NHS
South of England

Improving end of life care (EoLC) - a toolkit for care homes

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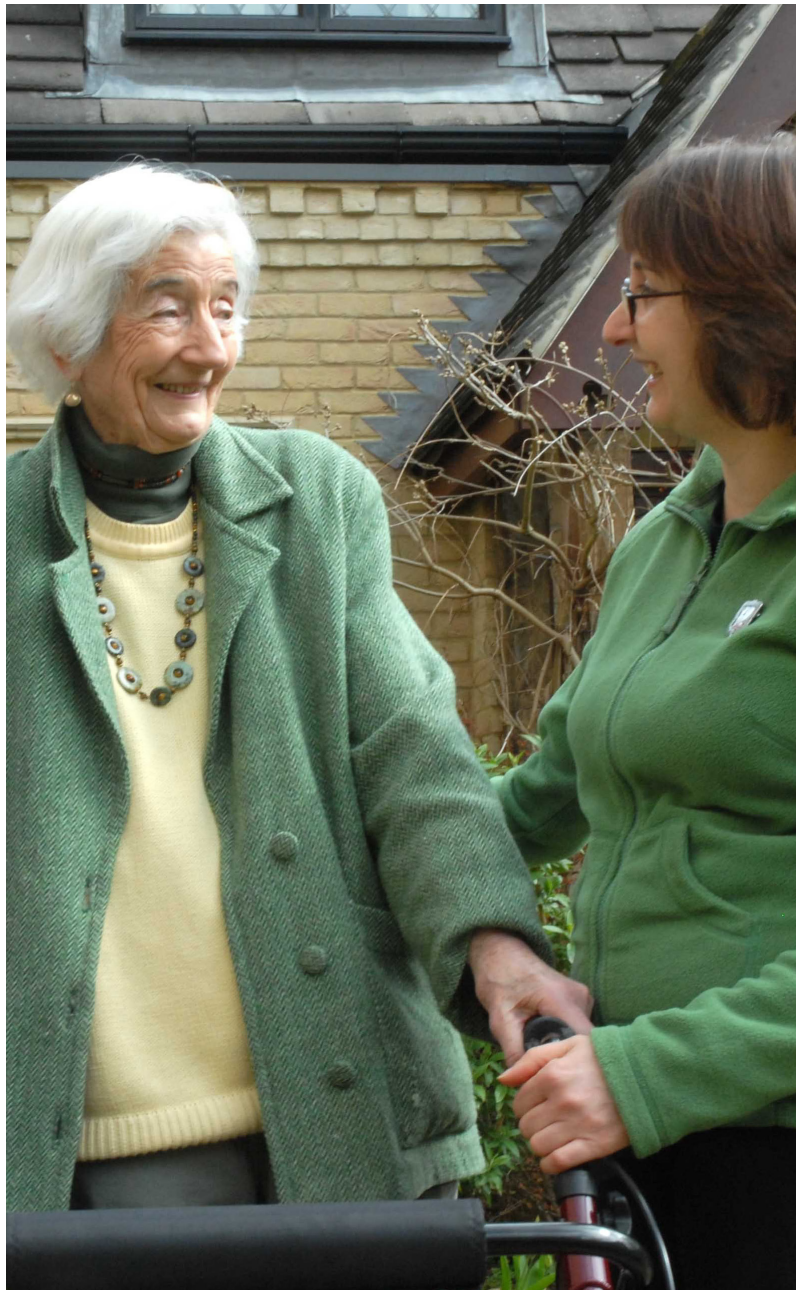

Background

This toolkit is designed for care homes to help you improve EoLC. It has been developed for, and piloted by care homes, so that it meets your needs. The toolkit covers all elements, from developing an organisational approach and EoLC Strategy to practical tips on day to day care and the support available to help you with this. The toolkit focuses on the four priority areas in the NHS South of England EoLC Programme for achieving quality and cost effective EoLC and the sustainability of this quality beyond the life of the Programme:

- Early identification of people nearing the end of life (Would I be surprised if this person died in the next year?)
- Registration/communication of this across sectors and settings;
- EoLC assessment/care planning and advance care planning;
- Enhanced community care services and
- The establishment of an organisational infrastructure to sustain the development of end of life care with the changes in the NHS.

Support is provided for you by The Care Homes Project which has developed this toolkit and is focused on developing the workforce to address the above priority areas within Care Homes and Social Care.

Therefore the aim of this toolkit is to provide a range of resources that will support care homes with their EoLC delivery, help them to meet many of their statutory and regulatory requirements and bring together good practice examples from across the NHS South of England EoLC programme.

Although specifically designed for care homes the toolkit will be relevant for all social care services including domiciliary care agencies and staff and extra care housing schemes.

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Introduction

This Tool Kit contains the steps that will help you implement an EoLC pathway in your Care Home. Then - this will lead you from an initial baseline of your existing EoLC and how to develop your organisation to enhance what you already do, onto a self-assessment tool to guide you through CQC Essential Standards of Quality and Safety.

The toolkit then provides you with some practical tools to help you assess and plan EoLC for residents and their family and also signposts you to additional support including training resources for your staff:

Step 1 How to develop an EoLC Pathway in a Care Home and includes a step by step guide for you to develop an organisational approach to the way you provide EoLC for your residents and their families.

Step 2 A Practical Guide for achieving (EoLC) Compliance and Quality Monitoring-and includes a series of prompts against which you can assess your EoLC services and also offers you some potential solutions to help you.

Step 3 Practical Tools to help you care for your residents and their families. This includes:

» **Improving EoLC for your residents** - Guidance for assessing your resident's needs ,asking the surprise question, developing an EoLC register, and how to use the coding system

» **EoLC triggers to help you decide when to do what for your residents** - practical guidance to test out EoLC triggers for example the surprise question and also provides a framework for developing End of Life Care knowledge and skills in the Care Home.

» **Think! When calling for Assistance Tool** - has been developed to support Care Home staff decisions when considering calling 999/GPs/Out of Hours Services.

» **Anticipatory Care for Chest Infections/ Urinary Tract Infections flow charts.** (Draft) Simple and easy to use guidelines to help staff to both manage and respond to symptoms and who to contact for additional care and support.

» **Medical Care Plan Summary for Care Homes** - This has been designed to go in the front of a resident's care home record, with core information for example,advance care planning decisions, and anticipatory care plans. A copy of which could accompany a resident on a hospital trip/ admission.

» **After Death Review**
This is a practical tool that can be used with staff to reflect on any death or any unplanned admission to hospital in the last year of life.

Step 4 Signposting to additional resources Training in EoLC is being rolled out across NHS South of England and details can be found on www.southofengland.nhs.uk/end-of-life-care .

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Benefits to your organisation

- Enhances the quality of EoLC that you offer to your residents and therefore the support you can offer their family and friends
- Earlier identification of residents coming to the end of their life will help you and your staff to plan care more proactively and effectively. This will include your residents with Dementia and Frailty
- Reduction of number of unplanned hospital admissions in the last year of life and increase in residents being able to die with you in their home
- Review of your internal processes to support an EoLC Pathway for example the development of policies, procedures and EoLC registers.
- Signposting to EoLC resources and support for staff
- Ensuring your staff are able to access all of the EoLC education that is available, much of which can be delivered within your care home
- Strengthen relationships with your GPs, commissioners, and external stakeholders.

- Ensures care homes are included within local EoLC and QIPPS plans
- Will help you to meet EoLC contractual obligations with Local Authorities
- Make you more competitive in the market place when tendering for EoLC services.
- Provide evidence for the - CQC Essential Standards of Quality and Safety
- Will support you to meet the EoLC Quality Markers for Care Homes
- Become part of a wider End of Life Network, by linking in with other Care Homes, EoLC leads and groups etc.
- Sustainable model for organisational development that can be shared as best practice with other Care Homes.

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Step 1 How to develop an EoLC Pathway in a care home

The Care Home project has developed the following programme to help you to develop an organisational approach to the EoLC you deliver. This includes how to organise your internal processes for EoLC, for example the development of documentation to support an EoLC pathway and formalising your relationships/processes with external stakeholders, for example building links GPs and commissioners Local Authority EoLC leads, this might take the form of tendering for EoLC beds or meeting CQC requirements (Step 2 of the toolkit will help you with this).

In addition, care homes in the future will have contractual obligations with their Local Authorities to meet end of life care outcomes and this organisational programme will help you achieve this.

Stage 1

This involves collating some information to provide you with a baseline from which to work from.

For example

- How many residents die each year in your care home?
- How many residents die each year in hospital?
- How does the answer to the two questions above differ from your figures for last year or 5 years ago?
- What are the main disease groups amongst the residents?
- How many GP practices provide medical care to your residents?
- Is this service provided free of charge?
- How do you think your services address EoLC needs? And what are some of the challenges?
- How do you identify those residents who are nearing the end of their lives?
- How do you as an organisation communicate this to other agencies?
- Do you and your staff feel confident having EoLC discussions at this point?
  - With the resident /
  - With their family / carers
- Do you and your staff feel competent to assess someone's needs including those around end of life?
- Do all your residents have up-to-date care or support plans including care at the end of life?
- Do you talk with your residents about their EoLC wishes and preferences?
- Is this documented on an Advance Care Plan for all to access?
- Do you use any other EoLC tools?
- Do you know who else in your area delivers EoLC?
- What links do you have with these including social care, primary care, Specialist Palliative Care/ hospices for example a link Macmillan Nurse?
- Do you know what the priorities of your commissioners are, whether there is an overall EoLC strategy/pathway and how care homes fit into these?

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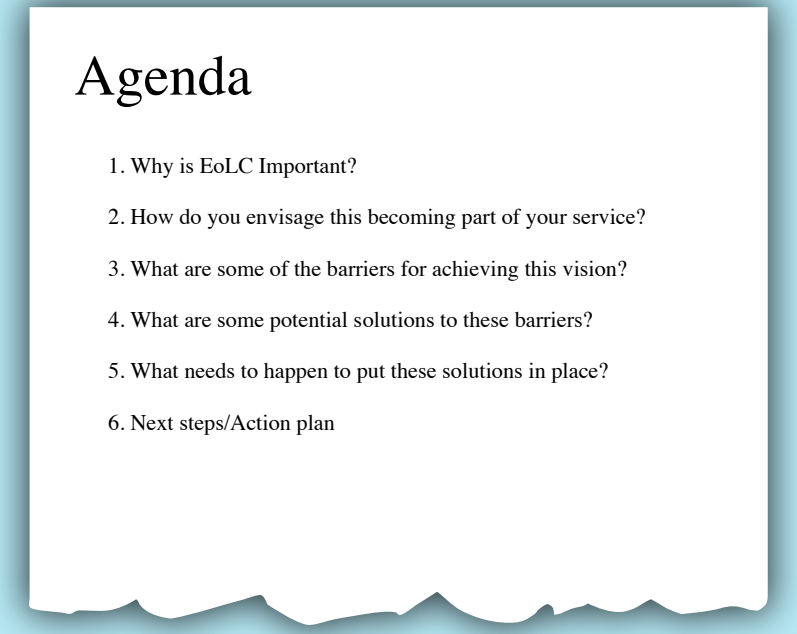
- Do you know who your local EoLC leads are? In the primary care trust? In the local authority? In the strategic health authority?
- Have you formed links with these?
- Do you have an EoLC practice educator/ facilitator supporting your organisation/Care Home?
- What training and resources are available within the Care Home to support staff to deliver EoLC?
- Embedding EoLC throughout your organisation / care home often involves a culture change. How can this be enhanced within your service?

Stage 2

The ideal is, with board [Senior/Operational Management] agreement to ensure organisational commitment, for the next stage to involve all home managers in a workshop to explore all of these aspects in a more personalized and detailed way.

If your Care Home is a smaller home do not be put off, the most important aspect is that the organisation as a whole signs up and is committed to this stage. An example agenda [**see below**] for this meeting could include, (you might want contact your local EoLC Lead or Practice Educator who would be willing to help you to facilitate the workshop).



Agenda

1. Why is EoLC Important?
2. How do you envisage this becoming part of your service?
3. What are some of the barriers for achieving this vision?
4. What are some potential solutions to these barriers?
5. What needs to happen to put these solutions in place?
6. Next steps/Action plan

Example agenda items

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Stage 3

This will be largely dependent on the above two steps but the emphasis should always be on you now developing an overall strategy. This could form part of your overall business plan and could require an outline proposal led by the care home / housing lead to the Senior management / operational to ensure their commitment and financial resource.

Following on from this a process should be determined of how to improve EoLC depending on the resources available. In care homes this probably means allocating lead responsibility within each home to either the manager or deputy. (Step 2 of the toolkit will help you on this aspect)

You may then decide you would like resource packs in each home these resource packs should be comprehensive and include the organisations policies and procedures for each aspect of EoLC (Steps 3 and 4 of the toolkit contains some useful resources that you might want to include). They should also be tailored by the organization so they reflect local aspects and also contain local contact details.

When a resource pack is introduced into either a chain or individual care home it must always be accompanied by at least one training session to help embed it. Extra training sessions can then be accessed to address particular training needs for example communication/ end of life care discussions (Details of free Training in EoLC that is being rolled out across NHS South of England can found in step 4 of the toolkit).

Models for the best way to help care homes/ housing improve EoLC through training are included in Building on Firm Foundations (NCPC 2007). One model may be training the lead in each home who is then responsible for cascade training.

Good practice would involve some basic EoLC training to be included in induction with the more extensive training carried out later at possibly 6 months post starting. It will also be important in any organisational strategy to include a regular review and update process. This ideally would be annually with an update session to the manager's conference at which time the strategy and any resources can be reviewed.

So that homes and housing learn from any deaths they should be encouraged to carry out reflective post death reviews, involving all staff discussing what went well and what didn't. An example to help you with this is provided in Step 3. Step 3 of the toolkit also includes a framework for reflecting on the identification of the EoLC Triggers. For a more formal process you could also, if using the Gold Standards Framework, buy into the After Death Analysis or if using the Liverpool Care Pathway, the National Care of the Dying Audit is likely to soon cover care homes.

It should be acknowledged that any tools including the EoLC programme tools can be very helpful to care homes and however these are only tools so need to sit within the overall context of an organisational and workforce development strategy.

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Stage 4

Monitoring of the impact of the organisational development programme will be important; one way may be to monitor the choice of place of death versus the actual place of death to see if there is a decrease in your residents being transferred to hospital or hospice to die. Ideally EoLC and improvements in this should be monitored at least annually at Board level. To monitor quality there should also be built in monitoring of the EoLC pathway and this is included in step 2 of the toolkit for example –

- Were there EoLC discussions held and documented?
- Was a comprehensive individual needs assessment carried out at key points of the pathway i.e. on recognition of end of life?
- Was a care plan in place which included EoLC?
- Were the person's wishes for their future care recorded?
- Is there evidence that all of the stages were documented and shared with the appropriate staff both 1) within the home/ 2) with external staff such as primary care?
- Was there evidence that the carer's needs and wishes had been assessed and a care plan developed?
- Was there evidence that staff had completed training and achieved an agreed level of competence?

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STEP 2

Prompts for (EoLC) Compliance and Quality Monitoring

The aim of Step 2 is to provide a range of prompts against which you can undertake a self assessment on the End of Life Care you provide in your Care Home. This step is not designed to be used as a checklist, but to promote discussion and also offers some potential solutions. The prompts will help you meet many of your statutory and regulatory requirements as per CQC Essential Standards of Quality and Safety.

Prompt	Key questions	Potential solutions
Does your Care Home/ Organisation have an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT	▶ Do you know who your local PCT/CCG End of Life Lead is and if there a locality plan in place? ▶ Do you have access to the locality plan? ▶ Do you know where your local specialist palliative care team are based?	▶ Links to Step 1 How to develop an End of Life Care Pathway in a Care Home. ▶ Availability of an action plan for end of life care ▶ Gold Standards Framework or equivalent in place ▶ Liverpool Care Pathway or equivalent in place ▶ Regular contact with GP ▶ Access to specialist palliative care advice ▶ Relevance to CQC Essential Standards of Care Outcomes: **4, 16**

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Prompt	Key questions	Potential solutions
Have your staff received EoLC training in identification, communication and Advance Care Plan (ACP)? Do they feel confident in identifying people in the last year of life? Are there mechanisms in place to discuss, record and communicate the wishes and preferences of those approaching the end of life: ACP?	▶ Can you identify those in your care who are approaching the end of life? ▶ Have you noted triggers that might indicate it is an appropriate time for discussion? ▶ Are you certain you know whether a resident does or does not wish to have a conversation about their future care? ▶ Do staff feel confident in identifying people in the last year of life? ▶ Do you do Advance Care planning on admission? ▶ Do you tell the GP who needs to be on the register when the ACP is completed? ▶ Do all your residents achieve their preferred place of death? ▶ How confident are staff in having these types of conversation? ▶ Have your staff received EoLC training in identification, communication & ACP? ▶ Do they need additional communication skills training? ▶ Are these decisions routinely documented and if so, where are they kept? ▶ How are they shared with other agencies? ▶ Do you have an EoLC lead and do they link to the EoLC group and network?	▶ Signpost to NHS South of England Website - www.southofengland.nhs.uk/end-of-life-care ▶ Use of the Traffic Lights communication tool ▶ Link into the work undertaken by the NHS South of England Clinical Fellow on ACP/ and ACP discussions in Care Homes ▶ Consider accessing NHS South of England Communication skills training www.southofengland.nhs.uk/end-of-life-care ▶ Documentation of processes for assessing and recording preferences for end of life care. ▶ Audits of numbers of residents with written record of their preferences for end of life care, such as preferred priorities for care, advance care plans and advance decisions. ▶ Protocols for sharing information with other health and social care professionals. ▶ Relevance to CQC Essential Standards of Care Outcomes: **1, 2, 6, 21**

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Prompt	Key questions	Potential solutions
Residents' needs for end of life care are assessed and reviewed on an ongoing basis	▶ Are you routinely using the surprise question? ▶ Are residents needs regularly discussed, assessed, and reviewed? ▶ Is this information shared with the GP and if so how often? ▶ Do you have an end of life care register in place? ▶ Would staff feel confident enough to tell the GP which residents need to be on a register? ▶ Do staff feel confident in using a coding system or equivalent as a basis for reviewing residents? ▶ Are staff able to anticipate needs? ▶ Are staff confident with prompting DNACPR decisions with the GP? ▶ Do you feel happy to anticipate needs and liaise with GP/DN? ▶ Do you feel happy to contact OOH knowing the info to give?	▶ Use of the NHS South of England Care Home Project Improving End of Life Care for your residents/Traffic Light Framework - which can be found in Step 3: Practical tools ▶ Signpost to NHS South of England Website - **uDNACPR - ACP** www.southofengland.nhs.uk/end-of-life-care ▶ Use of the surprise question. ▶ Refer to Improving EoLC for your residents - guidance which can be found in Step3: Practical tools ▶ Signpost to www.goldstandardsframework.org.uk Prognostic indicators guidance. ▶ Written evidence of continuing assessment of changes as death approaches, including changes in the desired place of death. ▶ Documentation of processes to review residents needs, including evidence of written record of assessment and review. ▶ Relevance to CQC Essential Standards of Care Outcomes: **1, 2, 4, 5, 9**.

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Prompt	Key questions	Potential solutions
Nominated key worker, if required, for each resident approaching the end of life.	▶ Are staff able to take on this role? ▶ Can the Care Home support staff in this role? ▶ Is there a local EoLC network who could also provide support? ▶ What other support can you access locally? ▶ Do staff need help with developing audit skills?	▶ Identify a named person who is willing to take on the role as End of Life Care link Nurse/Champion. ▶ Link into any local link Nurse forums. ▶ Documentation that each resident has been offered an appropriate key worker. ▶ Audits of the proportion of residents approaching the end of life with a documented key worker. ▶ Relevance to CQC Essential Standards of Care Outcomes: **12, 13, 14**.
Residents who are dying are entered onto a care pathway	▶ Do staff have any knowledge about integrated care plans? ▶ Do you need additional training in the use of the Liverpool Care pathway(or equivalent)? ▶ Does your Care Home have good links with the DN team/GPs /Specialist palliative care teams?	▶ Signpost to Liverpool Care Pathway website. ▶ www.mcpcil.org.uk/liverpool-care-pathway ▶ Link into local hospice. ▶ Number/proportion of deceased residents for whom the Liverpool Care Pathway(or equivalent) was used. ▶ Relevance to CQC Essential Standards of Care Outcomes: **1, 2, 4, 5, 6, 9**.
Families and carers are involved in end of life care decisions to the extent that they and the resident wish.	▶ How are families involved in these discussions ▶ Are staff confident in having these discussions?	▶ Structured best interest discussions. ▶ Use of the Traffic Lights communication tool ▶ Link into the work undertaken by the NHS South of England Clinical Fellow on ACP/ and ACP discussions in Care Homes. ▶ Consider accessing NHS South of England Communication skills training. ▶ Signpost to www.southofengland.nhs.uk/end-of-life-care ACP ▶ www.southofengland.nhs.uk/end-of-life-care ▶ www.healthtalkonline.org ▶ Audits of the care records of deceased residents assessing involvement of families and carers in end of life. ▶ Documented processes for involving families and carers in end of life care decisions. ▶ Relevance to CQC Essential Standards of Care Outcomes: **1, 2, 4**.

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Prompt	Key questions	Potential solutions
The quality of end of life provided by the care home is audited	▶ Does your care home have an audit tool in place? ▶ Do you a have system in place for routinely reflecting on a death of a resident? ▶ Does this include relatives; are you using the National VOICEs survey? ▶ Do you report the outcome of your audits to external agencies for example locality End of Life Care groups/CCG etc?	▶ Documented processes to audit and review end of life care. ▶ Results of surveys or other assessments of residents views regarding the death-After Death Analysis. ▶ Consider using After Death Review which can be found in Step 3: Practical Tools ▶ Reports of audits/reviews. ▶ Audit of complaints and compliments regarding end of life care. ▶ Relevance to CQC Essential Standards of Care Outcomes: **16**.
Other Residents are supported following a death in our care homes.	▶ How do you communicate to other residents when someone in the Care Home dies? ▶ Is this an open process? ▶ Do you have an after death process review with all staff?	▶ Annual memorials. ▶ Memory books. ▶ Attendance at Funerals. ▶ Participating in funeral plans. ▶ Documented processes to support other residents following a death. ▶ Relevance to CQC Essential Standards of Care Outcomes: **4**

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Prompt	Key questions	Potential solutions

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 the workforce development (communication skills, assessment and advance care planning and symptom management) as they apply to end of life care.	▶ Are there systems in place to identify training needs of both the staff and the organisation as a whole?	▶ Annual appraisals/Personal development plans.
		▶ Documentation showing processes for determining training needs, and a training investment plan link to training needs analysis.
		▶ Training mapped against
		▶ Common Core Competences and Principles-National End of Life Care Programme / Department of Health / Skills for Care / Skills for Health.
		▶ Where possible, access training around
		  ▶ communication skills
		  ▶ assessment
		  ▶ care planning
		  ▶ advance care planning
		  ▶ symptom management
		  ▶ comfort and well being
		▶ Documentary evidence of workers who have received training, including refresher courses.
		▶ Relevance to CQC Essential Standards of Care Outcomes: **12, 13, 14**.

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.	▶ Are your staff confident in having these discussions ▶ What do they find particularly difficult	▶ Availability of training programmes for workers involved in discussing end of life issues with residents and carers. ▶ Documentary evidence of workers who have received such training. ▶ Relevance to CQC Essential Standards of Care Outcomes: **12, 13, 14**

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Prompt	Key questions	Potential solutions
Awareness of available end of life care training including training related to the Liverpool Care Pathway	▶ What available training are you able to access? ▶ Is this in house, or externally delivered?	▶ www.southofengland.nhs.uk/end-of-life-care ▶ Signpost to Liverpool Care Pathway website ▶ www.mcpcil.org.uk/liverpool-care-pathway ▶ Availability of educational programmes related to the introduction of the Liverpool Care Pathway or an equivalent. ▶ Documentary evidence of workers who have received such training ▶ Relevance to CQC Essential Standards of Care Outcomes: **12, 13, 14**
Processes are in place to review all transfers into and out of the care home approaching end of life.	▶ Does the Care Home have a clear process in place to support appropriate transfers at the end of life? ▶ Do you have a clearly defined Out of Hours policy and procedure in place? ▶ Do staff feel able to make a call to the Out of Hours service? ▶ Are staff confident in supporting residents in the Care Home when they are dying? ▶ What support from other agencies are in place locally?	▶ Use of the Clinical Fellows Think! Document and Critical Points Paper which can be found in Step 3 of the toolkit: Practical Tools ▶ Documentation of all residents who are appropriately transferred and admitted to hospital, with the date of transfer, the date of return to the care home and the date of death. ▶ Consider use of Medical Care Plan Summary for Care Homes which can be found in Step3: Pratical Tools ▶ Relevance to CQC Essential Standards of Care Outcomes: **16**

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STEP 3

Review of End of Life Care triggers in practice: Model for improvement

Overview

During the implementation phase of the Organisational Development Programme the Care Home Project Manager delivered training sessions for Care Home staff including the earlier identification of residents who may be in the last year of life. Several approaches were used to support staff in this identification and the training covered the use of the surprise question and an overview of the End of Life Care triggers.

These triggers are mentioned widely in End of Life Care literature and are integral to many of the recommended End of Life Care models/approaches to improving practice for example the Gold Standards Framework and the National End of Life Care Programme/The Route to Success.

Whilst staff generally found it relatively easy to identify many of the End of Life triggers it became clear during the training that both the accuracy of the documentation of End of Life care symptoms and the understanding of their relevance was not readily translated into everyday practice and the subsequent implementation of an End of Life Care Pathway.

However, at this stage this interpretation of what might be occurring in practice was largely anecdotal and had not been tested or validated. The Care Home Project Manager decided to use the Plan, Do, Study, Act (PDSA) cycle as a practical approach to enhancing organisational performance (see table one).

This model provides a framework for Developing, (End of Life Care knowledge and skills) Testing (validating End of Life triggers in practice) and Implementing changes to the way that things are done that will lead to improvement(earlier identification of End of life Care triggers more effective management End of Life Care symptoms). Table 2 is an adapted approach to the use of the PDSA cycle within the Care Home Project.

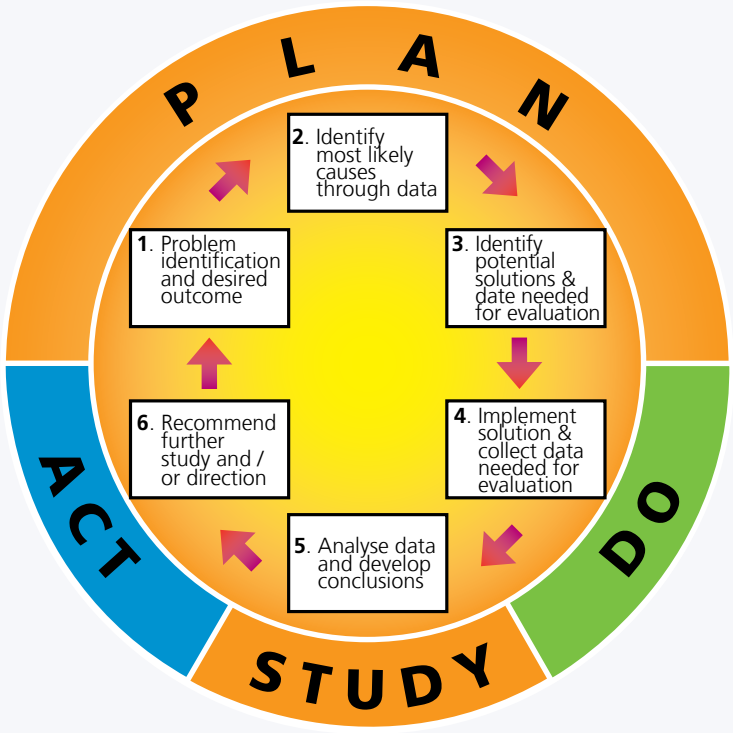

Table 2: PDSA Care Home Project adapted model

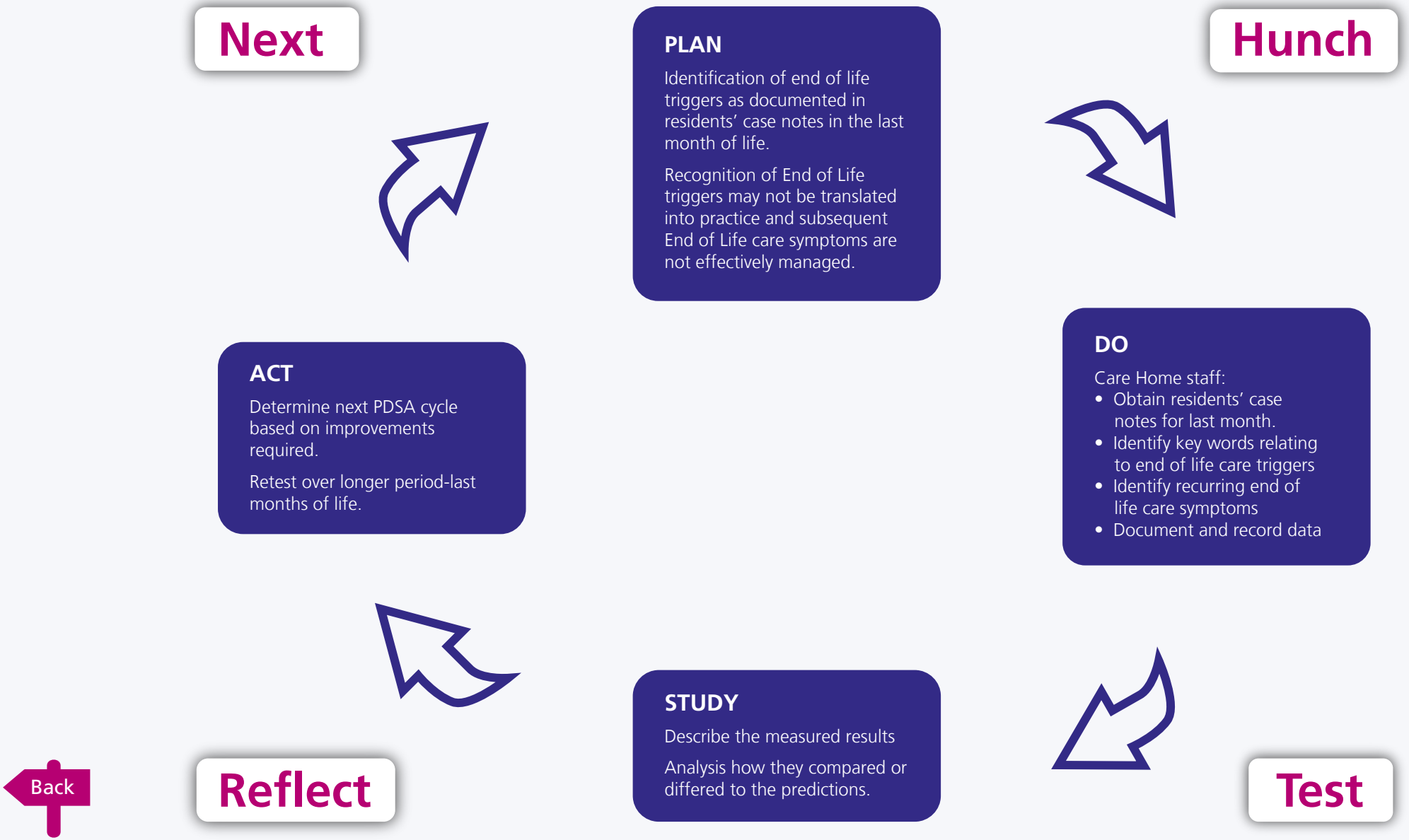

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Table 3

Clinical indicators that a resident with frailty and dementia are approaching the end stages of their disease process

The surprise question

- Would you be surprised if this resident were to die in the next 12 months? If you would not be surprised, then measures might be taken to improve their quality of life now and in preparation for the dying stage.

Frailty

- Multiple co-morbidities with signs of impairment in day to day functioning
- Deteriorating functional score
- Combination of at least three symptoms of: weakness, slow walking speed, low physical activity, reduced weight loss, self reported exhaustion

Dementia

- Unable to walk without assistance, and
- Urinary incontinence, and
- No consistently meaningful verbal communication, and
- Unable to dress without assistance
- Bartel Score < 3
- Reduced ability to perform activities of living

Plus any one of the following

- 10% weight loss in previous 6 months without other causes, urinary tract infections
- Severe pressure ulcers
- Recurrent fevers/high temperatures
- Reduced oral intake/weight loss
- Aspiration pneumonia.

Taken from the Gold Standards Framework (2008)

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Medical Care Plan Summary for Care Homes

This has been designed to go in the front of a resident's care home record, with core information for example,advance care planning decisions, and anticipatory care plans. A copy of which could accompany a resident on a hospital trip/admission.

Medical Care Plan Summary for Care Homes

Personal Information

Resident Details		GP Details	
Name		GP Name	
Care Home		Practice Name	Code
Address		Address	
Postcode		Postcode	
Tel		Tel	
NHS No		Community Nurse Name	
DoB		Tel	Mobile
First language		Community Nurse Name	
Spiritual beliefs		Tel	Mobile

Next of kin		Tel	Mobile	Lasting Power of Attorney for Welfare held?
Name 1.	Relationship			YES / NO
Name 2.	Relationship			YES / NO

Active medical conditions

Significant past medical history

Allergies

DOLS (Deprivation of Liberty Safeguards) held?	YES / NO	Assessment Date

Brief details

Advance Care Planning

DNACPR (Do Not Attempt CPR) form held?	YES / NO	Date
ADRT (Advance Decision to Refuse Treatment) form held?	YES / NO	Date

Brief details

Preferred place of care

Other wishes to be taken into consideration

Anticipatory Care Planning

Potential problem	Management plan

Document Review

To be reviewed: DNACPR, ADRT, Advance Care Plan

Date	Staff name	Signature	Document details

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Improving End of Life Care for your residents

Guidance for assessing your residents needs and developing an End of Life Care register

Many of your residents will be within the last year of life, by identifying them early on and making sure they are on a register you can make sure that they have the appropriate care plan and improve the quality and co-ordination of care they receive, enabling them to die in their preferred place.

'Would you be surprised if this resident were to die or be alive within the next 12 months'?

Predicting when someone is in their last year of life is not an exact science particularly in Care Homes where residents can have complex problems and needs. However, there are considerable benefits in doing so, for example regular review meetings, more effective ways of working with the GP to ensure that everything is in place in anticipation so there are fewer crisis and unplanned events/hospital admission. It also provides an opportunity to discuss the resident's wishes and preferences to ensure that best care is delivered, and enables access to the services they need at this time.

Ask yourself 'Would you be surprised if this resident were to die or be alive within the next 12 months'? This has been found to be 75% accurate. Once the answer is no the resident should be entered on to the end of life care register.

If no enter your resident onto the End of Life Care Register

The register uses a coding system to group residents according to life expectancy so appropriate end of life care can be delivered and tailored to individual needs which will differ depending on their prognosis. This system uses a traffic light system, from green (stable), potential breakdown (amber) to unstable or the resident is in the dying phase.

See example below:

The decision about how to code a particular resident should result from a discussion between care home staff, the residents GP and any other relevant health and social professionals to ensure that all information related to life expectancy is shared to enable effective and appropriate care planning and advance care planning. The resident should also be on the GPs End of Life Care register.

Once you have entered your resident on the register, health staff will support and work with you to assess their needs, develop their care plan and help them to advance care plan (express their wishes)

The End of Life Care Register therefore needs to be reviewed regularly (monthly is the suggested minimum frequency) to check whether there have been any changes that will affect their coding which should then be adjusted accordingly. (It is quite common for residents' to fluctuate between coding categories and they do not necessarily occur sequentially).

Additional Information is available to help you, this includes free communication and advance care planning skills training, practice educators to work with you in the home and a care homes project to support you. Details can be found by clicking here.

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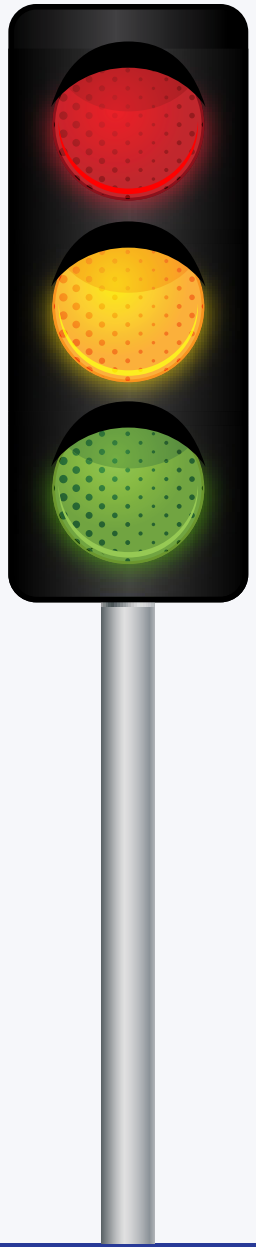
End of Life Care “Traffic Light” framework



Resident identified as having End of Life Care but currently stable

Prompts

- Would you be surprised if the resident were to die within the next 12 months? (surprise question)
- Entering resident on the homes EoLC register and alerting the GP so they can be entered on their EoLC register
- Residents receive an assessment and care plan review
- DNACPR completed where appropriate
- Assessing needs of carers

Resident’s needs are changing or condition slowly deteriorating

Prompts

- End of Life Care assessment
- Agreed care plan
- DNACPR completed where appropriate
- Revisit ACP
- Consider financial assessment
- Alert GP and ensure their register alerts out of hours
- Request anticipatory medications where appropriate

Resident condition is rapidly changing or deteriorating identified as being in the dying phase

Prompts

- Regular discussions with GP and other health and social professionals
- Weekly review of EoLC register, coding and needs for example symptom management, psychological care and alert GP to any changes for the EoLC register
- Revisit ACP to include review of wishes and preferences for example place of death, organ donation, resuscitation
- Appropriate medication and equipment in place
- Involve the wider team for example the specialist nurses
- Consider the use of the Liverpool Care Pathway in last 72 hours
- Consider bereavement needs of family or relatives and staff
- Assess needs of carers

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Care Home Admission Guidance When Choosing 999, GP, or Out of Hours Services

This is only guidance; if in doubt use your own professional judgement when referring for assistance

THINK..... When calling for assistance

WHAT CAN THE HOSPITAL DO THAT THE CARE HOME CAN'T?

Do you REALLY need to call 999?

YES

Is there a valid uDNACPR (lilac form) in place?

NO → **CALL 999** if you believe this is an Emergency Situation

Commence CPR if NOT Breathing and **NO** uDNACPR

(As Per Your Organisations Resuscitation Guidance)

YES

Is your resident for active treatment?

YES →

NO

Include the details below when making the request for assistance

NO / NOT SURE

Is there a change in your residents condition you are concerned about?

YES

Call GP / OOH / 111 for advice and give these details

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Call GP / OOH / 111
to request visit or advice

Include the details below when making the request for assistance

Your name and location - including postcode

Residents personal details

Explain symptoms and change in condition

Diagnosis

If your resident on a supportive care register –

- 6 - 12 months to live - stable
- Weeks to live - unstable
- Days to live - daily deterioration

Advance care plan and/or ADRT in place

Anticipatory drugs in place

If resident on the integrated care pathway for the dying

What do you need from the service you are calling?

What to do next?

Support Resident

Give Anticipatory Drugs if Prescribed

Complete Admission Form if Needed

Advise Next Of Kin

Advise GP and other HCP's of Admission or Change

Discuss with Resident Future Wishes for Care (ACP) if not completed previously

Glossary

ADRT – Advance Decision to Refuse Treatment
CPR – Cardio Pulmonary Resuscitation
uDNACPR – unified Do Not Attempt CPR
OOH – Out of Hours
HCP – Health Care Professional
ACP – Advance Care Plan

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Do you suspect your resident has a chest infection?

YES

Refer for nurse assessment

Nurse Assessment

Has the patient got a temperature ≥ 37.9°c?

Does the patient have productive coloured sputum?

Is the patient showing signs of cyanosis?

YES TO ANY OF THE ABOVE

Has patient a history of COPD / Asthma?

Check allergy status

Contact GP to report suspected chest infection and discuss need for antibiotics + steroids if appropriate

If agreed initiate commencement of antibiotics and/or steroids as directed

Advise staff to contact GP if deterioration occurs before planned review

To be reviewed by GP / Key Worker in next 48 – 72 hours

NO

Do you still have urgent concerns about this patient?

YES

Contact your GP for visit

NO

Review in 24 hours and discuss with GP / key worker when possible

Does your resident have any of the following:

New cough or increase of usual cough

Increased sputum

Shortness of breath and cough

NO

Continue to monitor resident

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Do you suspect your resident has a urinary tract infection

YES

Refer for nurse assessment

Nurse Assessment

Has the patient got a temperature ≥ 37.9°c?

Does the resident have abdominal pain / loin pain?

Is urine positive on dipstick test?

Is there obvious new confusion?

Is the urine offensive smelling?

Is there incontinence / frequency?

Is there blood in urine?

YES TO ANY 2 OF THE ABOVE

Does your resident have any of the following:

Burning pain when passing urine

Blood in their urine

Increased incontinence

Increased frequency of passing urine

NO

NO

Do you still have urgent concerns about this patient?

YES

NO

Check allergy status

Contact GP / OOHs to report suspected UTI

If GP agrees to initiate commencement of antibiotics

Commence fluid balance chart

Encourage oral fluids as tolerated

Inform Key Worker and GP as soon as available

Advise care home staff to contact GP / OOHs if deterioration before review

Review from GP / Key Worker in 72 hours maximum

Continue to monitor for signs

Increase fluid intake

Refer to GP

Review in 24 hours and discuss with GP / key worker when possible

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After death review

This can help to improve your practice and to evidence this. However as with everything it is important this works for you so do adapt it to your local situation perhaps as a whole group so you all feel it makes sense for your service. Ideally you should all sit down following a death, ideally within a week, to discuss the post death review. Remember that all staff are affected by the death of a resident so this should include all who wish to attend including cleaners, catering staff etc. The experiences of family/carers can really help in this process so you may need to feed in the thoughts from the family/carers or they may wish to attend. This is very individual to the family/carer and home and situation so each time should be considered individually.

Post death review template

One of the best ways to improve the end of life care you provide is to sit down after a death and discuss what went well and what didn't go so well. This helps all of you to learn but also to reflect on the death's impact on yourself and your colleagues.

There is no hard and fast way to do this but below are some suggestions including a template of questions:

- However you choose to do this it is important you involve all of your colleagues, not just care staff, but also cleaners, cooks etc. who may have been directly affected.
- People who are not able to be involved in a face to face meeting still need to benefit so someone should be tasked with taking notes and documenting any actions arising as a result of the post death review. This should be circulated to all and can be kept to show how care is improving.
- It is important to hold the meeting shortly after the death as otherwise memory fades. Ideally this should be within a week.
- It is important to try to gain feedback from family/carers as to how they felt the death was managed and to feed this into the post death review.
- Sometimes it can be even more beneficial to involve staff that were involved in the care from outside your service for example, Macmillan nurse, GP, district nurse. This is when you can gain the most learning.

Possible questions to reflect on:

1. Were the resident's wishes for future care (including where she wanted to be cared for i.e. stay in her care home) recorded?
2. Were these wishes achieved?
3. Was the resident fully aware of what was happening, were end of life care discussions held?
4. Was a comprehensive individual needs assessment carried out?
5. Was a care plan in place which included end of life care?
6. Is there evidence that all of the stages were documented and shared with the appropriate staff both within the home/housing, and with external staff such as primary care?
7. Was there evidence that the carer's needs and wishes had been assessed and a care plan developed?
8. Consider the overall dying process – what do you think went well?
9. What could be improved?
10. What would you do differently next time?
11. How are you going to make sure improvements happen within the home/housing?
12. How are you going to make sure this is shared with the rest of your organisation?

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Step 4 Signposting to additional resources

- Training in EoLC is being rolled out across NHS South of England and details can be found on www.southofengland.nhs.uk/end-of-life-care
- For information on the national work in support of the EoLC Strategy and additional resources including EoLC E-Learning visit: www.endoflifecareforadults.nhs.uk
- End of Life Care Learning Resource Pack: Information and resources for housing, care and support staff in extra care housing can be found at www.housing21.co.uk
- Resources for people who work with adults approaching end of life including people with Dementia can be found at www.scie.org.uk/endoflifecare
- Raising awareness of dying death, and bereavement for the public and Health and Social care staff can be at www.dyingmatters.org

Also, you will have many local resources that can guide you as well providing support for example local bereavement services, EoLC groups, local libraries, carers groups etc.

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