UNIT 307:
Understand how to support individuals during the last days of life

Learner’s Workbook
Learning Activities
Acknowledgements

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In the course of developing these materials they have drawn on the resources available through the National End of Life Care Programme, Social Care Institute for Excellence, Help the Hospices, e-ELCA and others.

Skills for Care wishes also to thank all those individuals and organisations that supported the external consultation. All sources have been acknowledged and references have been cited at the point of contribution.

This unit of learning has been developed and written by

Judith Talbot.
BSc. (Hons.); RGN; PGCert. Ed.
St Luke’s Hospice Plymouth

Edited by

Jane Kellas
Director
Venus Training and Consultancy Limited

Katherine Kelleher
Director
Aspira Consultancy

Externally reviewed by

Geraldine Clay.
MSc; BA(Ed); RGN; RHV; RNT
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### Table 1: Learning Outcomes and Assessment Methods

**EOL 307: Understand how to support individuals during the last days of life**

**Unit level 3**
**Credit value 3**
**Study/activity Hours 28**

**Unit aim** The purpose of this unit is to assess the learner’s knowledge and understanding of how to support individuals during the last days of life.

<table>
<thead>
<tr>
<th>Learning outcomes</th>
<th>Assessment criteria</th>
<th>Own evidence log (optional)</th>
<th>Assessment Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Understand common features of support during last days of life</td>
<td>1.1 Describe the common signs of approaching death</td>
<td></td>
<td>Knowledge</td>
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<td></td>
<td>1.2 Define the circumstances when life-prolonging treatment can be stopped or withheld</td>
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<td>Knowledge</td>
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<td></td>
<td>1.3 Analyse the importance of any advance care plan in the last days of life</td>
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<td>Knowledge</td>
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<td></td>
<td>1.4 Identify the signs that death has occurred</td>
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<td>Knowledge</td>
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<tr>
<td>2. Understand the impact of the last days of life on the individual and others</td>
<td>2.1 Describe the possible psychological aspects of the dying phase for the individual and others</td>
<td></td>
<td>Knowledge</td>
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<tr>
<td></td>
<td>2.2 Explain the impact of the last days of life on the relationships between individuals and others</td>
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<td></td>
<td>2.3 Outline possible changing needs of the individual during the last days of life</td>
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<td>Knowledge</td>
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<td>Learning outcomes</td>
<td>Assessment criteria</td>
<td>Own evidence log (optional)</td>
<td>Assessment Type</td>
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<td>The learner will:</td>
<td>The learner can:</td>
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<td>3. Know how to support individuals and others during the last days of life</td>
<td>3.1 Describe a range of ways to enhance an individual's wellbeing during the last days of life</td>
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<td></td>
<td>3.2 Explain the importance of working in partnership with key people to support the individual's wellbeing during the last days of life</td>
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<td>3.3 Describe how to use an integrated care pathway according to agreed ways of working</td>
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<td>3.4 Define key information about the process following death that should be made available to appropriate people according to agreed ways of working</td>
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<td>4. Understand the actions to be taken following an individual’s death</td>
<td>4.1 Explain national guidelines, local policies and procedures relating to care after death</td>
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<td>4.2 Explain the importance of being knowledgeable about an individual’s wishes for their after death care</td>
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<td>4.3 Explain the importance of acting in ways that respect the individual’s wishes immediately after death</td>
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<td>4.4 Describe agreed ways of working relating to prevention and control of infection when caring for and transferring a deceased person</td>
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<td>4.5 Describe ways to support others immediately following the death of a close relative or friend</td>
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<td>Knowledge</td>
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<td>5. Know how to manage own feelings in relation to an individual’s dying or death</td>
<td>5.1 Define possible impact of an individual’s death on own feelings</td>
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<td>Knowledge</td>
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<tr>
<td></td>
<td>5.2 Identify available support systems to manage own feelings in relation to an individual’s death</td>
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<td>Knowledge</td>
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Section 1: Introduction to EOL Unit 307

General Introduction

Over half a million people die in the United Kingdom each year (Department of Health, 2008). In the majority of cases, individuals will be recognised as being in the last days of life. The National End of Life Care Strategy (2008) identified the necessity for those who are involved in delivering care during the last few days of life to receive appropriate training. This helps to ensure the ultimate goal of ensuring a ‘good death’ is achieved. The 307 unit allows you to develop your understanding and knowledge of care and support for individuals and their relatives or close friends in the last days of life. It will assist you to identify when an individual is entering the last days of life and how you may contribute to appropriate care as part of the wider team.

Learning Support

Due to the sensitive nature of End of Life (EOL) care, sometimes learners can become upset whilst completing the learning activity. For example you may be asked to consider your thoughts about your own death, or watch video clips that include the views of people who are actually dying.

At your introductory session your tutor/assessor will ask you to complete a support agreement which will identify what you should do if you should become upset whilst undertaking any of the following learning activities.

- **Lone study** – The tutor/assessor will ask you to identify support networks (these could be friends, family, colleagues) if you should become upset.
- **One to one** – The tutor/assessor will ask how you would like to be supported by your tutor/assessor should you become upset.
- **Work based learning** - The tutor/assessor will ask you to identify a mentor/or supervisor to whom you could go if you became upset at work
- **Classroom based learning** - The tutor/assessor will ask how you would like to be supported should you become upset during classroom sessions. The tutor/assessor will not be able to leave the rest of the class, so you may wish to nominate a classroom buddy who could leave the classroom with you or identify a quiet place where you can go to be alone and have a cup of tea. This will be your decision and based on the facilities available.

Providing good EOL care can be one of the most rewarding caring experiences you can have. It is a privilege to know that you have cared for someone as they have taken their last breath in the world and that you have been part of their end of life journey. It is often a comfort to know that you have helped someone meet their EOL wishes and they have had a comfortable, dignified death. How you care for someone at end of life can remain with relatives and loved ones for a long time and you only have one chance to get it right. This is a big responsibility and so it is really important that you take the learning activities seriously and that you also ensure that you learn at your own pace, to fully reflect and absorb the new EOL knowledge and skills you will be developing throughout this unit.
Learning Activities

As everybody has different ways of learning new information, this workbook contains a range of learning activities, which will assist you in meeting the learning outcomes for the unit. Table 2 shows you the type of activities you may be asked to complete.

Table 2: Type of learning activities and symbols

<table>
<thead>
<tr>
<th>Activity Symbol</th>
<th>Explanation</th>
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<tbody>
<tr>
<td><img src="image" alt="Internet Icon" /></td>
<td>This symbol means you will need to access the internet *</td>
</tr>
<tr>
<td><img src="image" alt="Reading Icon" /></td>
<td>This symbol means you will be reading something</td>
</tr>
<tr>
<td><img src="image" alt="Speech Icon" /></td>
<td>This symbol means you will be asked to talk about something with friends, colleagues, your tutor or assessor</td>
</tr>
<tr>
<td><img src="image" alt="Thinking Icon" /></td>
<td>This symbol means you will be asked to think about something and you may be required to write your thoughts down</td>
</tr>
<tr>
<td><img src="image" alt="Video Icon" /></td>
<td>This symbol means you will be asked to watch a clip from a movie, TV programme or from the Internet e.g. youtube film clip *</td>
</tr>
<tr>
<td><img src="image" alt="Writing Icon" /></td>
<td>This symbol means you will be asked to write something in a workbook or a worksheet or even provide examples of your work with a service user e.g. a plan you have written</td>
</tr>
<tr>
<td><img src="image" alt="Information Icon" /></td>
<td>This symbol means you will be asked to research some information. This might be through the internet, books and articles or from talking to people you know</td>
</tr>
<tr>
<td><img src="image" alt="Assessor Icon" /></td>
<td>This symbol means your assessor will plan to conduct an observation of your practice or will examine a work product.</td>
</tr>
</tbody>
</table>

* Although every effort has been made to ensure video clips are appropriate, as they are often freely available to all, we cannot be held accountable for any inappropriate comments made about the clips. If you should see something offensive please following the offensive reporting guidelines of the web site concerned.
For each activity you will see a clock symbol, which will provide you with a guide to how long the activity could take you. Remember this is a guide and the activity may not take as long as it says!

Each activity will signpost you to a range of resources to support your learning and where appropriate learning materials will be provided e.g. an information leaflet or a section of a website for you to read.

As you complete the activities in each section, it will be important for you to log your evidence in the relevant evidence log that your awarding body has provided for you. You can see which learning outcomes each activity covers by the table at the top - below is an example; the learning outcome shaded in green is the one you have covered when you successfully complete the activity. Your tutor/assessor will support you to complete the activity, if you don't succeed at first they will give you further support to get it right!

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<tr>
<th>1.1</th>
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<td>4.1</td>
<td>4.2</td>
<td>4.3</td>
<td>4.4</td>
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<tr>
<td>5.1</td>
<td>5.2</td>
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</tbody>
</table>

Table 1 (page 4) shows you what learning outcomes you will have to achieve to pass this unit and what the assessment criteria will be. The table also identifies whether it is a skill or knowledge competency.

The table also provides you with an optional ‘own evidence log’. This is so you can keep your own learning log and can discuss your learning and evidence with your tutor and/or your assessor. Keeping your own learning log can be a useful tool to help you keep track of your learning and progress. At the end of each activity you will be reminded to complete the evidence log.

Each section will outline the activity and provide guidance on how to do the activity. Look for this symbol to help you with ideas and suggestions on completing the activity.

**Plagiarism and Confidentiality**

Plagiarism relates to claiming work to be your own when it is not. All work submitted must be your own and not copied from anyone or anywhere else unless the source of the information has been clearly referenced.

Confidentiality is essential in all aspects of care and that includes during your learning. You may be asked to reflect upon aspects of your role and people for whom you provide end of life care but it is very important that you do not disclose any personal information about them. You must also be very careful not to include any evidence that relates to them in your portfolio e.g. photographs or documents with their details on.
**Portfolio of Evidence**

It is recommended you keep a folder to record all the evidence you collect for this unit. This will be your portfolio, which demonstrates your understanding on the subject and will help your tutor/assessor ensure you are meeting the learning outcomes.

**End of Life Care for All (e-ELCA)**

End of Life Care for All (e-ELCA) is an e-learning platform from the Department of Health and e-Learning for Healthcare (e-LfH) in partnership with the Association for Palliative Medicine of Great Britain and Ireland to support the implementation of the Department of Health's National End of Life Care Strategy (July 2008).

The e-learning platform is aimed at health and social care staff working in end of life care. The e-learning enhances the training and education of these staff, increasing their confidence and competence to ensure well informed, high quality care is delivered to people at the end of their life.

There are over 150 highly interactive sessions of e-learning within e-ELCA. These are arranged in 4 core modules:

- Advance Care Planning
- Assessment
- Communications Skills
- Symptom Management, comfort and well being

Also, there are 3 additional modules in social care, bereavement and spirituality.

All of these sessions are freely available to NHS staff, social care staff who work in an organisation registered with the Skills for Care National Minimum Data Set (NMDS) or staff who work in a hospice. Staff who do not meet these criteria can register at a cost of £199.

There are twelve sessions which are freely available to everyone, including volunteers and clerical and administrative staff on an open access website: [www.endoflifecareforall.org.uk](http://www.endoflifecareforall.org.uk).

For further details see 'Access the e-learning'.

This is an additional resource and not mandatory for this unit as it may not be freely available to every learner.
Providing the right evidence
It is important that you provide the right type of evidence for the outcome you are trying to achieve. Remember there are 2 types of evidence:

a. Competence / Skill – This is where you need to demonstrate something about your practice.
b. Knowledge – This is where you need to demonstrate that you have learned and understood some new information.

Table 3 shows you the type of evidence that is acceptable for the type of outcome.

Table 3: Suitable Evidence

<table>
<thead>
<tr>
<th>Evidence methods</th>
<th>Explanation</th>
<th>Suitable for evidencing Competence</th>
<th>Suitable for evidencing Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct observation of you by assessor</td>
<td>You will be observed by your assessor carrying out your everyday work activities in your learning environment.</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Professional discussion</td>
<td>You will take part in a pre-planned and in-depth discussion with your assessor.</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Expert Witness evidence</td>
<td>An expert witness, such as a qualified professional, completes a testimony of your competence in the learning environment where it would not be possible for your assessor to observe.</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Work products</td>
<td>A work product is evidence used in your work setting and produced, or contributed to, by you. For example care plans, daily diaries, assessments.</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Reflective diary</td>
<td>An on-going record of events produced by you that take place relating to your work, including evaluation and reflection.</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Reflective statement</td>
<td>A record of events, produced by you, that relate to an event that happened in your learning environment, including evaluation and reflection.</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Written and pictorial information</td>
<td>Written answers and completed activities set by your tutor or assessor.</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>A scenario or case study</td>
<td>Written or verbal account of how you would respond to specific events set down by your tutor / assessor.</td>
<td>NO</td>
<td>YES</td>
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</tbody>
</table>
Reflective Practice and Reflective Accounts

Reflective practice is a process which enables you to achieve a better understanding of yourself, your skills, knowledge and practice. Although most of us engage in thinking about experiences either before, during or after an event, we need to document our understanding in order to clearly identify our learning, consider the outcomes and evaluate the experience. The aim is to identify what we have learnt in order to find new or different approaches to our future practice, or to recognise when something was best practice.

Learning comes from many different incidents and experiences that we have in life. We can learn much about ourselves, others, our job, our organisation and professional practice, as well as our abilities and skills, if we consciously take the time to reflect on our learning. A popular model of reflection is Gibbs 1988 – The Reflective Cycle. This is shown in the diagram below:

In some of the activities in this workbook, you will be asked to complete reflective accounts. We recommend that you follow the model above to ensure that you include everything.
Introduction to Understanding how to Support Individuals during the Last Days of Life

The NHS National End of Life Care Programme states:

“The point comes when an individual enters the dying phase. It is vital that staff can recognise that this person is dying, so they can deliver the care that is needed. How someone dies remains a lasting memory for the individual’s relatives, friends and the care staff involved.”

We hope to achieve a comfortable and dignified death, not only for the benefit of the individual we care for, but also so that the lasting memories of relatives, friends and carers involved are of a ‘good death’. To achieve this, it is necessary to recognise when an individual is in the last days of life so that the needs and wishes of the individual can be identified, allowing appropriate care to be delivered. This care extends to care after death including support of relatives and close friends.

The 307 unit will allow you to develop your knowledge and understanding of:

- How we endeavour to achieve comfort and dignity by looking at the needs and wishes of the dying individual which may be physical, psychological, social, faith, spiritual, or cultural needs.

- Exploring the changes which occur during the last days of life, including at point of death.

- The symptoms which a dying individual may experience.

- How the emotions, and feelings of those involved in caring for a dying individual are affected.

- How you may contribute to care as part of the multi-disciplinary team.

- The resources, systems and procedures necessary to support an individual in the last days of life.
**Pre-learning assessment** – Rate how confident you feel about understanding and supporting individuals who are in the last days of life.

1 = not very confident and 5 = very confident

<table>
<thead>
<tr>
<th>Confidence level</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>Understanding of the term a ‘good death’</td>
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<tr>
<td>Recognising when an individual is in the last days of life</td>
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<td>How to maintain comfort, and dignity, in the last days of life</td>
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<tr>
<td>Understanding of symptoms which may present in the last days of life</td>
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<td>Knowledge of support for relatives, or close friends, of a dying individual.</td>
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<td>Identifying an individual has died and the immediate procedure to take following death.</td>
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<td>Knowing who can support you and understanding how to care for yourself.</td>
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</table>
Section 2: Activities
Activity 1 – What is a good death?

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

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Assessment Method: Written tasks and research
Assessment Type: Knowledge

This learning activity allows you to develop an understanding of what a ‘good death’ is and what it means to different individuals. This helps develop your knowledge and understanding of what is needed to support individuals in the last days of life.

You will learn the variety of care settings where individuals may be cared for in the last days of life and why they should receive equitable care to ensure a ‘good death’ is achieved. You will also gain knowledge of the national strategy and national standards that guide health and social care workers in the standard of care expected. You will start to build on your understanding of the consequences of a ‘good death’ not being achieved, which will be looked at in a later learning activity.

**Activity 1: – What is a ‘good death’?**

**Approximately 4 hours**

When caring for individuals who are in the last days of life, relatives, close friends, health and social care workers strive to ensure the individual has a ‘good death’ but what does this term mean?

For most individuals this will mean they want a comfortable and dignified death. However, does ‘comfortable’ and ‘dignified’ mean the same thing to every individual? Write some thoughts about the following questions.

Are the wishes and needs of each dying individual the same?
Now we need to define what is meant by the key terms. Describe what the words ‘comfortable’ and ‘dignified’ mean to you:

Comfortable:

Dignified:

Now compare your descriptions with definitions in a dictionary – how did they compare?

Next read the Royal College of Nursing definition of dignity:
The National End of Life Care Strategy was produced by the Department of Health in 2008. Its aim is to ensure all adults, when dying have access to high quality care, in all care settings. It also provides findings of what, for many individuals in England, would constitute a ‘good death’. Access the document on the following link:


Look at page 1 of this document and then answer the following questions:

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 ____________, with ____________ and ____________;

Being without ____________ and other ____________;

Being in ____________;

Being in the company of ____________ and / or ____________

Where could care in the last days of life be delivered?

Place each care setting next to the appropriate number:

1 = where most individuals die, 5 = where least number of individuals die.

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According to the End of Life Care Strategy (2008) is the care setting where most individuals die the same as where most individuals say they would like to die?
Later on this activity will ask you to give reasons why individuals may not be cared for in the care setting of their choice.

Now listen to stories from individuals talking about their wishes and concerns when dying including where they would like to be cared for.

You will be able to start to:

- Build a picture of what a ‘good death’ means to different people.
- Develop an understanding of how physical, psychological, social, faith, cultural and spiritual factors affect the dying individual and those involved in their care.

Make notes and refer back to these as you continue with other learning activities.

Now click on the following links:

Healthtalkonline.org Living with dying: where people want to die  
http://www.healthtalkonline.org/Living_with_dying/Living_with_Dying/Topic/1204/

Healthtalkonline.org Living with dying: People’s stories  
http://www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying/People/Stories

Motor neurone disease. Thoughts about death, dying and bereavement.  
http://www.healthtalkonline.org/nerves_and_brain/motorneuronedisease/Topic/3452/

If you cannot access the internet then make notes on a radio or television programme, newspaper or magazine article where people are talking about dying.

Make some notes about what you learn from the clips and your research in the space (use more paper if you need it).

Notes:
Now consider what you would want for yourself when in the last days of life.

- What, for you, would be a ‘good death’?
- What would you want to ensure comfort and dignity?
- What would you not want?
- Where would you want to be cared for?
- How would others know what you wanted?
- Who would you want delivering your care?
- How would care you wanted, or needed, be communicated to these people?
- What extra resources do you think would be needed?
Now consider your relatives / friends / colleagues.

- Do you think they would want the same as you?

- Now ask a relative, a friend, and a colleague. Compare what you thought and what they said:
  - Are there any differences?
  - Are there any surprises?

Consider the following:
An individual who is being supported for end of life care dies on the floor.
Is this a ‘comfortable and dignified death’? Give reasons for your answer: You will have the opportunity to explore your answer later in this activity.
Now look at the following national document:

Information for adults who use NHS end of life care services and their families and carers. (2011)

Compare what you, your relatives, friends and colleagues would want with the quality standards in this document.

Do you feel your needs and wishes are covered by these standards? Would this help ensure a ‘good death’ is achieved?

Now look at the following:
Death and Dying: Religious Practices Wall Chart: A guide to general principles
http://www.cumbria.gov.uk/elibrary/Content/Internet/536/656/3838485955.pdf

Alternatively you may look at a resource on faiths and cultures in your working area. This will assist you with understanding what ‘dignified’ means to different faiths and cultures when dying.

After looking at the resource answer the following which links to the earlier question:

Individuals of which faith, or culture, may request to be placed on the floor to die?
Do you think it is always possible for individuals to die where they would like? Provide reasons why it may not be possible.

Are the wants/needs/wishes of all dying individuals achievable in all care settings?

How would the wants/needs/wishes of all the individuals you have listened and spoken to be known when they are in the last days of life?
You have now completed this learning activity. You should now be beginning to develop an understanding of the difference in what ‘comfortable’, ‘dignified’ and a ‘good death’ means to different individuals when providing resources, support and care in the last days of life. You are beginning to analyse ways to enhance wellbeing during the last days of life.

**Resources to support learning**


The following two resources will also support other learning activities in this unit.

(2012)  

My life until the end. Dying well with dementia. Alzheimer’s Society. (2012)  

**Completed Activity**

Now you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 2 – The Final Days: Identify, plan and communicate

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

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Assessment Method: Written tasks and research
Assessment Type: Knowledge

Identifying when an individual has reached the final days of life is essential to ensure appropriate planning and delivery of care. This helps to ensure the needs, wants and wishes of the individual are considered. It is important communication between all those involved, including the individual and relatives or close friends, is maintained.

This learning activity will develop your knowledge and understanding of:

- how an individual is identified as entering the last days of life, including physical signs.
- the planning of care, including incorporating the wishes of the individual.
- the systems and documentation put in place to enhance communication.
- key people involved in decision making and delivery of care.

Activity 2- The last few days: Identify, plan, communicate

Approximately 4 hours

Here we look at why is it important to recognise when an individual has reached the last few days of their life and what would be the consequences if nothing different was carried out, or put in place. Would they die with comfort and dignity? The first step is to identify when the individual is entering this stage.

For this activity you should reflect on individuals you have already cared for. If you have not cared for a dying individual look at the following leaflet available on the link provided:

Provide 4 examples of how you would identify an individual is entering the last days of their life, including symptoms you might expect to see.

1.

2.

3.

4.

Was there anything else, apart from the changes you observed in the individual, which helped to identify they were now dying?

List who would be involved in the decision making process to decide an individual is now entering the last days of life?

To aid planning, delivery and communication of care in the last days of life, appropriate documentation and systems are used. This helps to:

a) Ensure the dying person’s wants, needs and wishes are known

b) Aid communication between all those involved in providing care

c) Meet the requirement for appropriate recording of care delivered
Make a list of documentation and systems you are aware of being used in your working area - you may need to ask colleagues for advice:

Also make a list of the key workers responsible for initiating the documentation and systems used in your working area?

Out of those you have listed, is there one document which incorporates all of the following:

a) Ensure the dying person’s wants, needs and wishes are known

b) Aid communication between all those involved in providing care

c) Meets the requirement for appropriate recording of care delivered
If the answer is yes, is it an integrated care pathway used specifically for care in the last days of life?

An integrated care pathway:

- Provides a plan of anticipated care, to be used within a given period of time.
- Provides a plan of care specific to the condition which an individual has. In this case, the plan is specific to care required when an individual enters the last days of life.
- Provides a plan of care specific to the needs and wishes of the individual.
- Provides all health and social care workers with a guide to care and treatment required. This prevents inequality in care.
- Aids communication between health and social care workers providing care to an individual
- Incorporates national and local, policies and guidelines.
- May be used in any care setting where the individual is being cared for, provided the health and social care workers have been trained in its use.

An example of an integrated care pathway used in the last few days of life is the Liverpool Care Pathway. There are other pathways which may be known by a different name. They serve the same purpose and a different one to this example may be used.

Look at an integrated care plan used in the last days of life in your working area. If there is not one available go to the following link to access the Liverpool Care Pathway:


There are some other important documents which have to be considered in the initial assessment stage. It should always be clarified with the individual where possible, or their next of kin, if any prior records of wishes have been made. These documents may include:

**Advance Care Plan (ACP)**
Where possible, individuals who have prior knowledge of dying in the near future should be given the opportunity to record their wants, needs
and wishes. This is called an Advance Care Plan. It is sometimes called a ‘preferred priority of care document’. It is not legally binding and the individual may change their mind about what is recorded in it.

The support sheet 3 Advance Care Planning available on the link below demonstrates at what point an Advance Care Plan should be discussed.

http://www.endoflifecare.nhs.uk/assets/downloads/supportsheet3_1.pdf

The ‘Planning for your future care. Advance Care Planning’ document provides guidance on what information individuals may wish to have recorded. You may view a copy on the following link:

http://www.devon.gov.uk/d_0903_004_139223_v4 - a4_low_res2.pdf

Now list 5 things which an individual may record in an Advance Care Plan.

**Advance Decision to Refuse Treatment (ADRT)**

An individual may choose to make explicit instructions on care they DO NOT wish to receive in the future if they become unable to speak for themselves. They may make these wishes known, in advance, provided they have full mental capacity at that time. These decisions may be recorded as an ADRT. This document is legally binding and healthcare workers must respect the decisions. e.g. an individual has stated they do not wish to have an artificial feeding tube inserted should they be unable to swallow when their condition deteriorates. Individuals may change their minds about decisions, as long as they have full mental capacity. Adults have to be over 18 years of age to make an ADRT.

The following guide will assist you to develop an understanding of an ADRT.

“Advance decision to refuse treatment” A guide. N.H.S.

“Legal and ethical issues” available on the website: Dying Matters
http://dyingmatters.org/page/legal-and-ethical-issues

**Do not attempt cardio-pulmonary resuscitation (DNACPR)**
Cardio-pulmonary resuscitation is a treatment to be commenced if the heart stops beating. Unless specific, signed instructions have been documented by a doctor, then an individual has to have cardio-pulmonary resuscitation attempted. When an individual is recognised as being in the dying phase then a decision will be made to allow a dignified death and resuscitation will not be attempted. In this case, it is important that a DNACPR document has been signed by a doctor.

The DNACPR must be located with the individual, in the place where they are cared for. If paramedics are called out in an emergency they must see signed documented evidence that an individual is not for resuscitation. The individual, where possible, or relatives, if the individual lacks mental capacity, should be involved in the decision-making process with members of the multi-disciplinary team. However, the most senior medical professional can make a decision that a treatment is ‘futile’ - serves no benefit or purpose to the dying individual (General Medical Guidance 2010).

The following patient information leaflet provides guidance on DNACPR:

“Decisions about cardiopulmonary resuscitation” patient leaflet. St. Nicholas Hospice

Organ Donation:
Some individuals choose to donate organs or tissue, when they die.
An example of an organ is a kidney.
An example of tissue is the cornea (part of the eye).
Organ donation registration forms must always be signed by the individual. When an individual is dying, and has not been maintained on a life support machine, there are limitations on what may be donated.
If an individual dies at home then donation of the cornea is possible.
Some individuals choose to donate their body or other organs to medical science. This may be emotionally difficult for relatives as there is no immediate funeral held when a body is donated to medical science.

The following resources will help develop your understanding of organ / tissue donation:

Organ donation: What can be donated?
http://www.nhs.uk/Conditions/Organ-donation/Pages/Definition.aspx

Cornea donation
http://www.nerc.co.uk/helping_us_cornea_donation.htm
What if you are asked about assisted dying or euthanasia:

You may experience a dying individual who asks you about how they may be assisted to die, or even where they may go to allow the act of euthanasia. Assisting an individual to die and the act of euthanasia are both illegal in England. You should always inform a senior colleague if you are faced with this situation.

The following link provides further information on this subject:

Euthanasia and assisted suicide

http://www.nhs.uk/conditions/Euthanasiaandassistedsuicide/Pages/Introduction.aspx

Look at the video clip: Jill and Phil say: Do not resuscitate


How has Jill been able to make her wishes known?

Which of the documents you have learnt about are in place for Jill?

To allow an individual to have a dignified death and not have attempted cardio-pulmonary resuscitation, what must be in place?
You should now have a good understanding of identifying when an individual is in the last few days of life, the action and systems to be taken by the multidisciplinary team and the documentation to be put in place.

1. Explain the difference between an advance care plan and an integrated care pathway:

2. When may an individual make an advance decision to refuse treatment?
Reflect on an advance care plan you have seen in place for an individual.

- What did this help to ensure was in place for the individual?
- Was there anything which could not be put in place / achieved?
- Why may this have been the case?
Provide an anonymised example of an integrated care pathway for an individual and describe your involvement e.g. providing information during initial assessment, recording of care delivered, identifying changing needs.

You may not yet have been involved in the care of an individual on an integrated care pathway. Access an example copy of the Liverpool Care Pathway from the following site:


Provide 3 examples of what is recorded in the initial assessment section.

Provide 5 examples of what is recorded in the ongoing delivery of care.

Provide 2 examples of what is recorded in the Care after Death section.
You may wish to complete any of the following e-ELCA modules (see information at start of unit handbook) to support evidence of your learning. Remember once you have completed e-ELCA modules, print off your certificate and place in your portfolio

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(This e-learning module also relates to learning activity 5)

Resources to support your learning

Advance Care Planning: A guide for health and social care staff. National End of Life Care Programme


Liverpool Care Pathway for the Dying Patient (LCP) - FAQ


End of Life: The facts. A booklet for people in the final stages of their life and their carers.


Completed Activity

Now you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 3: Maintaining comfort and dignity

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

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Assessment Method: Research
Assessment Type: Knowledge

This learning activity looks at how comfort and dignity is maintained in the last few days of life. You will gain an understanding of what supports and hinders an individual's comfort and dignity and learn how you may contribute to care within the boundaries of your role. Knowledge will be gained in the management of some common symptoms which may occur in the last days.

Activity 3: Maintaining comfort and dignity

About 2 hours

As an individual enters the last days of life, it is essential an assessment is carried out. This enables relevant care and treatment to be implemented which assists with maintaining comfort and dignity. As you have already learnt in Learning Activity 2, an integrated care pathway may be used. The initial assessment of the integrated care plan used in the last days of life (e.g. the Liverpool Care Pathway) ensures a ‘holistic assessment’ is carried out. This guides health and social care workers on what needs to be put in place.

Holistic means ‘whole’. Therefore the physical, psychological, social, faith, culture and spiritual needs of the dying individual are assessed.
During this assessment, needs and wishes may necessitate stopping, continuing, or commencing treatment and care. The ultimate goal of all treatment and care is to maintain comfort and dignity.

The following are some examples of what may be stopped, continued or commenced.

Prior to the last days of life, individuals may have been receiving life sustaining treatment or had systems in place for commencing treatment if necessary. eg regular renal dialysis for kidney disease, cardio-pulmonary resuscitation if the heart stopped.

**Medication:**

Many patients, when dying, have difficulty swallowing and therefore medication given by mouth may be stopped. If tablets cannot be swallowed, medication in liquid form may be acceptable. Some medications may be stopped as they are of no benefit to the individual in the last days of life.

When dying, it is sometimes necessary for individuals to continue to receive medication to control symptoms of other conditions they may have. An example is Parkinson’s disease where medication helps control the tremors and rigidity (stiffness) of limbs. If the individual can no longer swallow oral medication then an injection at regular intervals may be necessary. There are different specialist nurses for specific conditions. They may need to be involved in the discussion of appropriate medication in the last days of life.

Sometimes an individual may already be receiving pain relief medication delivered via the transdermal route (absorbed through the skin) prior to the dying phase. Medication delivered via this route may continue.

**Personal care:**

It is essential all personal care needs are continued to maintain comfort and dignity. This includes washing, mouth care, care of hair and changing of clothing. Men should continue to be shaved regularly if this is what they have always maintained themselves.

There may be urinary and faecal incontinence necessitating use of continence pads which should be checked regularly.
Providing fluids and nutrition:

In the last few days of life only minimal amounts of food and fluids may be tolerated as there is a reduced need. This is because the body ‘shuts down’ in the dying phase and there is a reduced need. This sometimes requires careful explanation to relatives. The individual is NEVER refused fluids to drink, unless they have difficulty swallowing or are unconscious. Drips – the giving of fluid via a needle into the arm, may or may not be used depending on if it is deemed appropriate for the dying individual. Sometimes a drip may cause distress as the body cannot always cope with receiving large amounts of fluid in the last few days.

Re-positioning:

The frequency of re-positioning an individual when dying, should be as appropriate to maintain comfort. If individuals are re-positioned too frequently they may become distressed and comfort may not be achieved.

Relevant pressure relieving equipment and moving and handling equipment should be in place. If the individual is in pain or distressed during re-positioning, a healthcare worker should be notified as re-assessment will be necessary.

Respecting faith and cultural beliefs:

This may include ensuring certain jewellery or clothing is not removed. Faith leaders may visit or remain in attendance with other members of the faith. Certain rituals or ceremonies may be performed.

Meeting spiritual needs:

Some individuals have no faith beliefs but may wish to have things in place which bring them spiritual comfort. Examples include favourite music being played or a family photo in close view.
Mouth care:

As there will be reduced eating and drinking, mouth care is essential to keep it clean, moist and free from bad breath. There are also many drugs, including those used in end of life care, which may cause a dry mouth. It is important the mouth is regularly cleaned and kept moistened to remove bacteria which builds up and causes bad breath. If relatives see their loved one with a dry, dirty mouth they may feel there is neglect of care.

Equipment for mouth care:

- Soft bristled tooth brush. This may be a baby tooth brush or a tooth brush specifically for end of life care
- Non-foaming toothpaste (a small pea sized amount should be used)
- If possible, all surfaces of the teeth, the gums, the top of the tongue and inner cheek surfaces should be gently brushed
- The inside of the mouth may be kept moistened by frequently applying water and application of a gel prescribed by a healthcare worker. eg oral balance gel or pineapple juice if preferred by the dying individual
- Lip care should be provided to prevent them becoming dry and cracked. The following may be used: Lip balm, KY jelly or the same gel which is used to moisten the inside of the mouth. Some lip sticks, if already used by the individual, as they contain a moisturiser
- N.B. Vaseline (Petroleum jelly) should not be used, particularly if oxygen therapy is used, as it is flammable
- Dentures should be removed and cleaned at least daily
- Pink foam swabs are not appropriate for cleaning the mouth. The foam is rough and may cause tears to the inside mouth surfaces. There is also a risk of the swab coming apart from the stick and causing choking (Medical Device Alert 2012). They should therefore be used with caution.
- Lemon glycerine swabs. The glycerine content has a dehydrating effect and may contribute to causing a dry mouth. The lemon taste may be too strong and is not always tolerated.
Management of symptoms:

There are 5 main symptoms which may present in the last days of life:

- Pain
- Restlessness & agitation
- Breathlessness
- Nausea & vomiting
- Build up of secretions in the back of the throat. (This is sometimes called the ‘death rattle’ by relatives).

(Ellershaw and Wilkinson, 2011)

Medications will be made available for these symptoms if they are needed. This is called ‘anticipatory medication’. If the individual can still swallow then medication to control pain may continue to be given by this route. A number of other routes may also be used eg injections.

Your tutor will provide you with a work sheet to assist with your learning of identifying the different routes and an explanation of what each mean.

How many of these routes have you seen in use?

How would you identify a dying individual is in pain?
Pain assessment tools may be used to help identify if an individual is in pain and how much pain may be present.

How can we measure how much pain an individual has?

One example is asking the individual to use a score system where 0 = no pain and 10 = the worst possible pain. Another example is to observe facial expression. Is a pain assessment tool used in your working area?

‘Total pain’ is a term sometimes used to describe pain which although physical, may feel worse to the individual. This is because emotional factors such as fear or worry may be contributing factors.

Faith and culture may also influence an individual's tolerance to pain.

Remember - pain is what the individual says it is!

‘Non-pharmacological management’ is a term used when attempts are made to control symptoms without medication. This may be due to medication being refused for faith/ cultural reasons or there is a delay in medication being made available.

Some examples of non-pharmacological management are:

- Hand massage therapy
- Aromatherapy
- Music being played
- Meditation

What is your role in the management of pain for an individual in the last days of life?

The following resources will assist you with learning about the management of pain:


You may wish to have a professional discussion with your tutor to explain how you have identified an individual as being in pain and the action you took. Provide an example of a pain assessment tool you have used if possible. Otherwise find an example of a pain assessment tool which is appropriate for the individuals you care for.

**Restlessness & agitation:**

This may occur for a number of reasons and may include:

- **Death rattle** - the build up of secretions at the back of the throat. This may be present in the final hours of life and is caused by the individual being unable to swallow. Whilst the noise may be distressing to people around, it does not usually cause the individual distress. Re-positioning may help. Sometimes an injection is required which can also cause a very dry mouth and sometimes retention of urine.

- **Retention of urine.** This is a medical term used when an individual has a full bladder but cannot pass urine. Some medications may cause this. If you know the individual has not passed urine for a while and you see them looking agitated or restless, inform a healthcare worker.

- **Constipation.** Even when in the last days of life an individual may experience discomfort because of constipation. A healthcare worker will need to examine the individual if this is suspected.

- **The life styles of individuals may contribute to agitation and restlessness when dying.** e.g withdrawal effects of nicotine alcohol or substance misuse.
Look at the scenario below:

You are providing care for George, an 82 year old service user who is in the last few days of life. He is semi-conscious and unable to verbally communicate with you. Relatives, who are sat by George’s bed side, are concerned as George has become very restless.

What are the possible reasons for the restlessness?

State what actions you could take and explain the reasons why?

Support of relatives:

It is important to ensure communication is maintained with the relatives/ close friends and clear explanations of care should be given. Some relatives/ close friends may be glad to have the involvement of health and social care workers as they may be exhausted both physically and emotionally. However, sometimes they may feel left out and no longer needed when increased numbers of health and social care workers become involved. Relatives / close friends should always be asked if they would like to participate in care. This may help them psychologically, including in their bereavement process, knowing they were able to contribute to care.

In 2005 the Carers (Equal Opportunities) Act, came into effect. This entitles relatives/ close friends who are carers to be assessed for their own needs.
Stop, start, continue:

Make a list of treatments, medications and care you have seen stopped, continued or commenced when individuals are identified as in the last days of life.

Think about those that you have listed. Look at 2 of each and write what the consequences could be if they were not stopped, continued or commenced.

Stopped 1:

Stopped 2:

Continued 1:

Continued 2:

Started 1:

Started 2:
Look at each of the following scenarios which illustrate how the needs of dying individuals may change quite rapidly.

**SCENARIO 1:**

Josey, aged 53, is being cared for in hospital and has just been identified as being in the last days of life. She is being discharged home later today as that is her preferred place of care but is not yet on an integrated care pathway. Josey is prescribed regular oral medication, in liquid form, for pain relief. When offering Josey a drink you identify she is now having difficulty swallowing.

What are Josey's changing needs and what action should you take?

**SCENARIO 2:**

Aisha, aged 42, is being cared for at home. She is in the last few days of life having been diagnosed with cancer only six months before. Aisha’s advance care plan and integrated care plan state her preferred place of care is at home. You are providing personal care for Aisha when she suddenly starts crying. Aisha tells you she is such a burden to her husband whom she can see is exhausted with caring for her. Aisha tells you she wants to be admitted to a hospice.

What are Aisha’s changing needs and what action could you take?
Two of the main symptoms which may be present in the last days of life have been discussed earlier in this learning activity.

The other three symptoms which may be present are

   a) breathlessness   b) nausea and vomiting,
   c) build up of secretions in back of throat.

How may you support an individual who has one of these symptoms?

Watch the video clip: Dying at home (10 minutes approx.)

Access the video by following the link below:

As you watch, make notes on

1. How comfort and dignity is being maintained for the individuals who were cared for at home.

SCENARIO 3:
You are on night duty in a hospice and check on Jim, aged 80 years. Jim is in his last few days of life but can still verbally communicate. He is married to Jean who went home after visiting a couple of hours ago. You are aware that an integrated care pathway is in place. It states Jim has said he has no religious beliefs or needs. Jim tells you that he has been awake doing a lot of thinking. He is worried that although he has always said he is an atheist maybe there is a heaven. As his wife has been baptised and he has not, Jim is worried he may ‘go to a different place’ than his wife when she dies. Jim says ‘I know it’s too late to do anything about it now’.

What are Jim's changing needs and what action should you take?
Use the following headings when making notes:

- Physical needs
- Psychological needs (emotions and feelings)
- Faith, cultural and spiritual needs
- Social needs

2. Who was involved?

3. List other methods of enhancing comfort and wellbeing that you have carried out in your work role with people in the last days of their life.

Notes:
Additional resources to support your learning

A guide to carers' rights. NHS Choices
http://www.nhs.uk/CarersDirect/guide/rights/Pages/carers-rights.aspx


How would I know? What would I do? The National Council for Palliative Care.
www.ncpc.org.uk/news/how-would-i-know-what-can-i-do

Medical Device Alert: Oral swabs with a foam head, all manufacturers (MDA/2012/020) (2012)
http://www.mhra.gov.uk/Publications/Safetywarnings/MedicalDeviceAlerts/CON149697

Syringe drivers for giving pain control
http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Pain/Syringedrivers.aspx

Completed Activity

Now you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 4 – The final hours and care after death

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

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Assessment Method: Written tasks
Assessment Type: Knowledge

This learning activity provides the opportunity to develop your knowledge and understanding of identifying changes in the dying individual during the final hours and at point of death.

The relevance of identifying death and carrying out procedures in line with policies and protocols are explored as well as support of relatives. This learning activity will require you to be familiar with national guidelines and policies in your working area which are applicable to care after death procedures. You may be able to draw on your experiences to answer learning activities but a selection of suggested learning resources will support learning.

<table>
<thead>
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<th>Activity 4: The final hours and care after death.</th>
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The following learning resources will assist your learning for this learning activity:

Guidance for staff responsible for care after death.(2011)
http://www.endoflifecare.nhs.uk/assets/downloads/Care_After_Death__guidance.pdf

Step 6 – Care after death. What to do when someone dies –Support sheet

As the final hours of life approach further changes in the dying individual may be noticed. Identifying this is important as it allows any final needs, wishes and rituals to be carried out.
Relatives have the opportunity to gather at the bedside and emotionally prepare for the death. It is important to clarify emergency contact details with relatives who wish to be informed so they may be contacted day or night. As the dying individual deteriorates, further changes may be seen as further ‘shutting down’ of the body takes place. This may usually be identified in a number of ways although not all may be present:

- Facial appearance – becomes very pale in colour
- Hands and feet go cold and white, possibly blue
- Further reduced consciousness and probably unconscious
- Noisy breathing ‘death rattle’ - as learnt in Learning Activity 3
- The breathing pattern changes – longer pauses and bigger gaps in between breaths. This is called Cheyne Stokes breathing.

By watching and reading the following learning resources you will gain an understanding of the changes which occur in the final hours:

Illustrates possible changes to breathing:


What to expect when approaching death:


How to recognise when an individual has died.

- You will observe breathing as having stopped.
- You should wait a few minutes to ensure it was the final breath.
- The individual will be very still
- All the muscles will relax
- The eyes may remain closed or open
- The mouth may remain closed or open.

Look at the following learning resource:

What to expect at death.
Action to be taken:

- Make a note of the time to inform the healthcare worker.
- Inform relatives/close friends if present that you think the individual has died. Inform them this will need to be verified by a healthcare worker.

When you notify the healthcare worker of the death, you will need to inform them of:

- Time you noted death
- Any faith/cultural considerations
- If the individual has requested to donate organs or tissue following death

Depending on your area of work there may be a delay in arrival of the healthcare professional. Reassure the relatives and keep them informed of any possible delays.

Some faiths and cultures only permit their own faith leaders or members of the same sex to touch an individual when they have died.

Sometimes, in this situation, the wearing of gloves to touch the deceased may be acceptable. If it is acceptable, explain to relatives what you are doing and carry out the following:

- Lay the deceased individual flat, with one pillow under the head.
- Gently close the eyes and jaw if they are open. A rolled towel can be used to support the jaw. Stiffening of the limbs 'rigor mortis' does not usually take place until about two hours after death.

Infection control measures should be maintained in line with national guidelines and the policy of your working area. There is a risk of infection from:

- Leaking of urine and faeces as the body relaxes
- Blood, saliva and other oozing fluids.
- Skin contact
- Airborne, transmitted as air is released from the lungs when moved
The following resource provides national guidelines on infection control measures:

Prevention and control of infection in care homes – an information resource. See page 36 – Last Offices for a resident with an infectious disease.


If relatives/close friends are present then allow them time for initial grieving. Whilst it is often a relief that their loved one’s suffering has ended, the relatives will still need to grieve. Provide support and offer beverages.

You may wish to complete the following e-ELCA module to support your learning:

04 23 Recognising the dying phase, Last few days of life and verifying death.

How do you know when an individual is now in the final hours of life?

Complete the boxes on the next page and describe how you can identify by:

a) Observing
b) Hearing
c) Touch
How do you know when an individual has died?

Provide examples of 3 things that happen to the individual which suggest they have now died.

1. 

2. 

3.
What is the procedure to be followed, when an individual is identified as being dead, by a non-healthcare worker in your working area?

What support and advice would you give relatives/close friends if they were present at the time of the death?

Why is it important to maintain infection control measures when providing care for a deceased individual?
Are there any parts of the body that may be donated following a death at home? Name any that you are aware of:

Choose 3 faiths or cultures that differ to your own. For each, describe the specific care of the individual:

a) Prior to death
b) At death
c) Following death

Faith / Culture 1:

Faith / Culture 2:
Is the care you have identified for each achievable in your working area?

Look at the care of the deceased person and infection control policies for your working area. If possible include copies in your portfolio.

**Resources to support your learning**

After a death - If you are a partner, relative or friend. Macmillan Cancer Support.


Care of the deceased person policy (In relation to infection prevention and control)

Death and Bereavement in Islam

The Dying Process –Support sheet

What needs to happen after death

What to do after death in England and Wales
http://www.dwp.gov.uk/docs/dwp1027.pdf

What to do when someone dies –Support sheet 9 (2012)

Funeral directors in your locality may provide free educational sessions on care and procedures after death, including their role. You may use this to support evidence of learning for this learning activity.

You may wish to complete the Current Learning in Palliative Care 15 minute work sheet: The last hours and days 3: The death.

This may be printed off or used electronically from the following link: http://www.helpthehospices.org.uk/clip/lhd/lhd-3/index.htm
Completed Activity

Now you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 5 - Emotions, feelings and coping

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria. Those highlighted green are the ones you will cover when you have successfully completed it.

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**Assessment Method:** Written tasks and research  
**Assessment Type:** Knowledge

During the last few days of life and after death, a range of emotions can present. The feelings of everyone, including your own, may be affected to some degree. This learning activity will provide an understanding of how emotions may be affected at various stages of the dying phase, showing ways they may be identified and possible means of coping. As this learning activity looks at emotions and feelings including your own, you may prefer to do some of these learning activities in a group or with your tutor present. Discuss with your tutor/assessor as appropriate.

**Activity 5: Emotions, feelings and coping**

**Approximately 4 hours**

The emotions experienced when an individual is dying are unique and different for each person involved.

Emotions have the ability to influence how well individuals cope during this time and each individual may experience a multitude of emotions and feelings.

During the last days of life phase, apart from the dying individual, who else’s emotions and feelings may be affected?

First we need to define what emotions, and feelings are. Write a definition of each of the following:
Think about the different emotions and feelings that may be present and list some below:

How easy is it to tell the emotions and feelings of an individual?
How well are you able to identify the emotions of individuals by looking at them?

Try this on-line quiz “Emotional Intelligence Quiz | Greater Good” to see how many facial expressions you can identify correctly.

Do you think individuals of all faiths and cultures display emotions and feelings in the same way?
Recognising emotions by facial expression alone does not always provide a reliable means of knowing. How many times have you seen people with a big smile but on talking to them they tell you they are very sad? Have you heard relatives say "I have to put on a brave face, can’t let Dad see I’m upset"? This would identify the relative as having emotions different to what he/she displays when with their dying father.

Observation of facial expression and body language, as well as talking to an individual, provides a more reliable means of determining the emotional state. Clearly, emotions cannot always be identified by someone else. We are usually reliant on an individual telling us how they feel to determine their emotional state of mind. Even this is not always reliable though. Therefore it can be very difficult to appreciate the emotions that individuals experience when faced with the dying experience especially the dying individual who may no longer be able to communicate.

When an individual is in the last days of life, there is time for those involved to prepare for a death. There may be a range of emotions which individuals experience in this preparation phase. These same experiences may also be experienced by those involved in care following death.

Elisabeth Kübler-Ross, an expert on death and dying, described five stages of grief which may commonly be found:

- Denial - refusing to believe that the individual is going to die
- Negotiation - attempts to bargain by promising to do something so they may be spared from death or bereavement
- Anger - they don’t deserve to die!
- Depression - withdrawing and trying to come to terms with what is happening
- Acceptance - the inevitable is going to happen and individuals are resigned to that fact.

Now watch the video clip:

Dick and Di planned a formal, ritual goodbye so they would not have any last minute awkwardness with a long drawn out goodbye.

This can be found on the below link and then you will need to scroll down to the above title.

http://www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying/People/Stories
How do you think Dick and Di felt during those last days? Write your answers in the space provided:

How may their relationship have been affected during the last few days of Di’s life?

Now look at the following scenario:

Karisha’s father Samir is in the last days of life. He is being cared for at home by Karisha’s sister Naisha.

Karisha lives in another country hundreds of miles away and is unable to be with her father and sister.

What emotions and feelings may Karisha be experiencing?

How may you support Karisha’s father and sister?
Look at the following internet sites to help you answer the next question.

Supporting children and young people
http://www.crusebereavementcare.org.uk/Children.html

Child bereavement UK
http://www.childbereavement.org.uk/

Talking to children when someone is dying
http://www.liv.ac.uk/media/livacuk/mcpcil/migrated-files/patients-carers/Talking_to_Children_when_someone_is_dying_%28a_leaflet_for_par.pdf

If you are unable to access a computer ask your tutor to provide the information sheets available from Child Bereavement UK.
How may the emotions of a child be affected when a close relative is dying?

How can you support a relative or close friend, during the last few days and at the time of their loved one's death?

Now watch this video clip which looks at the continued effect of bereavement on care home staff:

http://www.nhslocal.nhs.uk/story/features/end-life-care-home-impact-staff

How have / could your feelings be affected by the death of a service user?
How have you supported a colleague when they have been affected by death of an individual?

What support systems are available to you in your working area?

Where would you access support outside of your working area?

What helps you to achieve a healthy work / life balance?
The following resources may be completed to support evidence of your learning:

Complete the 15 minute on-line tutorial:
Bereavement: 1: “The loss begins…..:” Help the Hospice Current Learning in Palliative Care on-line tutorial

Complete the 15 minute on-line tutorial:
The effect of death on staff: Help the Hospice Current Learning in Palliative Care on-line tutorial

The following e-ELCA module:
07 – 06 Children & Bereavement

Notes:
Resources to support your learning

Bereavement. Helping you deal with the death of someone close to you. Marie Curie Cancer Care

Bereavement: key facts Royal College of Psychiatrists.
http://www.rcpsych.ac.uk/expertadvice/problemsdisorders/bereavementkeyfacts.aspx

Emotional and spiritual support for carers. St. Christophers Hospice. Marie Curie Cancer Care
http://endoflifecareinformation.stchristophers.org.uk/looking-after-yourself/emotional-and-spiritual-support

SCIE Social care TV Supporting staff in care homes (10 mins approx in length)

Completed Activity

Now you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 6 – Was it a ‘good death’?

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

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Assessment Method: Scenarios
Assessment Type: Knowledge

From the learning activities already completed, you have gained knowledge about what needs to be in place to ensure a ‘good death’ is achieved. This learning activity gives you the opportunity to test your knowledge.

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<th>Activity 6: Was it a good death?</th>
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Below are two scenarios. Look at each one and decide if you consider a ‘good death’ was achieved.

First watch the video clip:
Supporting good end of life: a case study. Harry’s story - My home life. Available on the link below (you will need to scroll through the videos until you come to it): [http://www.myhomelifedvd.org.uk/](http://www.myhomelifedvd.org.uk/)

Then read Maud's story below.

For each one make notes of your thoughts on why it was or was not a ‘good death’. Think about:

- What was put in place?
- Was comfort and dignity maintained?
- Who was involved in the care?
- The emotions and feelings of those involved
- Was equitable care evident?

For each scenario also explain why it is important to be knowledgeable about an individual's wishes for their after death care and ensure those wishes are acted upon when they die.
Maud’s story:

Maud, age 79 years, has Parkinson’s disease and has lived in a Care Home for the past 10 years. Residents and staff are very fond of Maud and one resident, Elsie, has formed a close friendship with her. Maud’s only family is a granddaughter, Emily, who is next of kin. Emily has two children age 12 and 7yrs. They live 100 miles away but try to visit monthly.

Maud has had an increasing number of hospital admissions for treatment of chest infections over the past 12 months. On Friday staff suspect Maud is developing another chest infection and she is also having difficulty swallowing oral medication. They request a visit from the GP who informs staff that Maud is for ‘T.L.C’ (tender loving care) and suggests they contact the out-of-hours doctor if any problems occur over the weekend.

T.L.C. is a term sometimes used to suggest the individual is now dying and the treatment is for them to be kept comfortable.

At around 1am on Saturday morning Maud becomes agitated and restless leading care staff to believe that she may be in pain. They call the out-of-hours doctor service and the duty doctor asks staff about Maud’s medical history. The doctor arranges hospital admission as he feels antibiotics by infusion are needed. Due to limited number of staff on duty at night no-one can accompany Maud in the ambulance.

Care home staff are told later that Maud died about 2 hours after leaving them, on a trolley in A&E, waiting for admission to a ward. Unfortunately due to an emergency in the care home just after the ambulance took Maud to hospital, the care home staff had not informed Maud’s granddaughter that she was admitted to hospital.
Completed Activity

Now you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 7 - Case study – the last days of life

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

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Assessment Method: Case study
Assessment Type: Knowledge

Activity 7: Case Study - the last days of life

Approximately 5 hours

To fulfil this activity you will need to identify a specific individual whom you have cared for, both prior to and during the last few days of their life. Where possible, this should also include care after death. Remember to incorporate information from the other learning activities where appropriate.

If you have not yet cared for a dying individual you will need to discuss this with your tutor.

You may wish to use Mairead Smart’s story, found on the below video clip to use for your case study.


This case study should provide good evidence of learning you have gained from completing this unit. You may write the case study or arrange a professional discussion with your tutor.

You will need to produce evidence to demonstrate the following:

a) How was it identified the individual was entering the last few days of life?
b) Who was involved in making this decision?

c) What observations did you make?

d) What changes in care were necessary?

e) What additional resources did this necessitate being made available e.g. equipment?

f) How was the individual's wellbeing maintained during these last few days?

g) What treatments / investigations / medications were stopped, continued or commenced?

h) Identify key workers or people who contributed to the care of the individual and their wellbeing. Were these key people accessible 24 hours a day? How was communication achieved between key people? How many people were involved in care throughout the last days of life?

i) Provide any examples of where communication worked well and/or where there was lack of communication.

j) What changes occurred when death was approaching?

k) How was it known the patient had died? Was anyone with them at the moment of death?

l) Who was notified when death was identified?

m) What care was provided after death? How did the team know the needs/wishes of the individual following death?

n) What documentation was in place for recording and communicating decisions and care?

o) What care and support was provided to relatives and close friends?

p) Was a comfortable and dignified death achieved? Did all those involved in the care consider this a 'good death'? If not, what could have been done better?

q) What support was available for you and other team members, following the death?
Remember to include evidence of national, local and organisational guidelines and policies which supported the individual's care. Also include documents which guided the wishes of the individual in their last days of life.

Notes:
Completed Activity

Now you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Summary

The good news is that you have nearly completed this unit!

You have had the opportunity to learn the meaning of the term a ‘good death’. You have analysed how different individuals will want different things to achieve comfort and dignity in the last days of life. You have looked at factors which may contribute to a ‘good death’ not being achieved.

You have looked at the changes which help to identify an individual is now in the last days of life.

You have learnt how the needs, wants and wishes of the dying individual may be recognised including the importance of a holistic assessment.

You have looked at some of the systems and documentation put in place to support dying individuals, and aid communication between the multi-disciplinary team.

You have explored possible causes of some of the main symptoms in the last days of life how they may be managed.

You have learnt how in your role you may contribute to supporting a dying individual as part of a team. You have looked at who may form part of the multi-disciplinary team and those involved in decision making processes.

You have explored how the recommendations, policies and guidelines produced nationally affect the standards of care expected in your working area.

You have looked at how relatives and close friends caring for a dying individual may be supported.

You have looked at how emotions and feelings may impact on the dying individual and those involved in their care. You have explored the impact of changing needs in the last days of life.

You have learnt the changes which help to identify an individual as being in the final hours of life and following death. You have learnt the immediate action to be taken including the importance of infection control measures.

You have thought about how to access support for both you and colleagues when providing support to dying individuals and their relatives / close friends.

You have been able to demonstrate your learning by producing a case study.
As a last task, repeat the assessment you completed at the start of the unit to see if your confidence has increased and discuss this with your tutor/assessor. 1 being not very confident and 5 very confident

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<td>Understanding of the term a ‘good death’</td>
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<td>Recognising when an individual is in the last days of life</td>
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<td>How to maintain comfort, and dignity in the last days of life</td>
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<td>Understanding of symptoms which may present in the last days of life</td>
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<td>Knowledge of support for relatives or close friends of a dying individual.</td>
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<td>Identifying an individual has died and the immediate procedure to take following death.</td>
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<td>Knowing who can support you and understanding how to care for yourself.</td>
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CONGRATULATIONS!

Once you have successfully completed all the activities and had them signed off by your Tutor / Assessor - you have completed all the learning outcomes and therefore completed the unit:

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## Glossary

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<tr>
<th>Term</th>
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<tr>
<td>Assisted dying</td>
<td>The act of an individual who wants to die, asking and receiving assistance of someone else to help kill them. This act is illegal under English law.</td>
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<td>Bereavement Support</td>
<td>This is the emotional support that is given to an individual to help them cope with the death of someone important to them. Bereavement support can be given before the individual’s death, whilst the individual is dying or after death.</td>
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<tr>
<td>Best Interest decision</td>
<td>This has to occur if someone does not have the mental capacity (see below) to make a legal, healthcare, welfare or financial decision for themselves. This is one of the principles of the Mental Capacity Act 2005. The decision can only be made after an assessment has deemed the individual does not have capacity. Strict principles and codes of practice should be followed to carry out the assessment and to make the best interest decision, these are set out in the Mental Capacity Act.</td>
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<td>Culture</td>
<td>The shared knowledge, behavioural norms, values and beliefs that help people to live in families, groups and communities</td>
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<tr>
<td>Equitable care</td>
<td>Individuals should receive the same high standard of care in all care settings.</td>
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<tr>
<td>Euthanasia</td>
<td>The act of deliberately causing the death of an individual to relieve suffering. This act is illegal under English law.</td>
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<td>Futile treatment</td>
<td>Treatment which is deemed unlikely to be of benefit to an individual. The most senior healthcare worker is ultimately responsible for making the decision that a treatment is futile. e.g. attempting cardio-pulmonary resuscitation in the last days of life may be deemed futile.</td>
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<tr>
<td>A ‘good death’</td>
<td>A term used in the National End of Life Care Strategy (2008) to describe a death where everything is as the dying individual wishes for. The comfort and dignity of the individual is maintained.</td>
</tr>
<tr>
<td>Grieving</td>
<td>To experience or express a sense of loss</td>
</tr>
<tr>
<td>Holistic</td>
<td>Holistic means considering care or assessment from the physical, psychological, environmental and spiritual needs of an individual. This enables people to be treated as whole human beings and the impact of the illness on their quality of life is also considered.</td>
</tr>
<tr>
<td>Mental Capacity</td>
<td>The cognitive ability (see above) of an individual to make decisions that may have legal consequences for themselves and/or for others affected by the decision. In particular these decisions involve their health care, welfare and finances. An assessment must be carried out to determine mental capacity.</td>
</tr>
<tr>
<td>Multi-disciplinary Team</td>
<td>A team of health and social care workers who all have different roles and responsibilities. For example Social Worker, Doctor, Community Nurse, Dietician, Chaplain, Support Workers, Nurses, Occupational Therapists etc.</td>
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<tr>
<td>Non-pharmacological management</td>
<td>Managing symptoms without the use of medication. e.g. hand massage therapy</td>
</tr>
<tr>
<td>Pain Assessment Tools</td>
<td>This is a method which helps you collect detailed information regarding an individual's experience of pain. The information collected includes the type, intensity, location and pattern of pain. The tool can also be used to monitor changes in pain and the outcome of pain relief treatments.</td>
</tr>
</tbody>
</table>