, but we can make death better

Michelle (member of the action learning set)
Session 6  Care after death and final feedback session

Aims:

- Meeting the needs of Carers, family, friends and staff affected by a death
- To understand progress made in end of life care provision
- Embedding the learning
- Building in sustainability

Suggested content:

- Feedback and discussion of learning and follow on actions from session 5
- Providing space to grieve
- Practical actions after death
- Bereavement and other support services
- Reviewing and embedding the learning
- Managing change

Suggested Guest Participant

- Bereavement counsellor

Portfolio element to be complete and provide to trainer or mentor:

- Evidence of systems in place to provide appropriate information and support to relatives and significant others, and staff post bereavement.
- Ensuring other residents are supported following a death in the care home

Suggested materials/resources to use in session:

- DVD- Bereavement & Loss

As a residential care home this has opened up a new and challenging focus for us. The End of Life future care needs philosophy and good practice makes us feel proud to care for older people, and has brought a new concept and meaning to caring for people in the last stages of life. We are now providing social, emotional, spiritual, and meaningful care alongside physical care.

Thank you from Coleridge House
e) Level 1 introduction to End of Life Care

Level 1 training is included in this programme to ensure a wide enough spread of skills within the residential home for the EoL Champions to be able to implement change and develop a sympathetic culture around End of life. It is recommended that the ALS is underway before this level of training is introduced so that the EoL Champions are ready to support the development of other staff.

Introduction to End of Life Care

Outline Content

Aim
To give participants an opportunity to explore end of life care in a Care Home

Objectives

- Understood common terms used in end of life
- Explored how the six steps of the end of life pathway are implemented in care homes
- Increased knowledge about their role in end of life care
- Increased knowledge about the role of other health and social care professionals in meeting end of life care needs
- Increased confidence in talking to residents and relatives about sensitive subjects.

Content

- Reflection on the holistic needs of people at the end of life.
- Introduction to the six steps of end of life care
- Your role in meeting service user needs.
- The role of other health and social care staff in meeting the needs of people at end of life.
- Developing the confidence and competence to communicate in a meaningful way with service users and their Carers at end of their life.
- Supporting end of life champions to increase awareness of end of life care in their Home or Agency
- Using your end of life resource kit
- Taking care of your own needs

f) Complementary training to support the needs of family carers

Family carers identified the following two additional areas of training to support their needs. Local engagement would be necessary to identify local need.

- Developing staff skills to support families in making EoL care choices.
- Compassionate communication skills.
g) **Assessment and self-assessment**

A national (Gold Standard Framework) or local (e.g. Derbyshire End of Life Quality Award) framework can be used to assess progress with achievement measured against a range of criteria by a facilitator. There may be a charge for this in some areas. If this option is not available, progress can be measured by using a self-assessment tool and developing a portfolio evidencing achievements.

### Self-assessment for residential homes caring for people with dementia at End of Life

**Assess your service by giving a score of between 1 – 3 for each question**

**Identify areas for improvement and complete action plan**

**Repeat the assessment at a later date to measure improvement**

<table>
<thead>
<tr>
<th>Discussions as the end of life approaches</th>
<th>Score 1 - 3</th>
<th>Actions to bring about improvements</th>
<th>Person responsible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do your staff members have the skills and confidence to talk to people about issues related to their death or the death of their loved one and to recognise the right moment for this?</td>
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<tr>
<td>Does your home have mechanisms in place to discuss record and communicate the wishes of those approaching the end of life (advance care planning)?</td>
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<tr>
<td>Does your home have a procedure for finding out the wishes of people with if they have reduced capacity to make or communicate these wishes?</td>
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</tbody>
</table>

**Assessment, care planning and review**

<p>| Are residents’ needs for end of life care assessed and reviewed on an on-going basis making use of life history and ‘about me ‘documentation? | | | |
| Are all residents who are dying entered onto a relevant care pathway? | | | |
| Are families and carers involved in end of life care decisions to the extent that they and the resident wish? | | | |</p>
<table>
<thead>
<tr>
<th><strong>Co-ordination of care</strong></th>
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<tbody>
<tr>
<td>Is a key worker offered for each resident approaching the end of life?</td>
</tr>
<tr>
<td>Does your home have a system for communicating information about end of life needs between all staff, relatives and friends?</td>
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<tr>
<td>Does your home have a good network of contacts in health and social care and clear routes of communication with those services?</td>
</tr>
<tr>
<td>Is your home ready to respond to changes in levels of need as end of life approaches including accessing special equipment and anticipatory drugs?</td>
</tr>
<tr>
<td>Does your home have a good network of contacts outside of the home</td>
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</tbody>
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<table>
<thead>
<tr>
<th><strong>Delivery of high quality care</strong></th>
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<tbody>
<tr>
<td>Has your home developed an action plan for end of life care?</td>
</tr>
<tr>
<td>Is your home working towards achieving an End of Life Quality award?</td>
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<tr>
<td>Does your home have access to specialist palliative care advice?</td>
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<tr>
<td>Does your home identify training needs relevant to EoL care and enable relevant workers to access or attend appropriate programmes, dependent on their needs?</td>
</tr>
<tr>
<td>Does your home take particular account of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers?</td>
</tr>
<tr>
<td>Does your home identify training needs relevant to EoL care and enable relevant workers to access or attend appropriate programmes, dependent on their needs?</td>
</tr>
<tr>
<td>Does your home pro-actively offer appropriate information about Support Services for Carers, Dementia and End of Life?</td>
</tr>
<tr>
<td>Have you undertaken an environmental assessment to ensure that your home provides an environment that promotes the well-being of people with dementia</td>
</tr>
</tbody>
</table>
Are you able to provide a room that will ensure the privacy and dignity of people nearing the end of life?  

Does your home have a place in which relatives who wish to remain close to their loved one as they near the end of their life can feel welcomed and maintain their privacy?

**Care in the last days of life**

Are you able to recognise the signs that someone’s condition has deteriorated and that it may be time to consider the end of life pathway?  

Do you respect previously recorded wishes regarding end of life care?  

Are systems in place for involving families in providing care at the end of life?  

Do your staff members have the knowledge, skills and confidence to implement the Liverpool and / or other appropriate end of life care pathway?  

Does your home have a process in place for reviewing all transfers into and out of care homes for residents approaching End of life?

**Care after death**

Do your staff members have the confidence to support bereaved relatives and Carers?  

Are you able to provide information to relatives and Carers about what to do after death and about bereavement support services?  

Are staff and other residents supported following a death?  

Is the quality of end of life care provided by the care home reviewed after a death?

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## Appendix 1

Mapping across training modules - mirroring the six steps of The End of Life Care Programme route to success

<table>
<thead>
<tr>
<th>Action Learning Set</th>
<th>Foundations In Palliative care</th>
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<tbody>
<tr>
<td>1 Discussion as end of life approaches</td>
<td><strong>Session 1</strong></td>
</tr>
<tr>
<td></td>
<td>• Palliative Care &amp; End of life Care definitions</td>
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<td></td>
<td>• Dying trajectories [graphs ]</td>
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<td></td>
<td>• Session 2</td>
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<td></td>
<td>• Communication skills</td>
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<td>• Recognising hints residents want to talk</td>
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<td>• Advance Care Planning</td>
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<td>• Best Interest End of Life Care Plan</td>
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<td></td>
<td>• Planning your future care booklet and order form</td>
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<tr>
<td>2 Assessment, care planning and review</td>
<td><strong>Session 1</strong></td>
</tr>
<tr>
<td></td>
<td>• Palliative care Case Studies</td>
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<tr>
<td></td>
<td>• Session 3</td>
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<td></td>
<td>• Total Pain – physical, psychological, social and spiritual aspects of pain</td>
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<td></td>
<td>• Pain assessment tools</td>
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<tr>
<td>3 Coordination of care</td>
<td><strong>Session 1 &amp; 3</strong></td>
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<tr>
<td></td>
<td>• Case studies emphasising joint working</td>
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<td></td>
<td><strong>Session 3</strong></td>
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<td></td>
<td>• DNACPR decisions</td>
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<tr>
<td>4 Delivery of high quality care in Care Homes</td>
<td><strong>Session 1</strong></td>
</tr>
<tr>
<td></td>
<td>• Baseline information given out included After Death analysis &amp; Significant Event Analysis</td>
</tr>
<tr>
<td>5 Care in the last days of life</td>
<td><strong>Session 3</strong></td>
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<tr>
<td></td>
<td>• Liverpool Care Pathway Version 12</td>
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<td></td>
<td>• Case history around LCP</td>
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<tr>
<td>6 Care after death</td>
<td><strong>Session 4</strong></td>
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<td>Bereavement Care for relatives, residents and Staff</td>
</tr>
</tbody>
</table>
Appendix 2  Summary of Views Expressed by Family Carers

INFORMATION

What information do families want about progression of dementia towards E o L?
- Families want information about types of dementia and the way dementia progresses as well as information about support groups. They would prefer this to be produced in sections so that they can access as much as they are ready for at any time.

What information do families want about End of Life Care?
- What to expect at End of Life and what staff will do to help
- The level of care that a residential home offering ‘high dependency’ can provide and in what circumstances the resident may not be able to remain in the home.
- Information about what to do after death.

Is information available and do you know where to get it?
- Many relatives had not been pro-actively offered information about the progression of dementia and they had to ask specific questions of staff or doctor. They would like staff to give this to them rather than having to ask. Some found information on the internet or used help lines. This wasn’t by choice but because no one had given them what they needed.
- Some Carers don’t like pamphlets and were horrified by the messages they conveyed.
- Some found it most useful to talk to other Carers.

What would be the best way for the conversation about the end of life and EoL care to be introduced?
- Families would like bad news introduced to them in a private space although they understand that sometimes staff will take the opportunity to raise EoL issues as part of another conversation. They don’t want this to take place in front of the resident concerned.
- For some Carers there will never be a right way and they do not want this conversation.

When would you like it to be introduced?
- Many Carers think that introducing EoL conversations from the point of admission / at an early stage of diagnosis will make it easier in the long term and recognize the implications of dealing with issues such as powers of attorney during the early stages whilst the cared for person may be in a position to make decisions themselves, however some may experience feelings of guilt and mourning that need to be worked through first.

Who would you like to introduce this topic?
- Almost universally families would like the topic to be introduced by staff they already know from the home, and if possible the manager to be there for significant news.
- It was felt by relatives that staff would be in the best position to know when to introduce EoL conversations to residents who were able to understand, but they would like to be present.
- Some felt that care home staff may be reluctant to introduce EoL and the kind of sensitive conversations needed because they didn’t have training to do this.
- Some Carers might start the conversation themselves.
**SUPPORT**

What support do families want in respect of EoL?

- Families generally felt they could go to staff at any time and that communication was good but that they were only likely to be offered support from staff or doctors when really upset.
- Some Carers were given a diagnosis and then left to get on with it. They may want emotional support but are unlikely to ask for it.
- Carers felt that it would be a very good thing if there was somebody who they could talk to about guilty feelings, perhaps a counsellor or other Carers. One-to-one and group support are both appreciated. Few Carers had used or even heard of voluntary sector support organisations.

What do you think about having a lead person for EoL information and Support?

- Some think that the idea of a specialist EoL person to lead the difficult EoL conversation is a good one. Others were concerned that this might be a person they did not know well.
- Some families thought that a nominated EoL lead person to cover all daytime shifts would be good. They felt that if there were specific staff responsible for contact with relatives and liaison with other staff it would improve things.

What do you see as the main barriers and difficulties for families?

- Wanting to talk but not wanting to raise the issue themselves.
- Having already ‘lost’ the loved one to dementia and feelings of guilt
- Lack of open and clear communication about choices available to relatives including what facilities are possible for relative to use
- Being pressed to accept the inevitable and discuss EoL issues before they are ready.

**CARE AT END OF LIFE**

How could Homes approach EoL Care in a supportive and sensitive way?

**Dignity**
- Families don’t always feel relatives are treated with dignity and self-respect because of low staffing, lack of training around dementia, low skills and low pay.

**Competencies**
- Relatives think that Care work needs to be acknowledged as a profession and paid adequately otherwise quality of care may be low
- They think that all staff should have dementia training.
- One group of relatives suggested some kind of national benchmark that can be measured.

**Communication**
- Many Carers felt that communication was good although staff sometimes do not have time to talk.
- Sometimes the Carers wishes and instructions are not listened to. Failure to follow the family notes particularly during respite is detrimental.
- One home had begun to speak to those residents who could understand to try to find out what arrangements they would like. Carers appreciate this.
Supporting Relatives

- Some families like an open door policy for visiting at any time of day to any part of the home.
- They would like an easy to use complaints and suggestions process.
- A number of family carers do not want the relative to be alone as they die. They would like homes to provide beds for family at imminent EOL stage and want staff to be available to sit with their relative when not available themselves.

PLANNING FOR END OF LIFE CARE

Would you like to be involved in the plan for EoL Care?

- Carers would like to be involved and would like the resident involved where possible
- They want to sit down and make advanced plans in a structured way.
- Some think it would be useful to have a template about decisions the relative/Carer might be called upon to make at EOL so that they could consider the options at their own pace

When do you think is the right time to begin planning?

- Involvement at an early stage, whilst the affected person can participate creates less stress later however this is emotionally difficult and it is hard to balance with not introducing too early. Some people with dementia are able to make decisions early on and write them down – families think more would do this if they knew how important it is. When there was a definite deterioration planning should take place as soon as possible,

Would you like to be involved in decisions in the last days and hours?

- Family Carers often don’t feel that that decision making at this time is an equal partnership. They do not feel involved in key decisions even though they have all kinds of information about the relative which should be listened to and acted upon. Some Family Carers however are sure that they would not be able to make good decisions at this time and would want others to take the lead.

PROVISION OF END OF LIFE CARE

How do you see yourself being involved in EoL care for your relative?

- Families would want to be involved and to be present at the end of life and would like staff to guide them in the best way to do tasks.
- Most Family Carers would want staff to take care of the actual care and ‘nursing’ and they would provide comfort and hand-holding. However, they feel family should have the choice of helping with any aspect of care, including preparation after death if they wish.
- Carers would like to be helped to experience precious momentary connections with their loved ones.

Carers suggested:

- Homes should develop an “advanced Carer plan” that helps them know what options are available (e.g. can they sleep in relative’s room? Can they bring in their pet?)
- The idea of the “equal expert relationship” needs to be adopted so that the Family Carer can have an equal input into the care and support of their loved ones