Achieving success in end of life care

A guide to delivering quality standards across Yorkshire and Humber care homes

March 2012

“we identify new and innovative ways of working”
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Please note that if you are using a printed version of this guide, all of the referenced supporting materials are available on the accompanying memory stick.
Acknowledgements

The development and production of this guide is credited to many people. In particular, the efforts of a range of end of life care facilitators, educationalists and specialists from across Yorkshire and the Humber are acknowledged. They took time to review the guide, offer feedback and suggestions for improvement, and provide examples of useful resources. Their efforts are very much appreciated.

The advice and feedback of Yorkshire and Humber care home managers are similarly valued. Their perspective was crucial to secure. Julie Druce from Stubblefields Care Home in Bridlington is particularly thanked for trialling the guide in the context of her own care home and providing face to face feedback and advice.

The National End of Life Care Programme (NEoLCP) is specifically acknowledged as this guide is based on their Route to Success guide for care homes. The present work has used a significant amount of their design and content, which has been adapted and built upon to give it a Yorkshire and Humber theme.

Skills for Care has taken responsibility for leading on workforce development for end of life care for care homes. Skills for Care’s Anne Bagshaw (project manager) has worked with Chris Young, (contractor from Workforce Support of Equus Business Services) to ensure that this guide has been developed and produced through involvement and partnership.
Glossary of terms and abbreviations

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>Resident</td>
<td>This term is used almost exclusively throughout the guide as it reflects the term that is used in the National Quality Markers for End of Life Care in Care Homes. It refers to the person who lives in the care home and for whom end of life care will be delivered. Terms such as service user, tenant, client or patient may be used by some services to refer to the same individuals.</td>
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<tr>
<td>CQC</td>
<td>Care Quality Commission</td>
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<td>EoLC</td>
<td>End of life care</td>
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<td>Y&amp;H</td>
<td>Yorkshire and Humber</td>
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<tr>
<td>DH</td>
<td>Department of Health</td>
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<td>NOS</td>
<td>National Occupational Standards</td>
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<td>PPC</td>
<td>Preferred Priorities for Care</td>
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<td>GSF</td>
<td>Gold Standards Framework</td>
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<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>Carers</td>
<td>Family or friends who provide social care support, as distinct from care workers. This official use of ‘carer’ is important to note as the word is also used to mean ‘worker’ in some places.</td>
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<tr>
<td>NEoLCP</td>
<td>National End of Life Care Programme; part of the NHS.</td>
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</table>
1 Introduction and overview
Welcome to this Yorkshire and Humber (Y&H) guide to delivering end of life care (EoLC) quality standards in care homes. It is hoped that you will find it relevant and useful to you in your role within care homes.

First of all let us explain the background to the development of the guide.

**The national context**

End of life care (EoLC) has become an increasing area of focus since the Department of Health (DH) published its national EoLC strategy in 2008.

The strategy explains how around half a million people die in England each year but, despite this, we do not discuss death and dying openly as a society.

It acknowledges that although every individual may have a different idea about what would, for them, constitute a ‘good death’, for many this would involve:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings
- being in the company of close family and/or friends.

At about the same time as the present guide was being published, Skills for Care, Skills for Health and the National End of Life Care Programme were jointly publishing *Developing End of Life Care Practice*. This framework of skills, knowledge and values replaced the former framework of national occupational standards for EoLC, and puts greater emphasis on the place of sensitivity towards religion or similar belief (where they are held) and spirituality (understood as widely as possible) in EoLC, as well as dealing with bereavement.

**The regional context**

Within Yorkshire and the Humber (Y&H) approximately 50,000 people die each year, and whilst there is a great deal of good practice taking place in the area, there are many people who are not dying in the place that they would prefer and some people are not receiving care that is in line with known standards of good practice.

The Y&H End of Life Care pathway group has identified that there is often:

- a low priority given to end of life care within the NHS and social care
- inadequate education and training and support available
- a lack of robust measures in place to assess the quality and effectiveness of care

To see full details go to: www.healthyambitions.co.uk/HealthyAmbitions/End-Of-Life-Full.aspx
As part of a programme of work that aims to improve end of life care in Y&H care homes, a care home scoping project was undertaken across the area during 2010. The project investigated EoLC education in care homes with the purpose of exploring which education and training activity was resulting in the most sustainable delivery of good quality EoLC.

There was a range of findings from the work, one of which was that effective management and leadership is crucial to the delivery of good quality EoLC in these settings. In order for care homes to effectively manage good quality EoLC, however, it was suggested that they need:

1. consistency and clarity about EoLC quality expectations
2. clarity about how EoLC expectations link with their care home registration requirements
3. an understanding of the measures that can evidence how they meet the quality requirements
4. an understanding about the resources that are available to help them to deliver to the standards and produce good quality evidence.

The project report consequently recommended that further work should be undertaken and this guide is one of the products from those recommendations.

In addition to the development of this guide there is a wider programme of work being undertaken by Skills for Care on behalf of the EoLC Pathway Group. This includes:

- EoLC training (based on National Occupational Standards) for 800 Care Home Managers and 800 Champions across Y&H
- the development of networks for care homes to share best practice, learn from each other and access further EoLC support and advice
- an increase in the EoLC knowledge and capability of assessors and verifiers across Y&H
- an increase in the EoLC knowledge and capability of commissioners, regulators and contract holders across Y&H
- a project to explore the use of e-learning resources for EoLC in care homes.

There is also consideration being given by Yorkshire and Humber’s health and social care partnerships to incorporate EoLC quality standards within their contracts (if they are not already doing this by some other means, e.g. using the Gold Standard Framework).

This guide will therefore be an important tool for care homes to help to meet what are likely to become contractual standards.
The aim and structure of this guide

This guide aims to support care homes in the delivery of high quality person-centred care which is well planned, co-ordinated and monitored while being responsive to the individual’s needs and wishes.

The aim is to support care home managers to:

- increase the number of people who have care plans in place
- increase the number of people dying in their place of preference
- increase the number of people allocated a key worker
- increase the number of people on the End of Life Care pathway

It is hoped that it will be read and used by all care home staff but is particularly aimed at care home owners and managers and end of life care key workers and champions.

It is based on the National EoLC Programme’s 2010 publication, *The route to success in end of life care – achieving quality in care homes.*

In line with the national publication, this Y&H guide follows the six steps of the EoLC pathway:

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
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<th>Step 5</th>
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<tbody>
<tr>
<td>Discussion as the end of life approaches</td>
<td>Assessment, care planning and review</td>
<td>Coordination of care</td>
<td>Delivery of high quality services in different settings</td>
<td>Care in the last days of life</td>
<td>Care after death</td>
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</table>

1. Discussion as the end of life approaches
2. Assessment, care planning and review
3. Coordination of care
4. Delivery of high quality services in different settings
5. Care in the last days of life
6. Care after death
At each of the steps there are clear links shown to the national EoLC quality markers:

**EoLC Quality Markers for Care Homes**

Care homes are to demonstrate:

- they have developed an action plan for EoLC that is congruent with the strategic plan developed for the locality by the PCT
- they have mechanisms in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning)
- residents’ needs for EoLC are assessed and reviewed on an on-going basis
- they nominate a key worker, if required, for each resident approaching the end of life
- residents who are dying are entered onto a care pathway
- families and carers are involved in EoLC decisions to the extent that they and the resident wish
- other residents are supported following a death in a care home
- the quality of EoLC provided by the care home is audited and reviewed
- they have processes in place to identify the training needs of all workers (registered and unregistered) in the care home that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning and symptom management) as they apply to EoLC
- they take particular account of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers
- all care homes are aware of the available EoLC training (including training related to the Liverpool Care Pathway (LCP) or equivalent) and enable relevant workers to access or attend appropriate programmes, dependent on their needs
- processes are in place to review all transfers into and out of care homes for residents approaching the end of life.

This guide repeats the self-questioning techniques, role descriptions and top tips that are in the national *Route to Success* guide, although it offers additional regional resources as well as extra sections. The guide is described in more detail in section 2.

The CQC *Essential Standards of Care* have also been mapped to each step of the EoLC care pathway. A table that demonstrates all of these links is offered below.
The relationship between the EoLC National Quality Markers and the CQC Essential Standards of Care

The following table illustrates the relationships between three current sets of standards and outcomes.

<table>
<thead>
<tr>
<th>Quality Markers for Care Homes</th>
<th>Relevance to CQC: 4K Essential Standards of Quality &amp; Safety</th>
<th>Relevance to CQC Essential Standards of Care Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>QM1: An action plan is developed for EoLC that is congruent with the PCT strategic plan</td>
<td>People who use services who are at the end of their life will have their care, treatment and support needs met because, wherever possible:</td>
<td>4: Care and welfare of people who use services 16: Assessing and monitoring the quality of provision</td>
</tr>
<tr>
<td>QM2: Mechanisms are in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning)</td>
<td>1: Respecting and involving people 2: Consent to care and treatment 6: Co-operating with other providers 21: Records</td>
<td>■ they are involved in the assessment and planning for their EoLC and are able to make choices and decisions about their preferred options, particularly those relating to pain management. ■ the plan of care records their wishes with regards to how their body and possessions are handled after their death and staff respect their values and beliefs.</td>
</tr>
<tr>
<td>QM3: Residents needs for EoLC are assessed and reviewed on an on-going basis</td>
<td>1: Respecting and involving people 2: Consent to care and treatment 4: Care and welfare 5: Meeting nutritional need 9: Management of medicines.</td>
<td></td>
</tr>
<tr>
<td>QM4: There is a nominated key worker, if required, for each resident approaching the end of life</td>
<td>12: Requirements relating to workers 13: Staffing 14: Supporting workers</td>
<td></td>
</tr>
</tbody>
</table>

Table continues overleaf.
<table>
<thead>
<tr>
<th>Quality Markers for Care Homes</th>
<th>Relevance to CQC Essential Standards of Care Outcomes</th>
<th>Relevance to CQC: 4K Essential Standards of Quality &amp; Safety</th>
</tr>
</thead>
</table>
| QM5: Residents who are dying are entered onto a care pathway | 1: Respecting and involving people  
2: Consent to care and treatment  
4: Care and welfare of people who use services  
5: Meeting nutritional need  
6: Co-operating with other providers  
9: Management of medicines | ■ there are systems in place to ensure further assessments by specialist palliative care services and other specialists, where needed. |
| QM6: Families and carers are involved in EoLC decisions to the extent that they and the resident wish | 1: Respecting and involving people  
2: Consent to care and treatment  
4: Care and welfare of people who use services | ■ they have information relating to death and dying available to them, their families or those close to them.  
■ they are able to have those people who are important to them, with them at the end of their life. |
| QM7: Other residents are supported following a death in a care home | 4: Care and welfare of people who use services | |
| QM8: The quality of EoLC provided by the care home is audited and reviewed | 16: Assessing and monitoring the quality of provision | |
| QM9: There are processes in place to identify the training needs of all workers in the care home that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning and symptom management) as they apply to EoLC | 12: Requirements relating to workers  
13: Staffing  
14: Supporting workers | ■ they have a dignified death, because staff are respectful of their needs for privacy, dignity and comfort. |

Table continues overleaf.
<table>
<thead>
<tr>
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<th>Relevance to CQC Essential Standards of Care Outcomes</th>
<th>Relevance to CQC: 4K Essential Standards of Quality &amp; Safety</th>
</tr>
</thead>
</table>
| **QM10:** Particular account is taken of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers | 12: Requirements relating to workers  
13: Staffing  
14: Supporting workers | People who use services who are at the end of their life will have their care, treatment and support needs met because, wherever possible: |
| **QM11:** All care homes are aware of the available EoLC training and enable relevant workers to access or attend appropriate programmes, dependent on their needs | 12: Requirements relating to workers  
13: Staffing  
14: Supporting workers | |
| **QM12:** Processes are in place to review all transfers into and out of care homes for residents approaching the end of life | 16: Assessing and monitoring the quality of provision | ▪ there are arrangements to minimise unnecessary disruption to the care, treatment, support and accommodation of the person who uses the service, their family and those close to them. |
The benefits to care homes of delivering quality end of life care

By implementing the advice in this guide, care homes will achieve a range of benefits and improved outcomes.

The major benefit is that more residents will experience a ‘good end of life’ as they will:

■ be supported to die in their preferred place of care
■ have an advance care plan and care pathway in place that enables staff to have a good understanding of wishes, needs and preferences
■ have an allocated key worker in place who can co-ordinate their care
■ have a reduced risk of experiencing unplanned hospital admissions.

The benefits to care homes are:

■ fewer complaints about end of life care from relatives or friends
■ a skilled workforce with the potential for improved morale and retention
■ able to demonstrate how they meet the Care Quality Commission (CQC) essential standards and meet local authority contractual requirements for EoLC delivery.

The CQC has produced a ‘supporting note’ for CQC assessors and inspectors to help them make consistent judgements of compliance with the essential standards of quality and safety.

N.B. CQC ‘supporting notes’ help to clarify key aspects of essential standards; they do not introduce additional requirements. The national quality markers similarly do not require additional work. They are, instead, integral to the delivery of essential quality standards.
2

The guide in more detail
What the guide offers

This guide has drawn upon the NEoLCP Route to Success guide for care homes which uses the six step pathway for end of life care.

The guide is ‘adult care home specific’, but it is not specific to any particular resident group, e.g. those with learning disabilities or dementia. There are a few specialist resources highlighted within the guide, although it mainly acts as a ‘gateway’ through which you can access more information about caring for residents with specific needs.

The six step pathway on which this guide is based is one that is commonly used in many other guides and resources that you will come across on the journey to developing your care home’s end of life care knowledge and understanding:

<table>
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At each of the steps, this guide will remind you of the links to the national EoLC quality markers for care homes and the CQC Essential Standards of Care.

An important additional section identifies the potential sources of evidence and the measures that care homes can use to demonstrate to their contract officers and quality inspectors what they are achieving through high quality end of life care.

Many of these could also be used by care homes to promote the quality of their care to the public.
How to use this guide

This guide should be of use to all care home staff although care home managers or owners, EoLC key workers and champions are particularly targeted.

The different sections are designed to allow you to undertake the work that you might need to do to improve end of life care in your care home in ‘manageable chunks’. You can dip in and out of the sections as you need to on your journey to improving end of life care in your care home.

At each step of the care pathway, the following headings are offered.

A brief introduction to the pathway step

Relevant EoLC national quality marker
To remind you which of the EoLC national quality markers are relevant to this care pathway step.

Relevant CQC essential standards
To remind you which outcomes from the CQC essential standards are relevant to the care pathway step.

Relevant National EOL units / qualifications
To suggest nationally accredited units / qualifications to support learning in this care pathway step.

Ask yourself
The questions posed here will help you to assess what aspects of care delivery you think you are achieving, and which you think you need to take further action upon.

Your role
To help you understand the care home’s role at each of the care pathway steps.

Top tips
Help you to achieve improved quality of care relating to the step of the pathway.

Resources
Links to places where you can access more information or where you can download tools and templates that may be useful for you in delivering each pathway step. A paper copy of the guide can only briefly describe the resources that are available, however all of the referenced supporting materials are available on the accompanying memory stick. You will need to access the guide through a computer that is internet connected to be able to click on the links and be taken directly to the website or the resource that is described.

The resources are not exhaustive and are subject to change and development, which is why following the highly recommended advice section (offered below) will also be important. The majority of resources that are referred to are also ‘generic’ rather than ‘specific’ to a particular resident group.

Potential Sources of Evidence
This section offers suggestions about the sources of evidence that you should be able to provide to CQC officers and/or contract officers when they monitor the quality of your services. Throughout your EoLC improvement work you should therefore make sure that systems are in place to collect these evidence sources and that they are easily accessible. You may also want to use some of these evidence sources as a means of marketing your home to the public.
Care home to do list
Examples of the actions that you might want to take to help you to achieve good quality EoLC and give you some space to record any of your own actions.

E.g.
■ Register with the National End of Life Care Programme to receive their newsletter (see opposite)

■ Put end of life care on the agenda for next team meeting

■ Register with Skills for Care for the NMDS (see overleaf)

Highly recommended advice
To keep up to date with the development of resources and to access resources that are specific to your resident groups it is highly recommended that you regularly visit the NEoLCP website: www.endoflifecareforadults.nhs.uk

You will find it an advantage to sign up for the newsletter that the national team publishes as this will keep you informed about new developments that relate to care homes and/or to the care of people with specific diseases or conditions that you care for. This regional guide contains many links to documents that are on the NEoLCP website but there are many more that are available on their site and new ones are being developed regularly. By signing up to the newsletter you will be alerted to these and can visit the site when something is produced that is relevant to you.

NEoLCP works closely with many other organisations that have end of life care as a focus. You may also want to visit their websites:

The National Council for Palliative Care is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. They work with government, health and social care staff and people with personal experience to improve end of life care for all: www.ncpc.org.uk/site/about

The Dying Matters Coalition has the mission “to support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make ‘living and dying well’ the norm”: www.dyingmatters.org/overview/about-us
The Gold Standards Framework (GSF) is a systematic evidence-based approach to optimising the care for patients nearing the end of life (where care is delivered by generalist providers). The GSF team offer training and accreditation for care homes at a cost that varies in accordance with the care home size. However, they also make a number of tools and templates available free of charge and some of those are included in this guide: www.goldstandardsframework.org.uk

NEoLCP also works and liaises with organisations that may not have end of life care as their prime focus but who are undertaking research or developing resources to support end of life care for people with specific conditions or diseases, e.g. Mencap and MacMillan Cancer Care. It similarly works and liaises with organisations with interests in specific subject areas that relate to end of life care, e.g. skills and workforce development, policy development, environmental development.

There is such a wide range of activity going on that relates to end of life care that it can be quite daunting trying to find the information that you need. This is why signing up to the NEoLCP newsletter is useful and should help you to focus your search for resources on those that are relevant to you.

The Social Care Institute for Excellence (SCIE) may also be a helpful source of information. You can visit their EoLC pages at: www.scie.org.uk/adults/endoflifecare/index.asp

Another useful website may be Help the Hospices: www.helpthehospices.org.uk/about-us, who aim to support their members and other organisations as they strive to grow and improve end of life care throughout the UK and across the world.

The Yorkshire Cancer Network website is a valuable source of information, advice and resources for end of life care. You can access their EoLC pages at: www.ycn.nhs.uk/html/eol/index.htm

You should also familiarise yourself with any websites that your local or regional teams provide as they often produce their own resources and some have dedicated web pages that are care home specific. They will also provide you with valuable contact details.

At the time of this guide’s publication, the local websites (listed below) were found to have specific information about palliative and end of life care. To be taken directly to your local website you will need to be on an internet connected computer and click on the relevant link. If you are reading this guide in print format, the links are available on the accompanying memory stick in the document titled ‘Local websites’ which is in the ‘2. The guide in more detail’ folder.

Barnsley end of life care
Bradford and Airedale palliative care
Calderdale and Kirklees palliative care
Doncaster end of life care
Leeds palliative care
North East Lincs end of life care
North Yorkshire and York end of life care
Rotherham end of life care
Sheffield end of life care
Wakefield District palliative care
Staff learning and development

End of Life national qualifications
There is a wide range of national end of life qualifications which were developed by Skills for Care in conjunction with employers, learning providers, awarding organisations and people who use services. These qualifications are for those working in social care and can equip them not only to recognise end of life situations but to manage them more effectively, working in partnership with the individuals, their families and carers and other organisations to deliver the best quality of care. Take up of these is really growing as social care workers recognise the important role they have to play in delivering quality end of life care.

The End of Life qualifications
The new qualifications also build on the work of Common Core Competences and Principles for End of Life Care joint work carried out by Skills for Care and Skills for Health to underpin learning and development for health and social care workers in end of life care

The qualifications are:
- **Level 2 Award Awareness of End of Life Care** - A single unit award designed to provide a basic understanding of end of life care for those who work in the health and social care sector.
- **Level 3 Award Awareness of End of Life Care** - Made up of 3 mandatory units to support the learner to develop understanding of how to provide support to individuals and their families in end of life care, and in particular during the last days of life.
- **Level 3 Certificate in Working in End of Life care** – to support the learner to further develop their understanding of end of life care, especially around advance care planning, to develop specific communication skills and to demonstrate competence in managing symptoms and pain in end of life care, supporting individuals with loss and grief before death and in their spirituality.
- **Level 5 Certificate in Leading and Managing Services to Support End of Life and Significant Life Events** – a CPD qualification to support managers to demonstrate how they can lead and manage end of life care services that promote positive experiences for individuals and their families at the end of life.

The qualifications are aimed at all learners in health and social care with an interest in end of life care and the impact on individuals, their carers and families. For more information about the qualifications visit the Skills for Care website.

Learning materials freely downloadable
To support delivery of each of the 10 specialist end of life units within the qualifications Skills for Care have commissioned a wealth of learning materials which offer learners and trainers guides, and a whole lot more resources for trainers and others taking responsibility for learning. Each guide contains a number of activities and resources which can be used as a whole programme or individually to suit different audiences and situations.
Staff training and development

Delivering quality end of life care in care homes cannot be achieved without adequate training for all care home staff and regular reference is made to this throughout this guide. There is a wide range of learning resources available, many of which are free of charge and many of which are provided as an on-line resource to enable flexible learning.

As part of the wider programme of work that is being undertaken, Skills for Care is undertaking a project to explore and test out the use of the national end of life care e-learning modules (e-ELCA) that are available. Health and Social Care have worked in partnership across Yorkshire and the Humber has worked with employers to identify ‘taster modules’ for care homes. You can access e-ELCA if your care home is registered with the Skills for Care National Minimum Data Set for Social Care (NMDS-SC). To find out more go to: www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx

Skills for Care has co-ordinated the training of 800 care home managers and 800 care home champions across Yorkshire and the Humber in 2012. These individuals were offered the opportunity to develop competence in their practice, and they can receive credit from it towards Qualifications & Credit Framework (QCF) units. The training was based on National Occupational Standards in End of Life Care which are the basis of the QCF units. QCF end of life care units will become the main qualifications of health and social care workers in care homes and other care settings in the future.

The level of provision of EoLC training is variable across the localities in Y&H, although many health and local authorities do provide a wide range of training sessions that are delivered by end of life care specialists. It is therefore beneficial for you to find out what is on offer in your locality, in addition to the NEoLCP online resources already mentioned. MacMillan Cancer Care also provides a wide range of on-line learning resources free of charge. Many are specifically related to the care of people with cancer although they provide many generic learning resources such as those in communication skills. A simple registration process is all you need to access the learning. Visit: learnzone.macmillan.org.uk

Care home co-ordinators in the North West of England have also developed a workshop style training programme that follows the six step pathway that this guide is also based on, called ‘Six steps to success’. They are happy for this training resource to be used outside of the North West and provide a guide that can be adapted and followed in other areas.

A ‘one off’ approach to training care home staff will not, however, ensure the longer term sustainability of end of life care knowledge and skills. It is therefore important that care homes access any learning networks that are on offer in their area.

As part of the wider programme of work in Yorkshire and the Humber, there will be learning networks available to support 800 care home managers and 800 care home champions who attend the training programmes that are being provided. These may tap into existing networks and/or new networks will be created. Make sure that you find out about, and get involved with, a learning network in your area through the training programmes that are being provided by Skills for Care or by asking your local end of life care specialist or your district nurse.
### Step 1 - Relevant end of life units
- **EOL 201** Understand how to work in end of life care
- **EOL 301** Understand how to provide support when working in end of life care
- **EOL 305** Support individuals with loss and grief before death
- **EOL 501** Lead and manage end of life care services

### Step 2 - Relevant end of life units
- **EOL 303** Understand Advance Care Planning
- **EOL 304** Support the spiritual wellbeing of individuals
- **EOL 501** Lead and manage end of life care services

### Step 3 - Relevant end of life units
- **EOL 302** Managing symptoms in end of life care
- **EOL 502** Lead a service that supports individuals through significant life events

### Step 4 - Relevant end of life units
- **EOL 301** Understand how to provide support when working in end of life care
- **EOL 308** End of Life and dementia care
- **EOL 501** Lead and manage end of life care services
- **EOL 502** Lead a service that supports individuals through significant life events

### Step 5 - Relevant end of life units
- **EOL 305** Support individuals with loss and grief before death
- **EOL 306** Understand how to support individuals during last days of life
- **EOL 307** Support individuals during the last days of life

### Step 6 - Relevant end of life units
- **EOL 306** Understand how to support individuals during last days of life
- **EOL 307** Support individuals during the last days of life
- **EOL 501** Lead and manage end of life care services
3
The six step pathway
Step 1

Discussions as the end of life approaches

Enabling residents to live well before they die in comfort and with dignity are core functions of care homes. One of the key challenges for managers and staff is identifying residents who may be reaching the last months or weeks of their life and knowing how and when to open up a discussion with them (and their relatives) about what they would wish for as they approach this phase of their life. Agreement needs to be reached about when the discussion should happen, who should initiate it and what skills and competences care home staff require to take on this role.

Relevant EoLC national quality marker
Families and carers are involved in end of life decisions to the extent that they and the resident wish.

Relevant CQC essential standards
1: Respecting and involving people
2: Consent to care and treatment
4: Care and Welfare of people who use services

People who use services who are at the end of their life will have their care, treatment and support needs met because wherever possible:
- they have information relating to death and dying available to them, their families or those close to them
- they are able to have those people who are important to them, with them at the end of their life.

Ask yourself
- Can you, and do you, identify those in your care who are approaching the end of life?
- Are you/your team aware of the triggers that might indicate it is an appropriate time for discussion?
- Are you/your team aware of the tools that are available to help with the recognition of this?
- Are you certain you know whether a resident does or does not wish to have a conversation about their future care?
- Is there a policy in place to guide your actions?
- What do others involved in the direct care of the resident think?
- What do members of the wider multidisciplinary care team think? (e.g. GP, district nurse)
Do you have information available in the home for the advice and support of residents and their families?

**Your role**

- Recognise when a resident’s signs and symptoms have increased or their condition has deteriorated. Using ‘about me’ documents (see resources section) when residents are admitted will help you to recognise changes in their condition.
- Ask the question: “Would I be surprised if this resident were to die in the near future?”
- Check out what other team members think and what they have noticed.
- Remember to take account of triggers such as a recent change in the resident’s circumstances. These could include the death of a spouse, an increase in hospital admissions or a change in care setting, e.g. a move from a residential to a nursing home.
- Identify those who need to be receiving end of life supportive care. Discuss this with the resident’s GP to ensure that they can be put onto the EoLC register.
- Ensure that care home records are updated and maintained so that the number of residents on the EoLC register is readily available.
- Identify whether it is appropriate to open a supportive discussion with the resident and/or their family about their wishes for end of life care and the best time or circumstances in which to do that.
- Consider carefully whether the individual wishes to have open discussions about prognosis and possible future care options.
- Provide any relevant information that may be required by the resident or their family.
- If there is no policy in place, pursue the development of one.
- Ensure that care home staff develop an understanding about the recognition of the end of life.
- Keep records of complaints and compliments about discussions which have taken place as end of life approaches. Ensure any feedback is reflected on and that the care home team learns from this.

**Top tips**

- Use documents like ‘This is me’ (see resources section) for residents with dementia or communication difficulties to help you to recognise changes in their condition.
- Recognise that greater attention and support may be required for those residents who struggle to communicate their needs because of dementia or other health problems.
- Death and dying should not be hidden from residents, relatives and carers. Building a trusting relationship will help facilitate conversations that may include end of life care.
- As care givers it is important that you recognise how your own attitude to death and dying may influence the care you provide or your ability to talk openly.
- Facilitate staff reflection on their conversations with residents and families and how they followed things through with the wider care team.
- Undertake early identification of pre-bereavement needs and source appropriate support for relatives.
Resources
A quick guide to identifying patients for supportive and palliative care offers indicators that should be looked for in residents with particular diseases and conditions so that you may be alerted to the signs that they may be approaching the end of life.

GSF Prognostic Indicator Guidance – Sept 2011: This is the National GSF Centre’s guidance for clinicians which aims to support the earlier recognition of patients nearing the end of life.

Principles of good communication – This is a simple one page summary about the factors that aid good communication and which will be useful for all staff. It also provides a link to the national e-learning resources that are available.

This is me – This is an Alzheimer’s society document that is useful for use with dementia patients. It helps you to understand the resident and subsequently recognise any changes that take place.

Difficult conversations: Making it easier to talk to people with dementia about the end of life, July 2011 £5.00 from NCPC. This guidance aims to help anyone, unpaid or professional, caring for someone with dementia to open up conversations about end of life wishes and preferences.

Finding the words – NEoLCP workbook is a resource for health and social care professionals whose work brings them into contact with people and families at the end of life. It accompanies the DVD Finding the Words and can be used individually or in small groups, with or without a facilitator/trainer, to help explore the issues discussed on the DVD and some of the evidence surrounding end of life conversations.

‘Preferred priorities for care, an advance care plan’ is a single sided fact and ‘Preferred priorities for care’ is a support sheet that help to explain about ‘preferred priorities of care’.

Preferred priorities for care is an easy to read and easy to complete document for potential use with residents.

Thinking of you – This is a Dying matters leaflet used when someone is dying.

One last thing – This is a Dying matters leaflet that offers information to help those close to someone who is ill or old.

Remember me when – This is a Dying matters leaflet to help people to start the conversation when someone close to them is dying.

Potential sources of evidence

- A documented system is in place for identifying residents coming to the end of life.
- An up to date list of residents who are nearing the end of life is available.
- Appropriate tools are used in the identification of residents nearing the end of life.
- Documentary evidence of family and friends involvement is available and/or resident care plans clearly document their wishes not to involve family and friends.
- Complaints and compliments from residents, families and friends reflect the home’s good practice.
- Staff records show training and development in EoLC identification and communication skills.
Care home to do list
E.g.
■ Take whole of section 3 of this guide to staff meeting for discussion
■ Review existing policies re death and dying
Step 2

Assessment, care planning and review

Once a resident is identified as approaching the last months or weeks of their life, an early assessment of their wishes and needs is vital. This provides an opportunity to make plans for how and where they want to live out the rest of their life. They may also want to express their choices for care when they are dying (i.e. the last few days of their life) as well as for what they want to happen after their death. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, the environmental needs and wishes of each resident.

Relevant national EoLC quality markers

- There is a mechanism in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life.
- The resident’s needs for end of life care are assessed and reviewed on an on-going basis.

Relevant CQC essential standards

1: Respecting and involving people
2: Consent to care and treatment
4: Care and welfare
5: Meeting nutritional need
6: Co-operating with other providers
9: Management of medicines
21: Records

People who use services who are at the end of their life will have their care, treatment and support needs met because wherever possible:

- they are involved in the assessment and planning for their EoLC and are able to make choices and decisions about their preferred options, particularly those relating to pain management
- the plan of care records their wishes with regards to how their body and possessions are handled after their death and staff respect their values and beliefs.
Ask yourself

■ Do your care plan assessments include an exploration of all aspects of end of life care?
■ Do you feel sufficiently confident and skilled in supporting residents to identify their wishes and preferences about their future care, which may involve a decision to put in place an ‘advance decision to refuse treatment’? Might additional training and support be valuable?
■ Do you know about, and use, the Yorkshire and Humber Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form?
■ Have the wishes or concerns of the resident’s relatives or advocates been considered?
■ Have you considered how you might gather information from, or about, those of your residents who struggle to communicate, perhaps because of dementia or stroke?

Your role

■ Undertake a holistic assessment for end of life care needs and preferences in partnership with your residents and, where appropriate, their relatives and friends.
■ Ensure that records are kept up to date especially in relation to having the most up to date contacts in time of need.
■ Assess and respond sensitively to the social, psychological and spiritual needs and wishes of a resident as well as their physical care needs.
■ Ensure that you and your team understand the Mental Capacity Act and its implications.
■ If necessary, support an assessment of the resident’s ability to make decisions about their care.
■ Identify, record and respond to a resident’s personal wishes and preferences about their future care (advance care planning) and implement regular reviews. Ensure that a list of residents with Advance Care Plans in place is readily available.
■ If requested by a resident, you should support the resident in the recording of an ‘advance decision to refuse treatment’ using the Yorkshire and Humber DNACPR document as instructed in the accompanying guidance.
■ Communicate information about personal wishes and preferences (with permission) to relevant people, e.g. the emergency service and the GP out of hours service.
■ Ensure that care home staff acquire the skills and support they require to assess residents.
■ Keep records of complaints and compliments about assessment, care planning and review at end of life. Ensure any feedback is reflected on and that the care home team learns from this.

Top tips

■ If residents make an advanced decision to refuse life sustaining treatment (that includes resuscitation) it must be recorded on the Yorkshire and Humber DNACPR form.
■ Holding an open discussion meeting with residents and relatives can be a way of raising awareness about the possibility of expressing personal wishes and preferences.
■ Creating life books or collages may prompt discussions about personal beliefs and preferences.
■ Ensure that you are aware of, and that you use, local services that support end of life care. Many NHS organisations have EoLC specialists in post who provide training and support to care home staff. District nursing teams and hospices are also a valuable source of support.
Resources
A single page advice sheet about holistic assessment.

Planning for your future care - This is a booklet for members of the public that provides a simple explanation about advance care planning and the different options that are open to them at the end of life.

National Guide on Holistic Assessment - 2010 – This is a more comprehensive document that provides guidance for holistic common assessment of the supportive and palliative care needs of adults requiring end of life care. It sets out the main features of the process – including the who, when, where and how – of holistic common assessment.

The GSF problems and concerns overview enables a summary record of a resident’s or patient’s and carer’s problems or concerns.

These GSF forms support the assessment of pain in residents; GSF initial pain assessment and GSF continuous pain assessment.

The disability distress assessment tool helps to identify distress cues in people who have severely limited communication.

GSF thinking ahead – advance care planning discussion provides an example of how an ‘advance statement’ might be recorded.

The Yorkshire and the Humber Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form, contains guidance for completion. This is an important document which is recognised across all agencies in Yorkshire and the Humber. It is critical for a person to have this document in place to enable them to die without resuscitation interventions being undertaken.

Advance decisions to refuse treatment: A guide for Health and Social Care Professionals - This is a guide that can be used by for health and social care professionals to clarify the law relating to advance decisions to refuse treatment. It also offers practical information to enable the professional to support any person who might choose to make this decision.

This one page support sheet offers advice about making decisions in a person’s best interests when they lack the capacity to make decisions for themselves.

Five things to do before I die - This is a Dying matters leaflet that offers information to help people think about end of life plans.

Potential sources of evidence
- Care plans are holistic and document all aspects of care.
- Appropriate EoLC assessment tools are used.
- Advance care plans for residents identified as being at the end of life can be produced, and the number of residents with these in place is readily available.
- The Yorkshire and Humber DNACPR form is used within the home and the number of patients with this in place is readily available.
- Evidence is available that (in accordance with their permission) residents’ preferred wishes are shared with other professionals and services.
- Residents’ care plans demonstrate that regular reviews take place.
- Complaints and compliments from residents, families and friends reflect the home’s good practice.
- Staff records show training and development in EoLC assessment skills.
Care home to do list

E.g.
■ Talk to staff about the importance of checking that the details of any significant others are up to date at times of resident reviews
Step 3

Co-ordination of care

Once a care plan has been agreed it is important that all the services that the resident needs are effectively co-ordinated. Many end of life care cases are complex and involve residents receiving care from many different professionals from many different agencies and organisations. A lack of communication and co-ordination can result in the unnecessary hospitalisation of care home residents in contradiction of their wishes to be cared for, and to die, in their care home.

Relevant national EoLC quality markers

- Have an action plan for end of life care which is congruent with the strategic plan developed by the local PCT.
- Nominate a key worker, if required, for each resident approaching end of life.

Relevant CQC essential standards

4: Care and welfare of people who use services
16: Assessing and monitoring the quality of provision
12: Requirements relating to workers
13: Staffing
14: Supporting workers

Ask yourself

- Is there a communication system in place to keep all members of the care home team and others from outside the home (relatives, friends and health and social care professionals) fully informed of end of life care plans?
- Is that system clearly described in the care home’s EoLC policy and action plan and are all care home staff familiar with it?
- Are key workers identified within the home who can develop strong personal relationships with end of life care residents and their families and strong working relationships with the key professionals who will help to meet end of life care plans?
- Are systems in place for services to respond rapidly and appropriately (out of hours as well as in working hours) to any changes in circumstances as end of life approaches? Examples include anticipatory drug prescribing and access to special equipment such as syringe drivers.
- Are those systems clearly described in the EoLC action plan and are all care home staff familiar with it?
Your role

- Ensure that your care home has a clear policy and plan for end of life care and that all staff are familiar with it.
- Ensure local health and social care professionals are aware of residents who are approaching end of life so they can be entered onto an appropriate end of life care register.
- Make sure good communication systems are in place within the home and across all relevant services.
- Ensure you know who the key contacts are across provider services, voluntary bodies and social care sectors.
- Make sure there are key workers within the home, who can also act as the link between services.
- Ensure that timely access to relevant equipment and any to drugs that may be required by the resident is available.
- Ensure that out of hours services are informed of anticipatory care needs.
- Ensure that ambulance services are informed of anticipated care needs.
- Keep records of complaints and compliments about coordination of care at end of life. Ensure any feedback is reflected on and that the care home team learns from this.

Top tips

- Find out which pharmacies your local hospice uses as these are more likely to have relevant drugs in stock and offer out of hours delivery of drugs.
- Build strong relationships with other services e.g. GPs, district nursing teams, palliative care teams and clinical nurse specialists as these will be crucial to helping you to provide good end of life care to residents.
- Join EoLC networks or ensure that existing networks specifically discuss end of life care issues.
- Try new approaches to improving communication in the home, e.g. use tape-recorded handovers to supplement face-to-face handovers.

Resources

The care home staff champions for end of life care resource from Leeds offers an example of the role of care home end of life care champions and other key people.

Potential sources of evidence

- A policy/action plan for EoLC is in place.
- Staff are aware of the EoLC policies and practices that are in place.
- Documentary evidence of the allocation of key workers is available.
- Complaints and compliments from residents, families and friends reflect the home’s good practice.
- Complaints and compliments from other professionals/agencies reflect the home’s good practice.
- Staff records show that EoLC key workers receive appropriate training and development.
- Records show that inappropriate transfers to hospital or to other care settings for residents at the end of life are eliminated or reduced.
- The number of residents who die in the care home (where this is their preferred place of care) increases.

Care home to do list

E.g.

- Ask palliative care nurse about training opportunities for key workers in the area
Step 4
Delivery of high quality end of life care

Residents and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless of whether they are living independently at home or in a care home.

The skills and competences of the staff delivering their care are crucial to the delivery of high quality care.

Relevant national EoLC quality markers
- A process is in place to identify the training needs of all workers.
- Take particular account of the training needs of those involved in discussing end of life care with residents, families and carers.
- Be aware of available end of life care training including around the use of the Liverpool Care Pathway (LCP) or equivalent.

Relevant CQC essential standards
12: Requirements relating to workers
13: Staffing
14: Supporting workers

People who use services who are at the end of their life will have their care, treatment and support needs met because wherever possible:
- they have a dignified death, because staff are respectful of their needs for privacy, dignity and comfort.

Ask yourself
- Are policies and procedures for end of life care in place within your care home and are all staff aware of them? For example, does the team know what to do in various end of life scenarios, such as at a weekends and during the night?
- Are processes in place to identify staff skills needs?
- Can all staff access internal and external training and support?
- Does the environment within the care home offer privacy, dignity and respect for individuals and their families as end of life approaches?
- Are systems in place to monitor and evaluate the quality and delivery of end of life care? For example, resident and family feedback systems, staff systems for critical incident analysis, care audits.
Are you confident that for those who have expressed a wish to stay in the home, hospital admission or transfer to other care settings are absolutely necessary?

Can you ensure that any necessary transition from the care home to a hospital or other care setting is well coordinated and minimises any distress?

**Your role**

- Ensure there is an operational policy in place for implementing end of life care in your care home.
- Ensure you have awareness and understanding of end of life care core principles and values.
- Promote or participate in the different aspects of end of life care training that may be available to you. There is no one set format for the delivery of training.
- Where possible, access training in communication skills, assessment and care planning, advance care planning, symptom management (including comfort and wellbeing).
- Give consideration to the environment in which end of life care and support are delivered, e.g. is there access to a quiet room or facilities for relatives?
- Use the experience of a relative, staff member or advocate to help provide constructive feedback to support continuous practice improvement.
- Keep records of all resident hospital admissions and transfers. Ensure these records are reflected on and that the care home team learn from this.
- Keep records of complaints and compliments about the quality of delivery of care at end of life. Ensure any feedback is reflected on and that the care home team learns from this.

**Top tips**

- Do not forget the role that other residents, particularly those who have developed a close relationship with the person who is dying, may be able to play in the planning and delivery of care.
- Staff training needs will include not only the physical aspects of care but also the psychological and spiritual aspects.
- Enable residents to maintain the maximum level of independence, choice and control for as long as possible.

**Resources**

Remember to access the learning resources that were referenced in the staff training and development chapter in section 2 of this guide. Additionally, you could look at any of the following that are relevant, as well as using the NEoLCP website to find more specialist resources.

**Dignity in End of Life Care – support sheet** offers the ten principles of dignity in care.

**GSF significant event analysis** will help you to structure and record reflective learning using the ‘significant event analysis’ technique.

The **Routes to Success guide** for achieving quality environments for end of life care.

**Care towards the end of life for people with dementia** is a specialist resource that provides links to information sources, resources and good practice in end of life care (EoLC) for people with dementia. It will help those who work with people with dementia who are not EoLC experts and EoLC experts who are not particularly knowledgeable about dementia.

**The end of life care learning disability resource pack** is designed for anyone who is caring for or giving support to someone with a learning disability who is terminally ill.
Potential sources of evidence
■ EoLC policies and procedures can be produced.
■ Care home staff can describe what they would do in different scenarios.
■ Complaints and compliments from residents, families and friends reflect the home’s good practice.
■ Staff records show training and development in a wide range of EoLC skills.
■ Care home audits relating to end of life care can be produced.
■ Quiet and private facilities are available for residents and their relatives and friends.
■ There is evidence that the home conducts critical incident analysis and reflective practice for the purpose of continuous improvement.
■ The detail of all EoLC resident transfers and hospital admissions is readily available.

Care home to do list
E.g.
■ Print off copies of critical incident analysis documents and start to use in staff meetings
■ Look at e-learning modules for end of life care and identify the staff who need to access them
Step 5

Care in the last days of life

The point comes when a resident enters the dying phase. It is vital that staff should recognise that the person is dying and take the appropriate action. How the person dies remains a lasting memory for the resident’s relatives, friends and care home staff involved.

Relevant national EoLC quality markers

■ A process is in place to review all transfers into and out of the care home for residents approaching the end of life.
■ Residents who are dying are entered onto a care pathway.

Relevant CQC essential standards

1: Respecting and involving people
2: Consent to care and treatment
4: Care and welfare of people who use services
5: Meeting nutritional need
6: Co-operating with other providers
9: Management of medicines
16: Assessing and monitoring the quality of provision

People who use services who are at the end of their life will have their care, treatment and support needs met because wherever possible:

■ there are systems in place to ensure further assessments by specialist palliative care services and other specialists, where needed
■ there are arrangements to minimise unnecessary disruption to the care, treatment, support and accommodation of the person who uses the service, their family and those close to them.
Ask yourself

■ Are you and the team aware of the changes that may occur in a resident’s condition during the dying phase? Are you all aware of what needs to be done as these changes present?
■ Are the team confident to act as an advocate for the resident’s wishes, particularly out of hours, when someone who doesn’t know them might suggest hospital admission instead of care in the home?
■ Are systems in place for involving family and friends in some aspects of the care-giving or in discussions as death approaches?
■ Have any specific wishes or preferences been identified by the resident for this time?
■ Have you ensured that any DNACPR decision is up to date? Have you re-visited this with the resident and their family (where appropriate)?
■ Has the Liverpool Care Pathway (LCP) for care homes or another equivalent pathway been implemented?
■ Have you responded to any particular spiritual or cultural needs that have been recorded as part of EoLC planning?

Your role

■ Ensure that the team are aware of the processes that occur during the last days and hours of life.
■ Ensure that the team understand the support that is available (if required) and how this can be accessed 24 hours a day, 7 days a week.
■ Have open discussions with relatives and friends to ensure that they also know what to expect during the last days of life, and offer support when needed.
■ Where possible, adhere to a resident’s stated wishes and preferences. If they have expressed a wish to die in their care home do everything that you can to ensure that happens. You should ensure that the DNACPR decision form is completed to reflect resident’s wishes.
■ If a person lacks mental capacity, try to identify what they would take into account if they could make their own decisions.
■ With appropriate training, follow a validated integrated care pathway for the last days of life such as the Liverpool Care Pathway (LCP).
■ Ensure that care home records can readily show the number of residents that are on a Care Pathway.
■ Where possible, have anticipatory prescribing systems in place or a system for rapid access to necessary medication.
■ Ensure that medicines are regularly checked and that there is access to appropriately competent and confident staff who can deliver end of life medicines via syringe driver if needed. This may be through the district nursing service or from staff internal to the home who have had appropriate training.
■ Anticipate and be prepared for any specific religious, spiritual or cultural needs a resident might have.
■ Keep records of complaints and compliments about the care in the last days of life. Ensure any feedback is reflected on and that the care home team learns from this.

Top tips

■ Where possible, plan to have someone available to sit with the dying resident to provide them with comfort and reassurance (a member of staff or a volunteer).
■ Consider ways to support the relatives that the resident wishes to have present by providing, where possible, transport, accommodation, meals and emotional support.
■ Start thinking about any bereavement support needs that may be needed once the resident dies.
Build in some time to support the team and reflect with them about how things are going.

Support people with the same respect you would wish to have for yourself or a member of your own family.

Resources
The dying process support sheet offers information about the dying process and will help you to be better prepared to deal with the changes that occur.

The Liverpool Care Pathway for the dying patient is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life.

Barnsley area homes & local NHS have developed their own care pathway for the last few days of life which may be useful for homes in that area.

Barnsley has developed this leaflet for relatives and carers to help them better understand the dying process. It will be useful for care homes in that area or could be adapted by others.

Leeds has produced a guiding framework for symptom management in the last days of life which would support Leeds care homes.

Symptom guidelines for care in the last few days of life offers guidelines for the management (and anticipatory management) of a range of common symptoms that present at the end of life, e.g. pain, restlessness, respiratory problems, nausea and vomiting. It is an LCP guide that has been locally enhanced for Bradford & Airedale.

This link will take you to the Yorkshire and Humber symptom management guidelines which will support any home that does not have anything locally developed.

Potential sources of evidence
- Evidence is available of the use of the Liverpool Care Pathway (or equivalent) for patients who are dying.
- Procedures for the rapid access of medication and equipment are in place.
- Plans are in place for the support of residents during the dying phase, e.g. emergency staff rotas, voluntary systems.
- Plans are in place for the support of family and friends during the dying phase.
- Care home staff can describe what they would expect to happen in the dying phase.
- Complaints and compliments from residents, families and friends reflect the home’s good practice.
- Staff records show training and development about the dying phase.
- Records show that inappropriate transfers to hospital or to other care settings for residents at the end of life are eliminated or reduced.

Care home to do list
E.g.
- Ask district nurse about the systems that are in place for accessing equipment in urgent situations
- Talk to staff about how we can set up an emergency rota system
Step 6

Care after death

Good end of life care does not stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to family wishes. The support and care provided for relatives and friends (including other care home residents) will help them to cope with their loss and is essential for achieving a “good death”. This is important for staff as well, many of whom will have become emotionally connected to the resident.

Relevant national EoLC quality markers
- Other residents are supported following a death in the home.
- The quality of end of life care is audited and reviewed.

Relevant CQC essential standards
4: Care and welfare of people who use services
16: Assessing and monitoring the quality of provision.

Ask yourself
- Are the team aware of what needs to be done after the death of a resident? E.g. does the care home policy clearly state who should be contacted following an expected death so that emergency services are not contacted inappropriately?
- Are the team confident in talking to relatives, friends and other residents about death and do they how to support them when a resident has died?
- Do staff know about the local services for bereavement and are relatives and friends provided with the appropriate support and information to access them?
- Are adequate facilities available for dealing with death and bereavement?
- Are systems in place for advising on, or offering bereavement support?
- Do mechanisms exist to support non-family members such as staff, other residents and friends who may also be affected by a death?
- Does the home record and gather information sufficiently to enable reflection, audit, and review of the quality of end of life care? E.g. is there an up to date record of all resident deaths and what has been learnt from them?
Your role

- Respect individual faiths and beliefs and take steps to meet their requirements.
- Be aware of the verification and certification of death policies.
- Provide appropriate information (specific to the geographical area where possible) to relatives and carers about what to do after a death.
- Offer information about bereavement services (specific to the geographical area where possible) if required.
- Provide a comfortable environment in which staff and, where appropriate, other residents, can discuss or share their feelings.
- Provide staff, residents and relatives with the opportunity for remembrance and to show their respect.
- Ensure staff are adequately informed and trained about death and bereavement.
- Ensure that the home reflects on and learns from all resident deaths, regardless of where they have taken place, as part of continuous improvement.
- Ensure that records are kept in a way that can demonstrate the extent to which a resident’s wishes are followed e.g. the number of residents who have died in their preferred place of care should be readily available.
- Keep records of complaints and compliments about care after death. Ensure any feedback is reflected on and that the care home team learns from this.

Advice from Yorkshire Ambulance Service

- Ensure that staff are aware that 999 is an emergency service but will also support in a time of crisis if required however it is encouraged that staff only ring 999 if there is no advanced care plan and DNA and CPR forms are not place or they need support.
- Ensure that staff are aware that if there is an advanced care plan and DNA and CPR forms are in place contact should be made to the deceased’s GPs, District Nursing teams or our of hour doctors service. It is the lack of valid DNACPR forms that creates a problem if an ambulance is called and the patient has just died.
- Ensure that staff are aware that if a resident has just died and 999 is called (and no DNA CPR form) there will be advice given over the phone to commence CPR and the ambulance clinicians may continue to resuscitate on arrival. It is therefore important that DNA and CPR forms are in place as calling an ambulance is an emergency service and the care home is requesting urgent assistance for a resident not just informing that the person has died.
- Ensure that staff are aware the ambulance service will always support in an emergency but wish to encourage staff within care homes follow their own processes. Some nursing teams are verifying death across the region so it is important to clarify whether your local nursing service offers this service.
- Ensure that staff are aware that if an ambulance is called for general deterioration or a sudden problem the resident may then be conveyed to hospital (and this may not always be appropriate).
- Ensure you liaise with your colleagues in health and the resident in advance care planning so that we can ensure that their place of choice in death is considered.
Top tips

- Think of ways you could support the grieving process, e.g. create memory books of photos, create a memorial garden and plant trees or shrubs to remember those who have died.
- Be open and provide residents, relatives and staff with the opportunity to acknowledge that a resident has died and allow them to pay their respects in their own way.
- Recognise that a resident’s death may be more significant to some than to others and they may require additional support.

Resources

Guidance for staff responsible for care after death is aimed at nurses and other healthcare staff who have responsibility for care after death. It covers what needs to be done with the body and who needs to be involved in care after death.

The following link takes you to Marie Curie advice that explains a number of practical issues that need to be dealt with when a person has died: What needs to happen after death - Marie Curie advice www.mariecurie.org.uk/en-gb/patients-carers/carers/after-death/

Measuring the quality of care that you have provided for a dying resident and their families is important to do for continuous improvement purposes. Find out about any processes that are in place for after death audits in your locality. For more information about audits after death look at the following GSF resource: GSF After Death Audit www.goldstandardsframework.org.uk/GSFAuditTool

I could do with a chat - This is a Dying matters leaflet that offers advice for talking to someone who is bereaved.

What to do if someone you know has been bereaved - This is another Dying matters leaflet that offers useful advice.

All areas across Yorkshire and the Humber should have advice leaflets available on bereavement. Here is an example of a bereavement support and advice leaflet from Barnsley.

Potential sources of evidence

- Policies/plans clearly identify the processes that should be followed when a resident dies and staff are aware of it.
- Memory books (or similar) are used in the home to remember those who have died.
- Bereavement information for families/friends is readily available in the home.
- Private and quiet space is available for the bereaved.
- Staff support systems are in place.
- Complaints and compliments from residents, families and friends reflect the home’s good practice.
- Staff records show training and development relating to bereavement.
- The number of deaths in the care home should be recorded. This information should be readily available and learning should be taken from them.
Care home to do list
E.g.

- Obtain bereavement leaflets to be available in the home
- Make a list of resident deaths over the past year and reflect on them in next staff meeting
4

Next steps
Remember

■ To use the top tips in the guide
■ To use the supporting documents
■ To use the notes section to make notes
■ To attend a local network and link to your GP, community matron, district nurse, facilitator, local hospice and local authority for support in managing end of life care. For further information about the networks in your area please visit the Skills for Care website.
  www.skillsforcare.org.uk/endoflifecareinyh

How to access the guide and its resources

If you are reading the guide in hard copy, all of the resources can be found on the accompanying memory stick.

An electronic version of the guide is available on our website.
  www.skillsforcare.org.uk/endoflifecareinyh

If you are reading the guide electronically, and are on an internet connected computer, you can click on a link and you will be taken directly to the relevant resource.

The resources are also available to download from the Skills for Care website.
  www.skillsforcare.org.uk/endoflifecareinyh

This guide is due for review in 2013.