

**UNIT 201:
Understand How to Work in End of Life
Care**

Tutor's / Assessor's Handbook

Acknowledgements

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Table of Contents

Section	Content	Page
	Table of the learning outcomes and assessment criteria	5
Section 1	Introduction to the unit: <ul style="list-style-type: none"> • Introduction to the unit and the activities • What types of evidence are acceptable for each learning outcome 	8
Section 2	Activity 1 – Let’s talk about death (meets learning outcomes 1.1 and 1.2)	18
	Activity 2 – How views on death and dying can impact on practice (meets learning outcome 1.3)	31
	Activity 3 – End of Life Influence (meets learning outcome 1.4)	37
	Activity 4 – Aims and Principles of End of Life Care (meets learning outcomes 2.1 and 2.2)	41
	Activity 5 – Maintaining Comfort and Wellbeing (meets learning outcomes 2.3)	51
	Activity 6 – The End of Life Care Pathway (meets learning outcome 2.4)	59
	Activity 7 – Advance Care Planning (meets learning outcome 2.5)	65
	Activity 8 – Local and National Policy for Care after Death (meets learning outcome 2.6)	73
	Activity 9 – Communicating with Ill People (meets learning outcome 3.1)	80
	Activity 10 –Communication Quiz (meets learning outcomes 3.1; 3.2; 3.3 and 3.4)	84
	Activity 11 –Communication Scenario (meets learning outcomes 3.1; 3.2; 3.3 and 3.4)	89
	Activity 12 –Sharing Information: Acceptable or Unacceptable? (meets learning outcome 3.5)	95
	Activity 13 – Reflective Account (meets learning outcomes 3.1; 3.2; 3.3; 3.4 and 3.5)	100
	Activity 14 –Support Services (meets learning outcomes 4.1 and 4.2)	106
	Activity 15 –Barriers to End of Life Care (meets learning outcomes 4.3 and 4.4)	114
	Appendix <ul style="list-style-type: none"> • Continuation sheets for photocopying as required • Glossary of Terms • Template Support Agreement • Lesson Plans 	128

The purpose of this tutor book

This book illustrates the learner's resource and provides you with the answers and the learning points for each activity contained in the learner's workbook. The answers provided are indicative answers and have been highlighted in red. It is important to note that a lot of questions ask the learners for their own views and opinions therefore in these cases there are no right or wrong answers.

This book also provides a resources guide at the end of each activity. This will signpost you to the various learning resources you will need to support the learner on an individual basis and/or support classroom based activities.

The resource guide will inform you about lesson plans which can be found in the appendices of this document. The resource guide also signposts you to the e-learning resources that are available to support the units learning activities, which are an optional resource. This information can also be found in the appendices. The resources are all in an editable format so that you can amend them as required. The way you deliver this unit is at your discretion and calls upon you to modify the materials in the way that suits your learner's needs.

These workbooks have been formatted for print and it is therefore advised that you print the PDF version of the Learner Handbook for learners to use as a hard copy. PDF versions should also be available to the learner electronically so they can access the links to various Internet sites directly.

The Word version is available, however, for those who wish to use the workbook electronically, please note that in this instance the formatting of the workbook will be altered.

All the resources to support this learning can be found on the following website:

Table 1: Learning Outcomes and Assessment Methods

EOL 201: Understand how to work in end of life care

Unit level 2

Credit value 3

Study/activity hours 28

Unit aim The purpose of this unit is to assess the learner's knowledge and understanding when beginning to work in End of Life Care.

Learning outcomes The learner will:	Assessment criteria The learner can:	Own evidence log (optional)		Assessment Type
		Page No	Type of evidence presented	
1. Know different perspectives on death and dying.	1.1. Outline the factors that can affect an individual's views on death and dying.			Knowledge
	1.2. Outline the factors that can affect own views on death and dying.			Knowledge
	1.3. Outline how the factors relating to views on death and dying can impact on practice.			Knowledge
	1.4. Define how attitudes of others may influence an individual's choices around death and dying.			Knowledge

Table 1 continued

Learning outcomes The learner will:	Assessment criteria The learner can:	Own evidence log (optional)		Assessment Type
		Page No	Type of evidence presented	
2. Understand the aims, principles and policies of end of life care.	2.1. Explain the aims and principles of end of life care			Knowledge
	2.2. Explain why it is important to support an individual in a way that promotes their dignity.			Knowledge
	2.3. Describe the importance of maintaining comfort and well being in end of life care			Knowledge
	2.4. Explain the stages of the local end of life care pathway			Knowledge
	2.5. Describe the principles of advance care planning			Knowledge
	2.6. Define local and national policy and guidance for care after death.			Knowledge

Table 1 continued

Learning outcomes The learner will:	Assessment criteria The learner can:	Own evidence log (optional)		Assessment Type
		Page No	Type of evidence presented	
3. Understand factors regarding communication in end of life care.	3.1. Explain how an individual's priorities and the ability to communicate may vary over time			Knowledge
	3.2. Explain your role in responding to key questions and cues from individuals and others regarding their end of life experience			Knowledge
	3.3. Describe how you might respond to difficult questions from individuals and others			Knowledge
	3.4. Outline strategies to manage emotional responses from individuals and others			Knowledge
	3.5. Explain the importance of sharing appropriate information according to the principles and local policy on confidentiality and data protection			Knowledge
4. Know how to access the range of support services available to individuals and others	4.1. Identify the range of support services and facilities available to an individual and others			Knowledge
	4.2. Identify the key people who may be involved within a multi-disciplinary end of life care team			Knowledge

Section 1: Introduction to EOL Unit 201

General Introduction

This unit provides learners with ways to develop their understanding of the different views of death and dying in our society and how these views may affect an individual's thoughts and feelings about death. The 201 unit covers the main aims and principles of end of life care, as well as the various ways to communicate with someone about end of life. It will also discuss how learners might get help and support from a range of support services.

Learning Support

Due to the sensitive nature of End of Life (EOL) care, topics may be covered that can cause upset to learners, for example asking them to consider their thoughts about their own death or watch video clips that include the views of people who are actually dying. Tutors / Assessors have a responsibility to ensure that learners are supported to learn safely and at their own pace, through a blended delivery style. It is recommended that at the introductory session with learners you complete a Support Agreement together, which will identify how they wish to be supported if they become upset whilst undertaking any of the following learning activities. You have a template Support Agreement in the appendix of this pack to use if you wish.









- **Lone study** – Identify support networks (these could be friends, family, colleagues) if the learner becomes upset.
- **One to one** – Ask the learner how they would like to be supported if they become upset.
- **Work based learning**- Ask the learner to identify a mentor or supervisor to whom they can go if they became upset at work.
- **Class room based learning** - ask the learner how they would like to be supported should they become upset during classroom sessions. You will not be able to leave the rest of the class, so you should encourage learners to nominate a classroom buddy who could leave the classroom with them or identify a quiet place where they can go to be alone and have a cup of tea. This will be their decision and based on the facilities available.

Learner's workbooks remind them that providing good EOL care can be one of the most rewarding caring experiences they can have. It is a privilege to know that they have cared for someone as they have taken their last breath in the world and that they have been part of their end of life journey. It is often a comfort to know that they have helped someone meet their EOL wishes and they have had a comfortable, dignified death. How they 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 learners take the learning activities seriously and that they also ensure that they learn at their own pace, to fully reflect and absorb the new EOL knowledge and skills they will be developing throughout this unit.

Learning Activities

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

Table 2: Type of learning activities and symbols

Activity Symbol	Explanation
	This symbol means you will need to access the internet *
	This symbol means you will be reading something
	This symbol means you will be asked to talk about something with friends, colleagues, your tutor or assessor
	This symbol means you will be asked to think about something and you may be required to write your thoughts down
	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 *
	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
	This symbol means you be asked to research some information. This might be through the internet, books, and articles or from talking to people you know
	This symbol means your assessor will plan to conduct an observation of your practice or will examine a work product

* 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, learners will see a clock symbol which will provide you and them with a guide to how long the activity could take. Remember this is a guide and the activity may not take as long as it says!

Each activity will signpost learners to a range of resources to support their learning and where appropriate learning materials will be provided e.g. an information leaflet or a section of a website for them to read. If they are not in the Learner workbook you will find these in the appendices of this handbook for photocopying.

Here is an example of how each activity works: The Learner Workbook shows each activity in the style below:

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.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4			
4.1	4.2	4.3	4.4			

Assessment Method: Reflective account
Assessment Type: Knowledge

Learners are provided with space to complete each activity where appropriate. You will be provided with suggested answers. The answers given may not be exhaustive and you will need to draw upon your own knowledge and experience as well as additional research if required.

The appendices relating to this unit will provide you with all the resources you will need to deliver learning and support assessment for this unit. It supports classroom delivery, one to one delivery and distance learning for some aspects. We recommend that a blended delivery approach is most effective.

As learners complete the activities in each section, it is recommended that they log their evidence in table 1 (page 5). The grid at the beginning of each activity will show them assessment criteria they have covered (highlighted green). This will help you to map evidence across to awarding body matrix forms when you are confident that learners have demonstrated knowledge or competence. If learners don't succeed at first you can give your further support to get it right!

Table 1 (page 5) shows you and learners what learning outcomes will have to be achieved to pass this unit and what the assessment criteria will be. The table also identifies whether it is a skill or knowledge competency.



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

Plagiarism and Confidentiality

In their workbooks learners are reminded that plagiarism relates to claiming work to be your own when it is not. All work submitted must be the learners own and not copied from anyone or anywhere else unless the source of the information has been clearly referenced.

Learners are also reminded that confidentiality is essential in all aspects of care and that includes during their learning. They may be asked to reflect upon aspects of their role and people for whom they provide end of life care but it is very important that they do not disclose any personal information about them. They must also be very careful not to include any evidence that relates to individuals in their portfolios e.g. photographs or documents with their details on.

Portfolio of Evidence of Learning

We have recommended that learners keep a portfolio to record all the learning they have collected for this unit. This portfolio will demonstrate their understanding on the subject and will help you assess how the learner is meeting the relevant 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 wellbeing

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.

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

In their workbooks learners are informed that it is important that they provide the right type of evidence for the outcome they are trying to achieve. Remember there are 2 types of evidence:

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

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

Table 3: Suitable Evidence

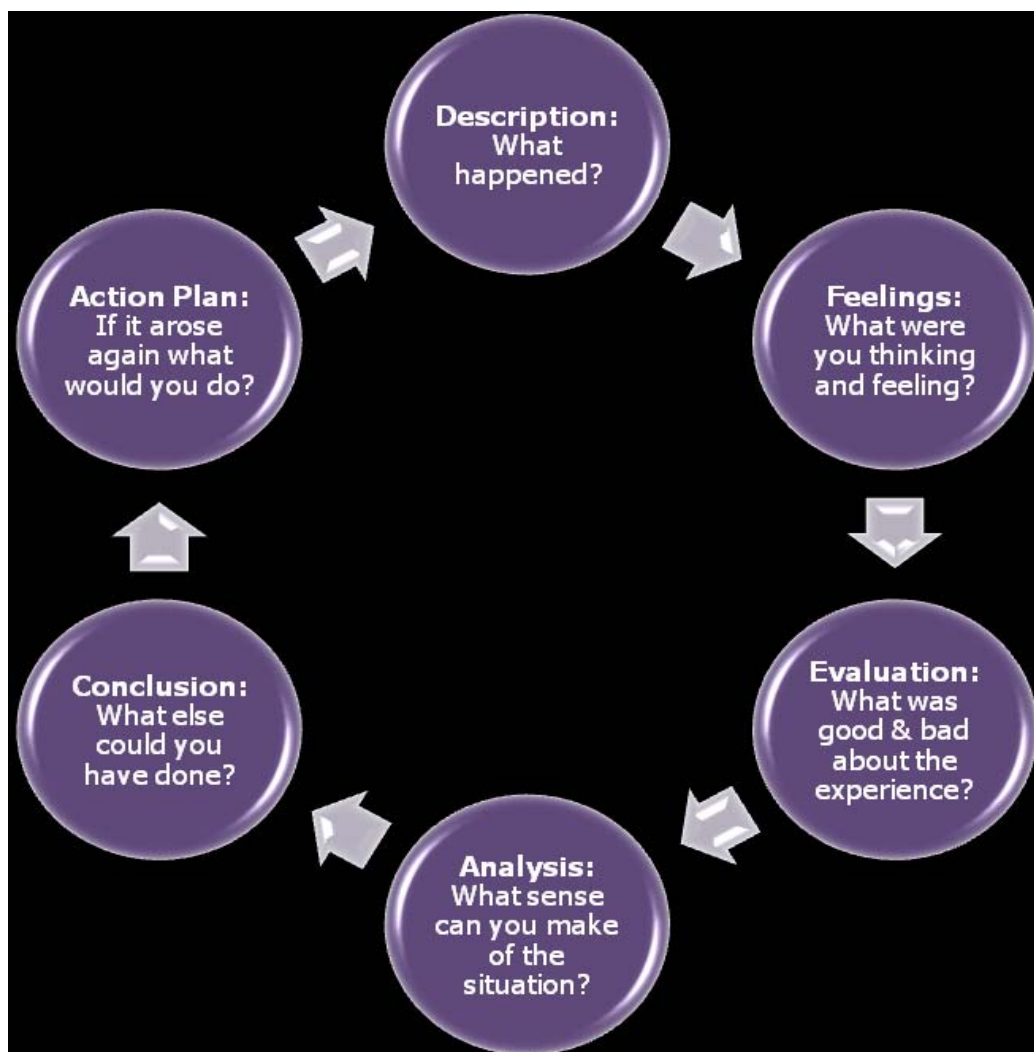
Evidence methods	Explanation	Suitable for evidencing Competence	Suitable for evidencing Knowledge
Direct observation of you by assessor	You will be observed by your assessor carrying out your everyday work activities in your learning environment	YES	YES
Professional discussion	You will take part in a pre-planned and in-depth discussion with your assessor	YES	YES
Expert Witness evidence	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	YES	YES
Work products	A work product is evidence used in your work setting and produced, or contributed to, by you. For example, care plans, daily diaries, assessments	YES	YES
Reflective diary	An on-going record of events produced by you that take place relating to your work, including evaluation and reflection	YES	YES
Reflective statement	A record of events, produced by you, that relate to an event that happened in your learning environment, including evaluation and reflection	YES	YES
Written and pictorial information	Written answers and completed activities set by your tutor or assessor	NO	YES
A scenario or case study	Written or verbal account of how you would respond to specific events set down by your tutor / assessor	NO	YES

Reflective Practice and Reflective Accounts

Learners have been provided with the following information:

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.

Pre and Post Learning Assessment

We have provided learners with pre and post learning assessments in their handbooks. This will support you and them to assess what they knew before and what they have learned when completed.

The Learner Workbook has a table asking the learner to rate how confident they feel about understanding and supporting the spiritual needs of those they care for. 1 being not very confident and 5 very confident. There is a second, identical table, at the end of the workbook for them to complete again.

Confidence level	1	2	3	4	5
Understanding the various factors that affect people views about death and dying					
Your knowledge about what an advance care plan is					
Understanding the national EOL care policy					
Knowing how to respond to difficult questions					
Recognising verbal and non verbal communication cues					
Understanding confidentiality and sharing of information					
Knowing what services support EOL care					
Knowledge of how to provide comfort at EOL					

Section 2: Activities

Introduction to understanding how to work in end of life care

In today's society, death has become a taboo subject. In the past it was not unusual for people to die at home, being cared for by family, friends and neighbours. Life expectancy was much shorter as people often died because of illness, infectious public diseases, childbirth or accidents.

However, with numerous public health advances such as clean water, better sanitation, improved housing conditions and nutrition, together with medical advances such as the discovery of new drugs and medical technologies to manage chronic illness, people's health and life expectancy has greatly improved.

As a result, there are generations who may not have cared for a dying person or seen a dead person. Death has become something that 'professionals' deal with and something that happens outside of the home; for many it has become 'medicalised' and depersonalised. Care of the dying person has moved away from the familiar surroundings of home and family to the less familiar more frightening world of hospitals and professionals. Many families and communities have lost the skills, knowledge and confidence to care for someone who is at the end of their life.

People's views on death and dying can be affected by a number of factors:

- Social
 - The attitude of family and friends
 - A person's own experiences of death and dying
 - The attitude of health or caring professionals
 - Individual characteristics such as gender or age
 - Exposure to life threatening, chronic illness
 - Media coverage
 - Their occupation e.g. nurse, doctor, carer

- Cultural
 - Death as Taboo
 - The rights of the individual
 - Role of the family
 - Role of medical profession

- Faith & Spirituality

Although many people wish to die at home, the reality for many is that they die in hospitals or care homes. Family structures have changed, family members do not always live near each other and some people do not have family. Many people have to rely on friends and neighbours and voluntary services to help them.

So what can be done, to help society regain these skills? The first thing we must do is tackle the taboo of death!

Activity 1 - 'Let's talk about death'

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			



Assessment Method: Written tasks and research

Assessment Type: Knowledge

Tutor/Assessor Guidance:

Before we can expect those we care for to talk to us about their wishes for end of life care, it is important that we understand some of the factors that can affect an individual's thoughts and feelings about death and dying.

The following activities will help learners explore how some of these factors might affect an individual's willingness to talk about the end of their life.

Activity 1: 'Let's Talk about Death'	
	Approximately 3 hours
	<p>This activity requires you to read an article and watch some video clips of people talking about death and dying. These resources look at people's views on death and dying and the factors that may contribute to them.</p> <p>'Let's Talk about Death' is a conversation about a research project which concluded that the British did not like talking about death.</p> <p>Access the BBC website below by pressing the control button on your key board and click on the link http://news.bbc.co.uk/1/hi/magazine/8058047.stm (If the link fails try copying and pasting the link into the URL bar of your web browser)</p> <p><i>Notes:</i> There should be evidence that learners have taken notes from the article and videos.</p>



Some people view death as a positive thing, as a time when they move onto another cycle of their life. Others view death as the end of life with nothing coming afterwards. As you will see, there are many factors that can affect how an individual views death and dying. These factors can include their own personal values, beliefs, religion and experiences of illness, death of a friend or someone close.

The website below contains over 50 peoples' views on death and dying, some have experienced the death of a loved one, others have been told they don't have long to live. All of them talk openly about death.

Later in this activity you will be asked to write down your thoughts about death and dying - what do you believe will happen at death? Think about this while you are watching the video clips.

Click on the link below to access the videos. Watch the Dawn French introduction before choosing the video clips that might help you answer the questions.

You should watch a range of video clips

http://www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying/Topic/1201/

Whilst you are watching and viewing, try and think about the factors that may influence an individual's views about death and dying. Write these down in the space below:

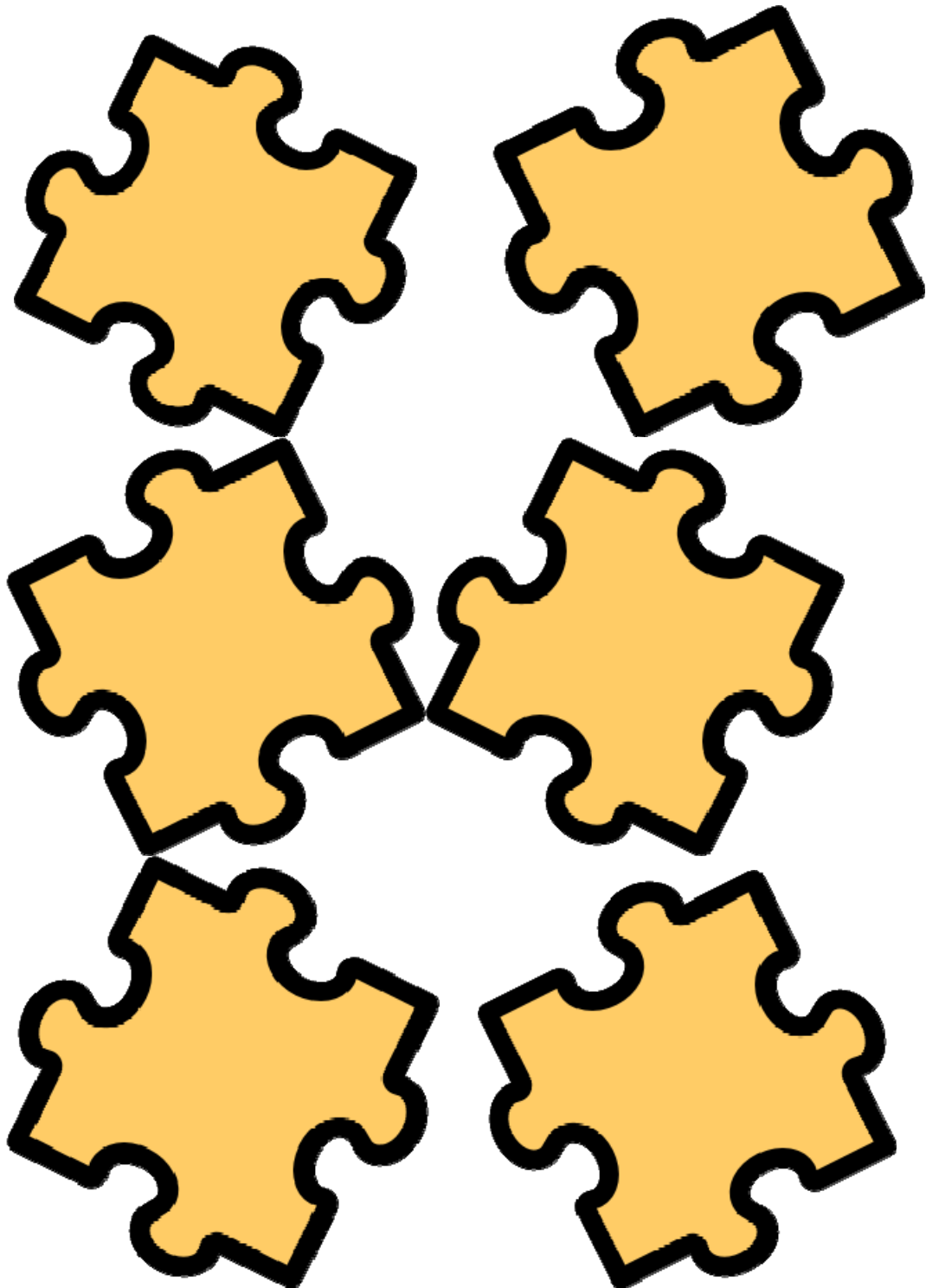
Notes:

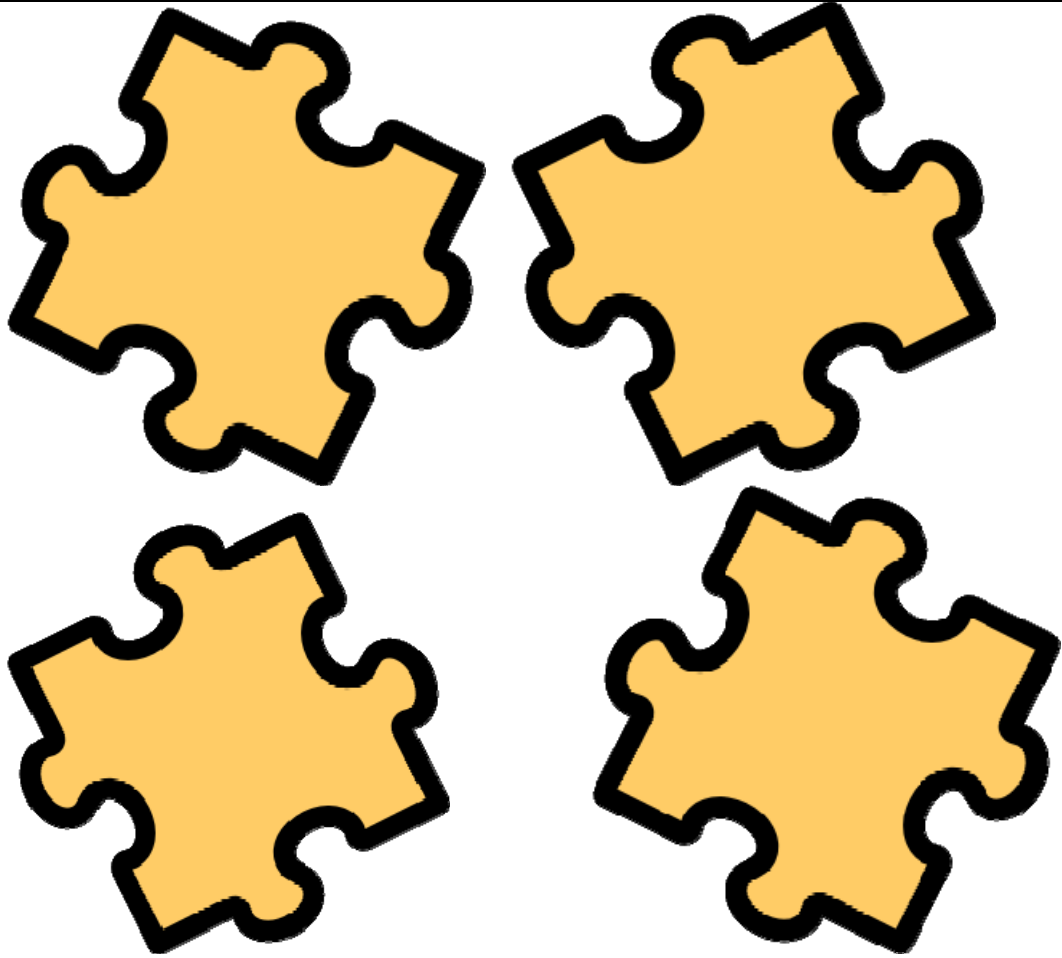


Again there should be notes to show the learner has taken information on board. Answers should include:

- Age (young people don't often talk about death)
- Gender (males are known to be more reluctant than females to talk about death)
- If they know someone who is ill
- Having a previous experience of someone dying
- If they have an illness that is getting worse
- Media coverage of death and dying
- Religious/ cultural beliefs
- Societal beliefs/ attitudes
- Family members' attitudes to dying
- Job e.g. doctors, nurse, carer
- Friends' attitudes
- Spiritual beliefs
- Exposure to crisis situations such as road traffic accidents
- Knowledge / education about EOL care

Now you have read the article and watched the video clips, review your notes and write down the factors that may affect a person's views on death and dying in the jigsaw pieces below.





Out of the 10 factors you have written down, what do you think are the 4 main factors that affect people's views and why?

1.

2.

3.

4.

The words in the jigsaw should reflect some of the factors already identified



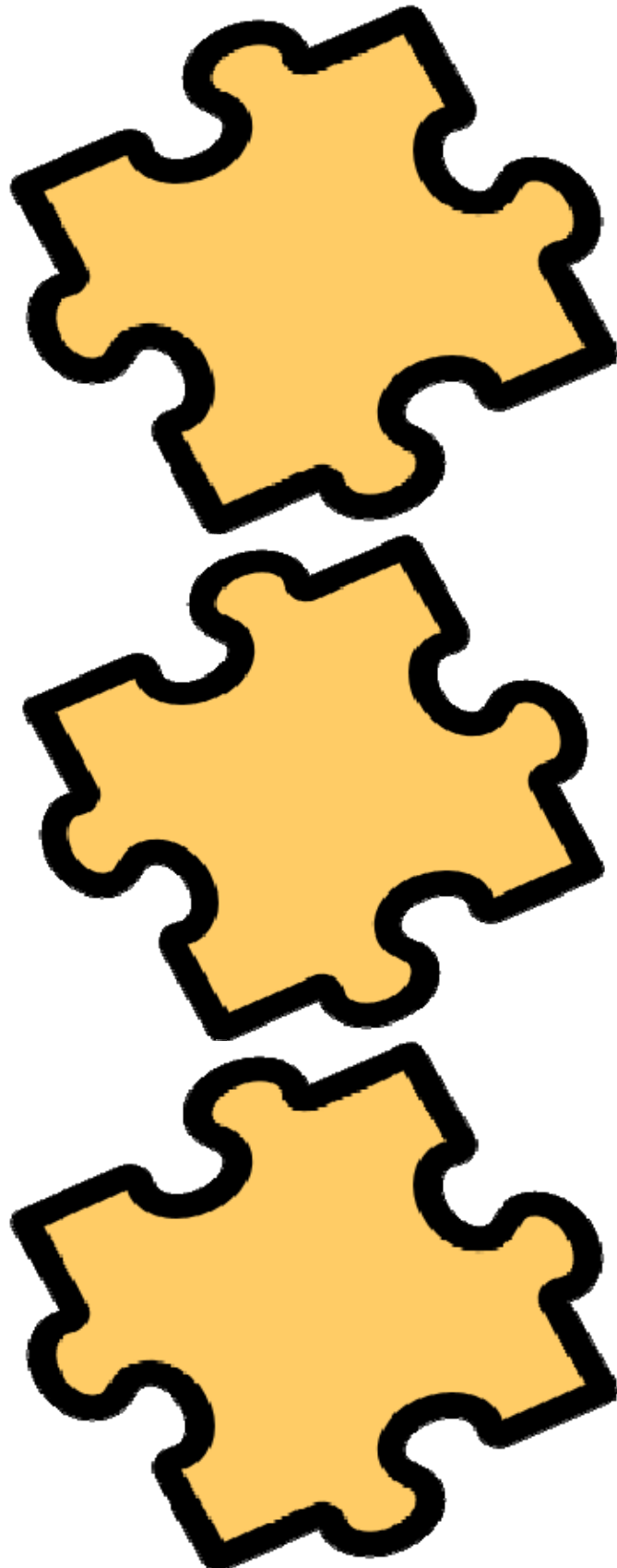
Completing this activity may have got you thinking about your thoughts about death and dying. Write your thoughts down here including:

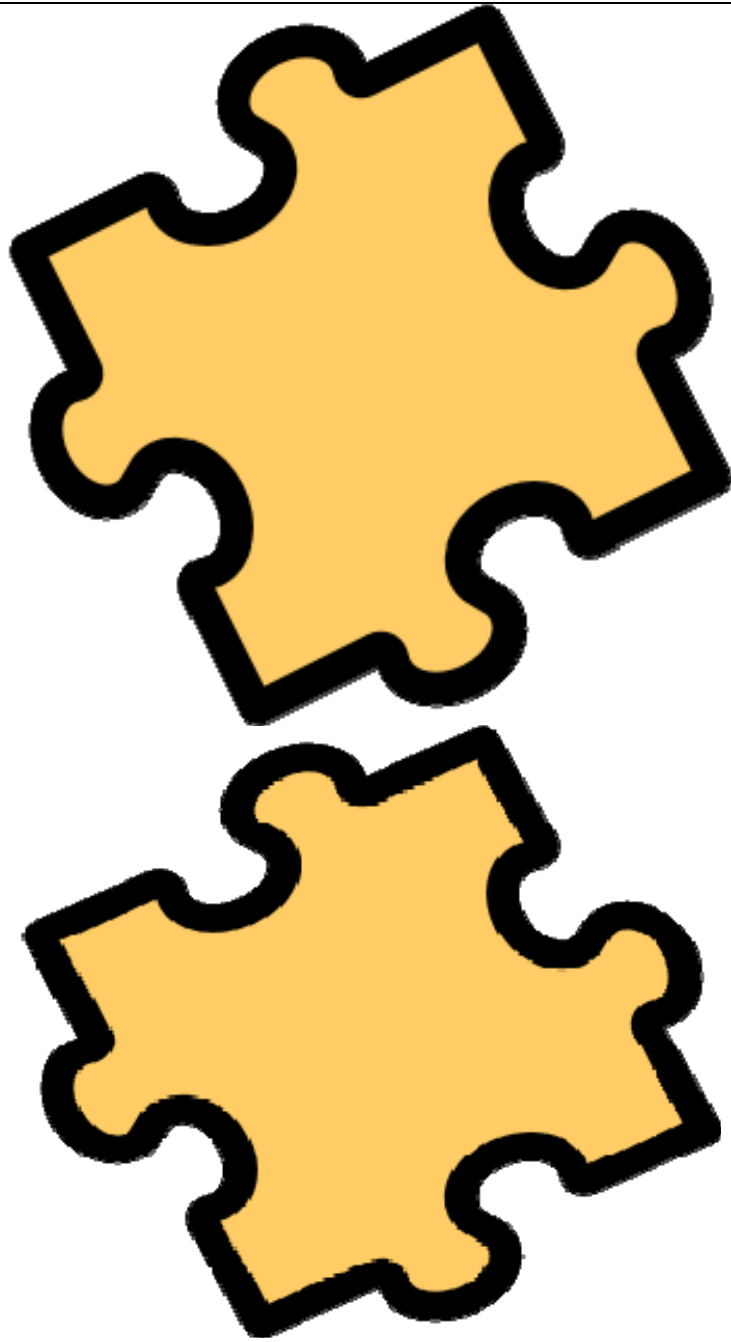
- What you believe happens at death
- Do you think there is life after death?
- Why do you think you believe what you do? Who or what may have influenced your views?

My thoughts on death and dying...

There is no right or wrong answer here but it should demonstrate learners have given thought to their own death.

Write down the 5 top factors which you feel may have influenced **your** views on death and dying in the jigsaw pieces below.





Think about experiences you may have had of death, even when you were very young. You should also think about the media and TV for influences.
This exercise is about YOUR views so make sure you write about how you really feel and not what you think you should feel or what most people feel.



Whilst still thinking about your views on death and dying, answer the following questions. **These answers are subjective but try and encourage the learner to give more than a one-word answer**

Q1

Would you want to be told you are dying, if you had an illness that was not curable and you would be expected to die within the next 12 months?

Q2

Who would you want to tell you that you were dying?

Q3

What would be your main fear or worry about dying?
Tick 1, 2 or 3 in the following table with 3 being the biggest fear or worry

EOL Concerns	1	2	3
1. Dying alone			
2. Dying in hospital			
3. Dying in pain			
4. Dying without having the chance to fulfil my religious/ cultural / spiritual customs			
5. Causing distress to my family or loved ones			
6. Leaving my loved ones behind			
7. Not having my after death wishes met			

You may have identified culture as a factor that might affect an individual's views on death and dying. Here we look at what cultural issues are.

What is culture?

Britain has become a multicultural society with a wide variety of cultures, religions and faiths. Culture can be described in general terms as “the predominating attitudes and behaviours that characterise a group or individual.”

It is important that anyone caring for others is culturally aware of the needs of others and is *culturally sensitive*. This involves an understanding of how culture shapes the values and beliefs of individuals. It is an acknowledgement of, and respect for, cultural differences.

Why is cultural awareness important?

If we ignore or fail to acknowledge another person's cultural beliefs, we run the risk of devaluing their beliefs. This can lead to a risk of stereotyping that can lead to biased or discriminatory treatment. People are individuals and do not necessarily share exactly the same cultural traits as other members of a culturally similar group.

For example let us consider British Christian culture, not all forms of Christianity are the same. Christianity has different religious churches such as Roman Catholic, Protestant and Eastern Orthodox, all with their own beliefs, values and customs.

How does cultural awareness affect EOL care?

It is important to know the cultural beliefs of the individual regardless of their ethnic origin in order to promote good EOL care. There are a number of key factors that we need to consider when thinking about EOL these are

- Individual autonomy and decision making
- Spirituality and end of life customs

Individual's right to make their own choices – cultural issues

In Western culture it is believed that the individual should make their **own choices** about treatments. It emphasises the rights of people to be **informed** of their condition, treatments and the ability to choose or refuse care. In EOL care, this knowledge helps the individual have an honest EOL discussion and helps them discuss and plan their EOL wishes.

However, not all cultures place the same value on the individual's right. In many non-Western cultures, families prefer to initially receive information before they decide how much to disclose to the person. Reasons for not telling the person include a view that such discussions are impolite or disrespectful or that open discussion may cause unnecessary upset.

However, clearly in all cases if an individual desires and is capable of understanding the implications of their illness, then their wishes should be respected and the matter must be discussed with family members who have differing views.

In modern Western cultures, a lot of importance is placed on an individual's right to make choices and decisions about treatment for themselves, this is known as **self-determination**. However some cultures place less emphasis on self-determination e.g. traditional Chinese society.

Mental Capacity

Some people do not have the ability to make their own decisions and this is known as *lacking mental capacity*. This can affect people with certain diseases such as Dementia or other conditions which affect the brain's ability to function.

It is important that if someone has a condition that may affect their ability to make decisions for themselves in the future, then they are informed about Advance Decision to Refuse Treatments. This is a legal form people can fill out which makes it clear to everybody what their decision would be for a treatment e.g. whether they would want in the future to be artificially fed.

Spirituality


Spirituality can be described as "matters concerned with or affecting the soul", something which gives meaning to an individual's life. It can include the belief that after death, a person's soul or spirit continues in another realm of existence. It is not necessarily the same as religion which is often more structured and has its own characteristics and values and beliefs.

Spirituality is more concerned with the individual's *own consideration of meaning and purpose of their lives* and their relationship with themselves and others.

Failing to address spiritual needs can cause concern, distress and potential conflict similar to that of failing to address religious beliefs. Getting spiritual care right can give strength, provide relief and build trusting relationships.

Religion

Spiritual or religious practices also play an important role in preparing for death. They include prayer, chanting, sacred texts or sacraments. Ceremonies can be performed at the bedside to ease the passage of dying and religious leaders may be present to pray with the family. In some cultures the whole of the extended family is expected to pray with the family at the bedside.

	<p>In addition to a broad understanding of beliefs, views relating to handling the body after death, organ donation and autopsy should be considered.</p> <p>British culture expects calm and controlled mourning which is often different to the natural practice of grief expressed in other cultures.</p> <p>Acknowledging cultural differences helps effective communication and enables trust between concerned parties. It also demonstrates your respect of the person and their values, which promotes dignity.</p> <p>Source: S.M. Carey, J.F. Cosgrove. <u>Cultural issues surrounding end-of-life care</u>. Journal Current Anaesthesia & Critical Care (2006) 17, 263–270.pub Elsevier accessed on line 09/02/2013</p>
	<p>Now look back at your answers for Q3 above - what factors do you think influenced the choices you made? This is again subjective to the learner's own experience.</p> <p>Circle as many as you like</p> <p>Religious Attitudes</p> <p>Attitude of the Family & Social Networks</p> <p>Cultural/ Societal Attitudes</p> <p>Personal experiences/ Factors</p> <p>Media Attitude</p> <p>Others Please State below:</p>



Helpful Further Reading/ Resources

If you want find out more about how the attitudes of others can influence individual EOL choices then you may find the following websites useful:

Dying Matters Coalition

<http://www.dyingmatters.org/>

Cultural Issues <http://sc->

[chepts.org/EndOfLife/004CulturalissuesSurroundingEndOfLifeCare.pdf](http://sc-chepts.org/EndOfLife/004CulturalissuesSurroundingEndOfLifeCare.pdf)

Factors that affect our views on deaths and dying

http://journeyofhearts.org/kirstimd/AMSA/self_assess.htm#Answers:

NB: Resources for this activity are combined with activity 2 & 3 and can be found at the end of activity 3.

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 2 – How views on death and dying can impact on practice

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Scenario

Assessment Type: Knowledge

Tutor/Assessor Guidance:

In activity 1 the learner identified a number of factors that can affect people's views on death and dying, including their own personal views. In this activity learners are going to explore how those factors and the views of others, can affect the way EOL care is delivered.

When talking about the practice of others it is important to introduce important ethical and legal issues that affect others practice.

In EOL, health & social care workers often have different views to family members; however it is important to ensure that learners understand that in this country the right of the individual to be informed about their care is a legal right.

Only in exceptional circumstances does the law allow this information to be withheld from someone who wishes to know.

1. The legal rights of patients in the United Kingdom

In the UK individuals have the following legal NHS rights:-

- ***The right to give or withhold consent for treatment*** (unless the person is detained under the Mental Health Act 1983) as somebody being held under this act would be deemed to have lost the ability to make choices whilst detained under the act.
- ***The right to information*** – individuals are entitled to clear information given to them in an appropriate language, so that they can make informed decisions about proposed treatments and the alternative options, and potential risks and side effects
- ***The right to an appropriate standard of care*** - health professionals must use reasonable care and skill when treating people, and patients are entitled to receive care of a standard which a 'responsible body of medical opinion' considers to be appropriate to their condition. If this duty of care is breached, the patient may win a negligence claim.
- ***The right to confidentiality***- information about a person's diagnosis, condition, prognosis, treatment and other personal matters must be kept confidential by health & social care workers. Confidential information may only be given to relatives if the patient consents, and should only be given to other people in very limited circumstances.

2. The Doctors Code of Ethics

General Medical Council: 'Duties of a doctor'

The General Medical Council (GMC) is responsible for the supervision of the medical profession. Doctors have to take what is known as the Hippocratic Oath (Hippocrates was a Greek philosopher)

Patients must be able to trust doctors with their lives and health. To justify that trust doctors must show respect for human life and they must:

- Make the care of their patient their first concern.
- Protect and promote the health of patients and the public.
- Provide a good standard of practice and care.
- Treat patients as individuals and respect their dignity.
- Work in partnership with patients:
 - Listen to patients and respond to their concerns and preferences.
 - Give patients the information they want or need in a way they can understand.
 - Respect patients' right to reach decisions about their treatment and care.
 - Support patients in caring for themselves to improve and maintain their health.
- Be honest and open and act with integrity:
 - Act without delay if you have good reason to believe that they or a colleague may be putting patients at risk.
 - Never discriminate unfairly against patients or colleagues.
 - Never abuse their patients' trust in them or the public's trust in the profession

In this country individuals have the legal right to be **informed** of their condition, treatments and to refuse care. However, not everyone wishes to be informed of their prognosis even though they have this right. This is where good communication skills and knowing the individual can help the doctor do the right thing. If someone is asking what is wrong with them, unless there is a very good reason not to, the doctor must legally inform them, so they can make informed decisions about treatments etc. At EOL this is a difficult conversation to have and many individuals will need support after receiving such news.

Activity 2: How views on death and dying impact on practice



Approximately 1 hour



Read the scenario below and answer the questions following it.

Mrs Delgado is a 68 year old Mexican lady who has a history of heart failure and during the last year she has had 3 unplanned admissions to the hospital. She has lived in the Sunny Days residential home for the last 5 years, ever since her husband died. Mrs Delgado has a key worker called Sunita whom she trusts.

On morning Sunita went to assist Mrs Delgado get dressed and she noted her breathing was very laboured. Sunita informed Mrs Delgado that she thought it would be a good idea for her to call the GP. Mrs Delgado asked Sunita for her rosary beads and asked her to call her son.

Sunita called the GP Dr Jones and Mr Delgado and both arrived very quickly. After the GP examined her, Mrs Delgado asked the GP if she was dying and should she call the priest. Before the GP could respond her son told his mother not to be so silly and she would get better soon with a change of pills and plenty of rest.

Mr Delgado said he wanted to see the GP right away in private. He asked the GP about his mother's prognosis. Dr Jones said he felt she was in the last few months of her life as the treatments were no longer working and her heart failure was now in the terminal phase.

Mr Delgado asked Dr Jones not to tell his mother that she was not going to get better as he did not want her to lose 'the hope of life'. Dr Jones explained he could not do this as his mother had full capacity and was asking about her condition and asking if she should call the priest.

Mr Delgado became quite annoyed, stating he knew his mother better than Dr Jones and in his culture the family decided when to tell somebody they were dying, not the doctor. He was very concerned that if his mother knew she was dying she would get depressed, give up on life and not be able to take the bad news. He blamed the shock of losing her husband for her bad heart and wanted to protect his mother from such shocking news. He then turned to Sunita and said under no circumstances was his mother to be told of her prognosis.



Questions & Answers

You may wish to talk this scenario over with your tutor/assessor or mentor before answering the questions. Use additional sheets.

1. What factors might be affecting Mr Delgado's views on how best to manage his mother's future care? Can you list them?

Factors that may be affecting Mr Delgado's views

- Cultural – role of family in decision making is important in South America
- Influence of previous loss of a parent
- Fear about how his mother will cope with the news
- Possibly own fear of losing both parents – facing his own mortality

2. Do you agree that Dr Jones should inform Mrs Delgado that she will not get better and is dying? Explain the reasons for your answer.

- It is best practice to be honest with patients
- Mrs Delgado has full capacity and can therefore make her own decisions about her future care
- Mrs Delgado clearly knows something is wrong which is why she is asking for the priest

3. If Dr Jones agreed with her son and did not inform Mrs Delgado what effect would this have on her ability to make her EOL plans, (which would include a blessing from the Roman Catholic Priest)

If Dr Jones does not tell the patient, the impact on her EOL plans will be affected in the following way

- Her EOL wishes will be unknown
- Her religious needs will not be met
- She will feel isolated as she cannot talk to her relatives about her wishes and death if they don't want to tell her she is dying

4. How might Sunita be feeling about this situation?

- Sunita might be feeling angry with Mr Delgado as he is not putting his mother's wishes first.
- She might be feeling confused and worried about how to handle Mr Delgado when the doctor goes



Helpful Further Reading/ Resources

If you want find out more about how the attitudes of others can influence individual EOL choices then you may find the following website useful

Dying Matters Coalition
<http://www.dyingmatters.org/>

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 3 – End of Life Influence

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Scenario

Assessment Type: Knowledge

Tutor/Assessor Guidance:

As we have seen, often families fail to talk to each other about EOL plans and wishes. The wishes of others can sometimes cause conflict within families and cause tension between health and social care workers, family members and individuals. This activity will enable the learner to appreciate how the views of a family member can influence an individual to change their mind about their EOL wishes. Encouraging family members to make advance care plans together can reduce this unnecessary distress during the last few weeks of life.

Activity 3: End of Life Influence



Approximately 1 hour



Read the scenario below and answer the questions following it.

Ron is an 86-year-old man who has Congestive Heart Failure. Ron has always been independent and still lives in his own home that he previously shared with his beloved wife Edith who died 5 years ago.



Having suffered a recent decline in his health, Ron is currently in hospital. The doctors have done what they can to make Ron comfortable but there is no further treatment they can give him.

Ron's daughter Mary has been visiting him when she can, although she has a very busy and stressful job. One morning when Mary visited, Ron found the courage to tell her that he knew he didn't have long left and he wanted to go home to die. Mary told him she didn't have the time to be with him at home all the time and that he was better off staying in

hospital where the staff could watch over him as she was worried about him being at home alone.

When the doctor did his rounds, Mary told him what Ron had said. The doctor sat down with them both and said it was Ron's decision and that arrangements could be made for him to return home. Mary got upset and told them she was really not comfortable with him going home alone and she would be very worried and unable to concentrate at work. Ron decided he would try to raise the subject again when she came to visit next time, as she was clearly upset, unfortunately Ron died in hospital 4 days later.

What was Ron's EOL wish and why was this important to him?

- Ron wanted to die at home
- It was important to him because that was where he had lived all his life with his wife.

What was Mary's wishes for her father's death and why ?

- Mary wanted Ron to stay in hospital
- She was worried she did not have the time to look after him with her job
- She was worried that he could not be left on his own at home.

What was the outcome for Ron?

- He did not get his EOL wishes met.

What feelings will Mary have now guilt or relief father died in hospital, or both? Discuss.

- Mary may be feeling guilty that she could not care for her father
- Sad that he has died
- Relieved that he died in hospital because she thought that was the best place for him as she could not care for him at home.

How do you feel about what happened to Ron? Is there anything that would have helped Mary and Ron agree what was best for him at EOL –write down what could be done?

Learners will have their own views on this scenario. However they should identify that if Mary and Ron had talked about his wishes earlier and made a plan in advance this would not have caused such tension between them and maybe Mary would have a better understanding of Ron's wishes and would have supported him more.

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 1 & 2 & 3 - Resources

Web resources

1. BBC website *Let's Talk about Death Baby'*
<http://news.bbc.co.uk/1/hi/magazine/8058047.stm>

2. *Living with Dying*
http://www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying/Topic/1201/

Activity Sheets

Introduction to Cultural Issues

2. *Personal experiences of death worksheet (classroom only) be aware that someone may get upset doing this.*
3. *Religious wall chart (classroom only)*
4. *Mrs Delgado Role Play + Ron Role Play (classroom only)*
5. *Spirituality Hand-out (classroom only)*

Power Points/ Lesson Plans

Power Point 1: Factors affecting Views on Death and Dying.
Lesson Plan 1: Factors affecting Views on Death and Dying.

E-learning resources

E: ELCA modules that support the 201 unit can be found in the following document
EOL 201-1.doc

Further Reading

If you want find out more about how the attitudes of others can influence individual EOL choices then you may find the following web site useful

1. *Dying Matters Coalition. Death as a Taboo Subject.*
<http://www.dyingmatters.org/>
2. *Cultural Issues*
<http://sc-chepps.org/EndOfLife/004CulturalissuesSurroundingEndOfLife.pdf>

Activity 4 – Aims and Principles of EoL Care

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			


Assessment Method: Written work and professional discussion

Assessment Type: Knowledge

Tutor/Assessor Guidance:

In the previous activities learners have explored the various factors that affect an individual's attitudes and values to EOL care and how cultural and societal influences can shape these individuals beliefs.

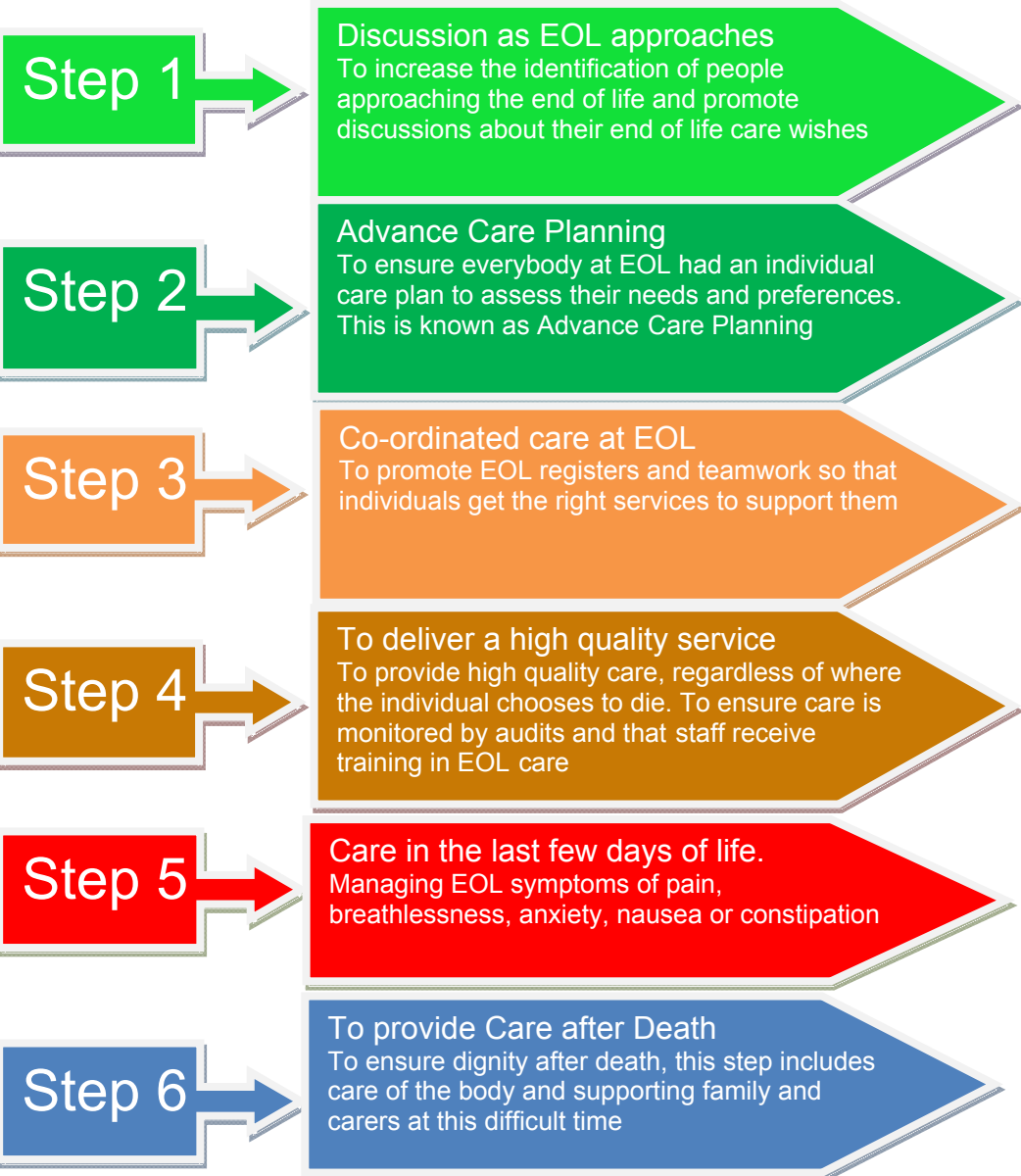
In this section learners will consider the aims and principles of end of life care, to ensure that they can understand how the National End of Life Strategy is shaping and influencing EOL care at a local level.

Activity 4: Aims and Principles of EoL Care	
	Approximately 2 hours and 30 minutes
	<p>Everybody deserves a 'good death' and although every individual may have a different idea about what would, for them, make a 'good death', for many this would involve the following 4 things:</p> <div style="border: 1px solid black; border-radius: 15px; padding: 10px; background-color: #e6f2ff;"> <ol style="list-style-type: none"> 1. Being treated as an individual with dignity and respect 2. Being without pain and other symptoms 3. Being in familiar surroundings 4. Being in the company of close family/friends </div> <p>To make this happen the Department of Health identified some main aims and principles to help people have a 'good death' in the National End of Life Strategy (DH 2008). The strategy promotes high quality care for all adults at the end of life, by providing people with more choice about where they would like to live and die.</p>

Aims of EOL Care

1. To treat people as individuals, with dignity and respect
2. To ensure people have a comfortable death with their physical and psychological needs met.
3. To ensure people can die in the place of their choosing, in familiar surroundings and in the company of close family/friends.
4. To ensure religious and spiritual needs are met.
5. To ensure cultural needs are met.

The strategy developed a EOL care pathway which had the following **6 principles. This is known as the Six Step EOL Care Pathway**





Thinking about Your Own Death

You have read what others have said would be a good death, what would be a good death for you? Write down your thoughts in the clouds.

These answers will be subjective



As a health/social care worker you will often talk to individuals about their death; it is not a subject that is easy to talk about. How did thinking about your own death make you feel? Write your feelings in the boxes.

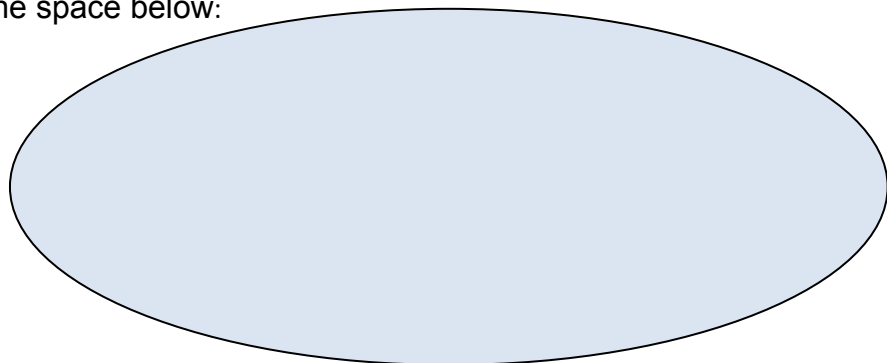
These answers will be subjective

Talk to 5 people, possibly your friends, family or colleagues, about what having a good death would be to them. Write down their answers in the box below. **These answers will be subjective but similar themes should emerge.**

Person	Comments and thoughts about what a 'good death' would be
1.	
2.	
3.	
4.	
5.	

How many of the people you asked about what would make a good death for them mentioned:

1. Being treated with respect?
2. Management of pain, breathlessness or the other EOL symptoms?
3. Having friends and family close?
4. Dying in a place of their choosing?
5. What was the thing most people mentioned? Write key words in the space below:





Can you put the following places of death in order, with 1 being the most common place that you think people die



Home



Hospital



Hospice



Care/ Nursing home



Other place

1. Hospital----- 2. Home-----
 3. Nursing/Care Home----- 4. Hospice-----
 5. Other-----

Have you heard the saying 'an elephant in the room'? Do you know what it means? Here is a definition:

"An important and obvious topic, which everyone present is aware of, but which isn't discussed, as such discussion is considered to be uncomfortable."



As a society we do not talk about death and dying, this contributes to its low profile in health and social care

Most people do not discuss their own preferences for end of life care with their partner or family, hampering individual planning and the quality of their EOL care.

- Most would probably like to die at home but only 18% manage to do this.
- 17% die in care homes or nursing homes
- 58% of all deaths occur in hospital
- Around 4% take place in hospices
- The rest die in other places such as streets, roads etc.

It is clear from the figures above that despite many people saying they would like to die at home only 18% manage to do this, with the majority of deaths occurring in the hospital.

Look back at your answers to where you thought most people died, did you get any of them right? Use the space below to say what you got right and wrong and why you put the answers you did.



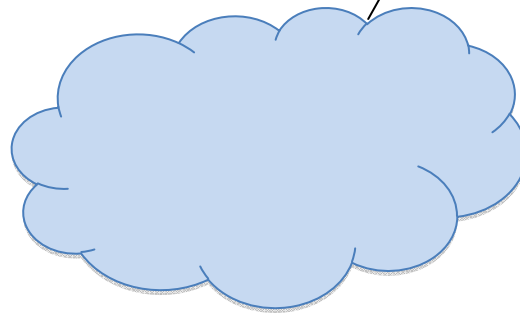
Learners should identify where their answers were different and why they put places of death in the order they did



The Main Aims of EOL Care

What do you think the main aims of End of Life care are?
Write your thoughts below.

To meet people's wishes



1. To treat people as individuals with dignity and respect
2. To ensure people have a comfortable death with physical and psychological needs met
3. To ensure people can die in the place of their choosing, in familiar surroundings with the company of close family and/or friends
4. To ensure religious, spiritual needs met
5. To ensure cultural needs are met

Introduction to Dignity

Dignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals.

In care situations, dignity may be promoted or diminished by the physical environment; organisational culture; by the attitudes and behaviours of care teams and others and by the way in which care activities are carried out.

When dignity is present people feel in control, valued, confident, comfortable and able to make decisions for themselves. When dignity is absent people feel devalued, lacking control and comfort. They may lack confidence and be unable to make decisions for themselves. They may feel humiliated, embarrassed or ashamed (RCN 2006).

In this activity we will explore the concept of dignity and highlight how this can help to personalise the care for someone at the end of their lives.



Write your thoughts to the following questions.

Q. How do you think you could promote someone's dignity in end of life care?

Learners should relate this to the paragraph above and the 8 dignity factors on the SCIE web site that are identified below.

Research indicates that there are eight main factors that promote dignity in care. Each of these Dignity Factors contributes to a person's sense of self-respect and they should all be present in care.

Choice and Control

Enabling people to make choices about the way they live and the care they receive

Communication

Speaking to people respectfully and listening to what they have to say; ensuring clear dialogue between workers and services

Eating and Nutritional Care

Providing a choice of nutritious, appetising meals that meet the needs and choices of individuals and support with eating where needed

Pain Management

Ensuring that people living with pain have the right help and medication to reduce suffering and improve their quality of life

Personal Hygiene

Enabling people to maintain their usual standards of personal hygiene

Giving Practical Assistance

Enabling people to maintain their independence by providing 'that little bit of help'

Privacy

Respecting people's personal space, privacy in personal care and confidentiality of personal information

Social Inclusion

Supporting people to keep in contact with family and friends, and to participate in social activities

Promoting Dignity at EOL

- Recording the likes, dislikes and preferences of a person at the end of life in one place is a simple but important step towards achieving personalised care whether from health or social care services.
- When people receive care that reflects what is important for them, it helps to make them feel more in control, more secure and helps maintain their dignity.
- An understanding of what is important for a person at the end of life means staff will have better ideas of how to support and reassure them.

(from SCIE website)

Compare what you have read above to your answer above - did you miss out any of the main factors of dignity? If so which ones, write them in the box below

Learners should compare their answer above; did they miss any of the 8 dignity factors? If they did, they should ensure that they include them here.

For people approaching the end of life, a personalised approach gives them a voice and influence over their care at EOL and helps maintain their dignity.

Click on the following link to access SCIE Personalisation at EOL and watch the video clip

<http://www.scie.org.uk/socialcaretv/video-player.asp?v=endoflifecarepersonalisation>



Now you have watched the video clip and read the dignity information explain in your own words why you think it is important to support somebody's dignity at EOL.

Learner should identify some of the following dignity factors in their explanation.

1. Choice and Control
2. Communication
3. Eating and Nutritional Care
4. Pain Management
5. Personal Hygiene
6. Giving Practical Assistance
7. Privacy
8. Social Inclusion



Helpful Further Reading

National End of Life Programme: EOL dignity in care support sheet.
RCN (2006) Definition of Dignity
http://www.rcn.org.uk/_data/assets/pdf_file/0003/191730/003298.pdf

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activities 4 - Resources

Web resources

SCIE Personalisation at EOL video clip

<http://www.scie.org.uk/socialcaretv/video-player.asp?v=endoflifecarepersonalisation>

Activity Sheets

1. Actual Place of Death worksheet (classroom only)
2. Having a Good Death worksheet (classroom only)
3. NHS Support Sheet 6 Promoting Dignity and Dignity Information sheet 8 dignity factors (classroom only)

Power Points/ Lesson Plans

1. Lesson Plan 2: Aims and Principles of EOL Care and Dignity
2. Power Point: Aims and Principles of EOL Care and Dignity

E-learning resources

E: ELCA modules that support the 201 unit can be found in the following document
EOL 201-1.doc

Further Reading

1. National End Of Life Strategy (DH 2008)
2. Six Steps to Success Programme

Activity 5 – Maintaining Comfort and Wellbeing

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Written tasks and research



Assessment Type: Knowledge

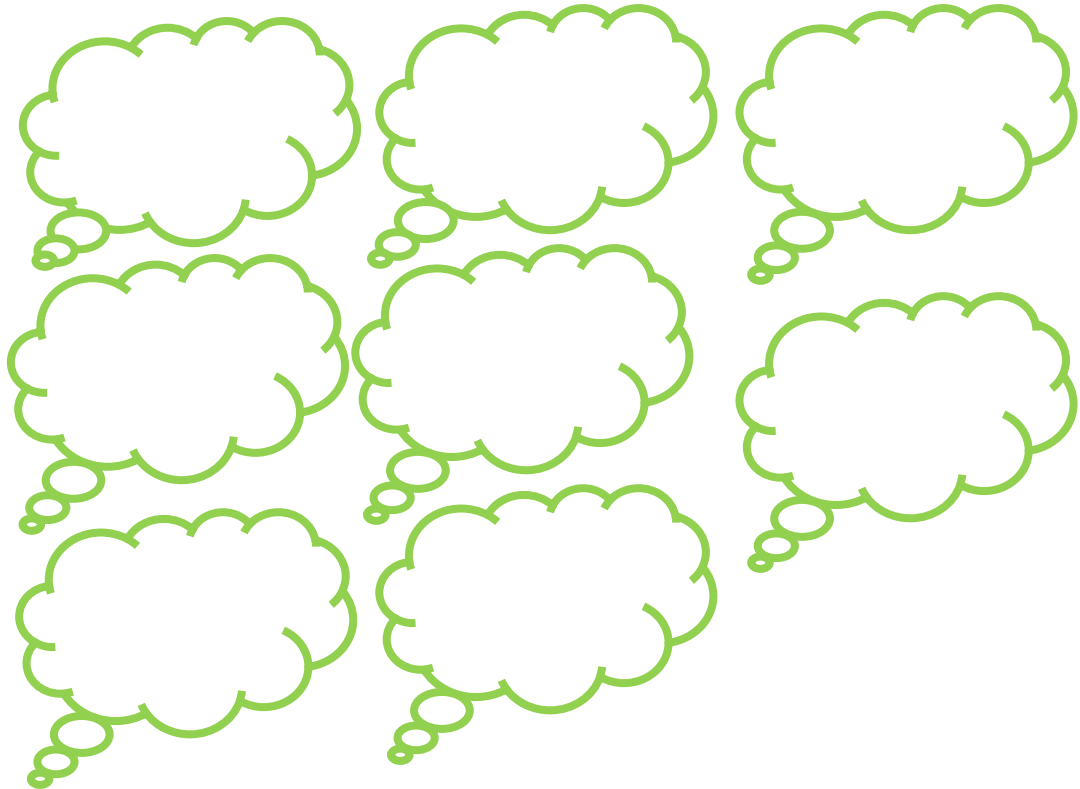
Tutor/Assessor Guidance:

Learners will now explore the importance of keeping somebody comfortable at the end of their life.

The end of life phase can be the 12 month period before they die.

There are some common symptoms that affect people at EOL and it is important that individuals at EOL are helped to feel comfortable and that they are supported to live well until they die. These activities can be upsetting for learners so please consult support agreements.

Activity 5: Maintaining comfort and wellbeing	
	Approximately 1 hour and fifteen minutes
	<p>Can you think of some of the symptoms individuals may have at EOL, write them in the bubbles below</p> <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 2px solid green; border-radius: 50%; width: 200px; height: 150px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 200px; height: 150px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 200px; height: 150px; margin: 10px;"></div> </div>



You may have identified some of the symptoms below.

Pain

Pain is probably the most feared symptom at the end of life. Not every illness that leads to death causes pain but other underlying conditions may still exist -- an individual dying of heart failure who also has arthritis, for example. Other diseases, like cancer, usually do cause pain. Whatever the illness is, the ability to recognise and help manage pain is essential.

Click on this link to hear how people cope with their pain

http://www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying/Topic/1199/



Breathlessness

Shortness of breath occurs more frequently than pain at the end of life and can be even more troubling. Some degree of breathlessness is common in most individuals as they near death. This can usually be well managed by a few really simple and effective treatments that can bring quick relief.

Anxiety

Anxiety is perfectly normal and quite common at the end of life. It is important that the cause of the individual's anxiety is identified in order for this to be reduced. If the anxiety is severe it may involve counselling and medical treatment

Nausea and vomiting

As illnesses become worse and medications such as painkillers become stronger, they are more likely to cause feelings of nausea with or without vomiting as a side effect. Sometime the illness itself can cause these symptoms too. This can be a really troubling symptom for the individual experiencing it. Medication can be given to reduce this symptom.

Constipation

Medications used to treat pain and shortness of breath can cause constipation, as can lack of activity when the person at EOL gets weaker and less mobile. Constipation is a symptom that can become severe and cause distress to individuals. Medication can help relieve this symptom.

Secretions building up in the chest (Death Rattle)

End-stage wet respirations are the medical term for secretions that build up in the airway when an individual becomes too weak to clear those secretions out. The accumulation of mucous and fluids causes a rattling sound with breathing that is not thought to be distressing to the dying person and is probably more distressing to the individual's loved ones. Medications given at end of life can sometimes reduce these.

Confusion and Agitation

Confusion, agitation and sleeplessness can occur in some individuals at the end of life. Delirium can be caused by disease process, medications, or a number of other things. Medications can help reduce this symptom.

(Reference Morrow .R. 2011: Common Symptoms at the End of Life)

Available at

<http://dying.about.com/od/thedyingprocess/tp/Common-Symptoms-At-The-End-Of-Life.htm>



Think about how you support the people you provide EOL care for to remain as comfortable as possible. If it helps, think of a specific individual but remember not to include names or personal information about them. Include what symptoms they had and how you managed to maintain their comfort and wellbeing.

Learners should reflect here about managing the symptoms at EOL and attending to cultural, spiritual and faith needs. They should also include psychological support to the dying person, their relatives and significant others.



Further reading

Tips to Help You Recognize and Manage End-of-Life Symptoms

<http://dying.about.com/od/thedyingprocess/tp/Common-Symptoms-At-The-End-Of-Life.htm>

One of the aims of EOL care is to keep people as comfortable as possible and manage their symptoms so they can make the most of the days they have left and, when the time comes, help them have a dignified, comfortable death.

Supporting an individual through the last stage of their life and helping them achieve their EOL wishes can be one of the most rewarding and precious things you can do for another human being.



Hospices provide specialist care for those who are terminally ill and offer specialist advice on how to manage symptoms at EOL and a range of other services to maintain well being.

Click here to see a film from Help the Hospices to see what good EOL and palliative care means to those people who are dying.

<http://www.helpthehospices.org.uk/about-us/film/>

Discuss the following question with friends/colleagues. How does society view terminally ill people? Write some key words down here:

Words Pity, avoidance, drain on resources, diseased, infectious, basically society views the terminally ill in a negative way.

Maintaining wellbeing for those at EOL is really important. Many people who are terminally ill say that people avoid them and treat them differently.

Looking at the words and comments above, what do you think the reasons are for these comments? Write your thoughts down here:

Views As a society we tend to shy from death, terminally ill people make us confront the reality we are mortal and this makes us feel threatened/ awkward.

Most terminally ill people say they want to be treated normally. They want to 'add life' to the time they have left and do the things they have always wanted to do.

The following film from Dying Matters highlights these wishes



<http://www.dyingmatters.org/page/last-laugh>

How do you think we can maintain an individual's wellbeing at EOL? Write your thoughts here:

Maintaining wellbeing – treat as normal, treat with respect and dignity, help them feel a whole person, encourage them to do the things they like, help them to live as well as they can until they die.

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activities 5 - Resources

Web resources

Click here to see a film from Help the Hospices to see what good EOL and palliative care means to those people who are dying.

<http://www.helpthehospices.org.uk/about-us/film/>

film from Dying Matters highlights these wishes

<http://www.dyingmatters.org/page/last-laugh>

Activity Sheets

Power Points/ Lesson Plans

Maintain Comfort and Wellbeing PowerPoint
Maintain Comfort and Wellbeing Lesson Plan

E-learning resources

E: ELCA modules that support the 201 unit can be found in the following document
EOL 201-1.doc

Further Reading

Activity 6 – The End of Life Care Pathway

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Written tasks and research

Assessment Type: Knowledge

Tutor/Assessor Guidance:

The Integrated End of Life Care Pathway, as set out in the End of Life Care Strategy (DH 2008), comprises of six steps and was developed to help anyone providing health and social care to people nearing the end of life. It aims to ensure that high quality, person-centred care is provided which is well planned, co-ordinated and monitored, while being responsive to the individual's needs and wishes.

However 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 good EOL care.

One of the national tools used to promote good care in the **last days** of life is called the Liverpool Care Pathway (LCP). The Liverpool Care Pathway is recognised as a model of good practice in the last hours and days of life and has been implemented in hospitals, care homes, in the individual's own home / community and into the hospice.

Currently the LCP is under a government review due to public concern following recent media coverage. A consensus statement has been produced by leading organisations in palliative care, supporting the LCP and this can be found in the resources folder for these activities along with a FAQ sheet.

It is useful to point out to learners that some areas use their own integrated pathway in the last few days of life and learners should find out which pathway is used in their own area. Whatever pathway /framework is used this subject often evokes strong emotions and it is important that any group session is carefully managed by a considered and informed debate.

Activity 6: The End of Life Care Pathway



Approximately 2 hours and 30 minutes



In activity 4 we considered the 'Six Steps EOL care pathway'. The 6 steps are identified again below for you, this time write an example in each arrowed box of how you could meet that step. For example:



Step 6

To provide care after death:
Ask the family if they would like a drink and to talk about anything before they leave

Then underneath each step write why you think that step is important and what would happen if it wasn't considered.

Step 1

Discussion as EOL approaches:

Step 1 is important because: Learner should identify that this is where the conversation can happen about someone's EOL life wishes. People are identified as being in the last 12 months of life. Some learners may note that not everyone wants to make EOL plans or discuss it.

Step 2

Advance Care Planning:

Step 2 is important because: Advance Care Planning, Preferred Priorities of Care, ADRT and lasting Power of Attorney can be discussed to ensure care is also holistic and personalised This will ensure that any unwanted treatments are known about in advance and ensures that an individual's views are known and respected.

Step 3

Co-ordinated care at EOL:

Step 3 is important because: Many people can be involved in providing care at EOL. It is important that the individual at EOL and their family have their care co-ordinated to avoid any duplication or omission of care and that everyone involved is kept up to date with the individual's condition and progress.

Step 4

To deliver a high quality service:

Step 4 is important because: Social care and health care providers have to meet the standards set for care by the Care Quality Commission (CQC) and meet the various quality markers for EOL care. It is important that the delivery of care is monitored, to ensure a good standard of care is maintained and any areas of concern are addressed.

Step 5

Care in the last few days of life:

Step 5 is important because: Managing the common symptoms of EOL care is very important. Individuals want to die pain free, with comfort and dignity. In addition how somebody dies stays in the memory of others and no one wants to see the person they care about suffer or have a traumatic death.

Step 6

To provide care after death:

Step 6 is important because: It ensures dignity after death, including care of the body and supporting family and carers at this difficult time.

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. The way in which someone dies is a lasting memory for the individual's relatives, friends and the care staff involved. It is important that the person dying can be confident that any expressed wishes, preferences and choices will be reviewed and acted upon and that their families and carers will be supported throughout.

One of the national EOL pathways used to promote good care in the last days of life is called the Liverpool Care Pathway (LCP).

The Liverpool Care Pathway for the Dying Patient is a model of care that helps health and social care workers to focus on care in the last hours or days of life when a death is expected. It is tailored to the person's individual needs and includes consideration of their physical, social, spiritual and psychological needs.

The LCP was developed by the Royal Liverpool & Broadgreen University Hospitals NHS Trust and the Marie Curie Palliative Care Institute Liverpool (MCPCIL), which is supported by Marie Curie Cancer Care. The MCPCIL oversees the development and dissemination of the Liverpool Care Pathway.

The LCP requires senior clinical decision-making, communication, a management plan and regular reassessment. It is not a treatment in itself but a plan for managing care that aims to support, but does not replace, clinical judgement.

The Liverpool Care Pathway is recognised as a model of good practice in the last hours and days of life and has been implemented in hospitals, care homes, in the individual's own home / community and into the hospice. The pathway guides staff in the treatment of the common EOL symptoms and requires staff to review the patient on a regular basis. The LCP ensures that the physical, psychological, social, religious, cultural, and spiritual needs of the individual are met at EOL



There are a number of myths about the LCP and it is important that as a care worker you know the fact from the fiction. This will enable you to support individuals and their families and loved ones etc.

In order to separate the fact from the fiction read

- The FAQ LCP fact sheet and
- Kate Granger's (2012) article. *The Liverpool Care Pathway for the Dying Patient improves the end of life*

<http://www.guardian.co.uk/society/2012/nov/13/importance-open-end-to-life>

Now answer the following questions by ticking Myth or Fact.

No	Statement	Myth	Fact
1	The LCP is used during the last months of life	Myth	
2	The LCP was developed by The Marie Curie Palliative Care Institute Liverpool		Fact
3	All treatment for somebody on the LCP should be stopped	Myth	
4	Discussions about placing someone on the LCP should not be discussed with the relatives/ family members due to confidentiality reasons	Myth	
5.	The LCP will ensure the individual is heavily sedated	Myth	
6	The LCP states that Clinical Artificial Hydration and Nutrition (AHN) such as drips should be stopped	Myth	
7	The LCP is a form of euthanasia	Myth	

Some areas use their own version of the EOL pathway. Find out which pathway your local area uses for people in the last few days of life and make a note of it in the box below.

Learner should seek out and provide local care pathway, it could be the LCP, it could be something else.



For information of EOL Pathway and each step click on the following link <http://www.endoflifecare.nhs.uk/care-pathway>

NB Resources guide can be found after activity 7

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 7 – Advance Care Planning

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Written tasks and research

Assessment Type: Knowledge

Tutor/Assessor Guidance:

In this unit so far learners have looked at a number of issues that affect an individual's EOL care, they have considered a number of issues:

- The different perspectives on death and dying
- How views on death and dying can impact on practice.
- How the attitudes of others may influence an individual's choices around death and dying
- The aims and principles of end of life care and why it is important to promote dignity

The learners will now explore Advance Care Planning and discuss issues such as Mental Capacity, Preferred Priorities of Care, Lasting Power of Attorney and Best Interest Meetings.

Activity 7: Advance care planning



Approximately 1 hour and 15 minutes



Making plans about your future care is called Advance Care Planning (essentially you are planning your care in advance)



Question:

In what step of the 6 steps programme does Advance Care Planning occur?

Answer:

Advance Care Planning can include one or more of the following three things:

1. Making a Preferred Priorities of Care Statement (known as a PPC document)
2. Making an Advanced Decision to Refuse Treatment (Known as a ADRT)
3. Appointing a Power of Attorney in case an individual loses the ability to make decisions for themselves.

1. Preferred Priorities of care

- This is a voluntary discussion with the individual re EOL planning
- Better accepted at an earlier stage of disease
- Individual must have capacity to have the conversation
- Maximises likelihood of end of life care in the setting of the person's choice
- Not legally binding

- Should be taken into account as part of best interest decision making

Note on Capacity:

“A person must be assumed to have capacity unless it is established that they lack capacity” (MCA 2005). If you suspect a lack of capacity due a condition that has affected their brain or cognitive function, a capacity assessment must be done before any decision is made.

2. Advanced Decision to Refuse Treatment

- This is a legally binding document
- Only comes into effect when individual loses mental capacity
- Can only be used to refuse treatment
- Applies to refusal of specific treatments e.g. IV antibiotics, PEG feeding
- Cannot be used to refuse basic comfort care

3. Lasting Power of Attorney

- This is a legal document
- Can appoint someone to deal with finance and property and / or health and welfare decisions on persons behalf.
- Needs to be registered with Office of Public Guardian
- Enduring Powers of Attorney made and signed before October 2007 can be used



Now Read the Planning For Your Future Care Document or access online

<http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/planning-for-your-future-care.aspx>

As a care worker it is important to talk to individuals who are at EOL



about Advance Care Planning as it is an essential part of providing good EOL care

Now watch this film by a gentleman called Peter Ashley who has Dementia and has made an Advance Care Plan.

<http://www.youtube.com/watch?v=-S--Y2mpESw>

In the box below explain the 3 principles of Advance Care Planning in your own words.

- Making a Preferred Priorities for Care Statement (known as a PPC document)
- Making an Advanced Decision to Refuse Treatment (known as an ADRT)
- Appointing a Power of Attorney in case an individual loses the ability to make decisions for themselves

Now write **your own** Preferred Priorities of Care Wishes in the box below

This will be subjective

How did doing this make you feel?

This will be subjective to the learner

How do they think it makes individuals feel?

Thoughts on process will be subjective, however learner should pick up some people may not want to do ACP. Some will be keen to do it, others may be unsure so it is important to recognise cues from people.

Do they think it is important to talk to people about EOL wishes?

Learner should identify that it is very important to try and promote Advance EOL discussions; however they should also be mindful that some people do not wish to have the conversation and they may need to wait for some other triggers, such as an admission to hospital to sensitively try again.



For further Information on Advance Care Planning clicking on this link

<http://www.endoflifecare.nhs.uk/care-pathway/step-2-assessment,-care-planning-and-review/advance-care-planning.aspx>

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 6 & 7 - Resources

Web resources

Guardian article on doctor use of LCP

<http://www.guardian.co.uk/society/2012/nov/13/importance-open-end-to-life>

Activity Sheets

Maud Scenario

Planning your future care document

supportsheet4_1 (2) (ADRT support sheet)

SS 18 Preferred Priorities of Care (PPC support sheet)

Power Points/ Lesson Plans

1. Lesson Plan 4 Care in last days of life
2. All about the LCP PowerPoint
3. Lesson Plan 5 Advance Care Planning
4. Advance Care Planning PowerPoint

E-learning resources

E: ELCA modules that support the 201 unit can be found in the following document
EOL 201-1.doc

Further Reading

LCP_V12_Core_Documentation

Liverpool_Care_Pathway___FAQ_23_August_2012

Activity 8 – Local and National Policy for Care after Death

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.



1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5	2.6	
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Written tasks and research

Assessment Type: Knowledge

Tutor/Assessor Guidance:

These activities will help the learner realise that good end of life care doesn't stop at the point of death. When someone dies all staff need to follow good practice, which includes being responsive to family wishes and helping relatives/ partners cope with their loss. In addition there are various health & safety procedures and legislation that need to be followed after a death has occurred. There are some reflective exercises in this section, so please refer to learners support agreement.

Activity 8: Local and national policy for care after death	
	Approximately 1 hour
	<p>Care after death includes honouring the spiritual or cultural wishes of the deceased person and their family and carers, and referring to any Advance Care plan will help identify these needs.' (NEOLP)</p> <p>The care of someone after death was often called the 'last offices' however the term that is used today is 'care after death'</p> <p>Now have a look at the national guidance on last offices. This useful guidance covers the following aspects of care after death:</p> <p>http://www.endoflifecare.nhs.uk/assets/downloads/Care_After_Death_guidance.pdf</p> <p>Care after death includes:</p> <ul style="list-style-type: none"> ➤ Honouring the spiritual or cultural wishes of the deceased person and their family/carers while ensuring legal obligations are met.

- Preparing the body for transfer to the mortuary or the funeral directors premises and offering the family the opportunity to participate in the process, supporting them if they wish to do so.
- Ensuring the privacy and dignity of the deceased person is maintained and wishes for organ and tissue donation are honoured.
- Ensuring that the health and safety of everyone who comes into contact with the deceased person is protected.
- Returning the deceased person's possessions to their relatives.



Find your local policy for 'last offices' or 'care after death', ensure you place a copy of your local policy in your portfolio. In the space below write some of the important points that you need to know from the policy:

Learner should find local policy and compare to national RCN one and ensure that the following are covered by the local policy.

- Care before death
- Care at time of death
- Care after death
- Transfer of deceased body

Summary

1. Care Before Death

- Use of LCP
- De-activation of implanted cardiac defibs
- Discuss wishes of individual (refer to ACP)
- Find out about organ donation
- Faith & spiritual wishes (especially quick cremation wishes)

2. Care at Time of Death

- Record time, who was present
- Inform medical practitioner, verify death (this can be done by trained nurse)
- Record if patient has known infection and if it is infectious then follow local infection control policy
- Follow local policy for personal care/ washing of the body 'last offices'
- Inform NOK if not present at death

3. Care After Death

- Meet legal requirements regarding coroner's reporting.
- Communicate with funeral directors arrange for body to be taken.
- Treat deceased person and possessions with respect.
- Support family to view deceased person.
- Provide family with written information about registering the death.

4. Transfer of deceased

- Ensure deceased is transferred in a suitable container.
- Try to avoid distressing others.
- Follow infection control procedures.
- Ensure all records are written up and completed

Discuss with friends/colleagues personal experiences of giving care after death before writing your thoughts here and include the following:

Answers should attempt to get people's views and experiences highlighted by the questions.

What was it like?

What did other staff members do?

How were relatives cared for or if not present, how were they informed?

What did the doctor/nurse do?

Who else was informed?

How did the staff react?

What support did they get from others after they had finished caring for the person at EOL?

Was the deceased person treated with dignity?



Further Reading

A student nurse's account of performing 'last offices'

<http://nursingstandard.rcnpublishing.co.uk/students/dealing-with-your-first-death/carrying-out-last-offices/dignity-of-the-last-offices-ritual-impressed-me>

What to do when someone dies – Dying Matters

<http://www.dyingmatters.org/page/what-do-when-someone-dies>

National End of Life Programme Fact Sheet : What to do when someone dies.

<http://www.endoflifecare.nhs.uk/care-pathway/step-6-care-after-death.aspx>

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 8 Resources

Web resources

A student nurse's account of performing 'last offices'

<http://nursingstandard.rcnpublishing.co.uk/students/dealing-with-your-first-death/carrying-out-last-offices/dignity-of-the-last-offices-ritual-impressed-me>

What to do when someone dies – Dying Matters

<http://www.dyingmatters.org/page/what-do-when-someone-dies>

Activity Sheets

NHS Support sheet SS 09 What to do when someone dies V2

Power Points/ Lesson Plans

Lesson Plan Care after Death
Care After Death PowerPoint

E-learning resources

E: ELCA modules that support the 201 unit can be found in the following document
EOL 201-1.doc

Further Reading

care_after_death___final_draft___20110610 (3) RCN national guidance PDF.

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

Activity 9 – Communicating with ill people

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: E-learning

Assessment Type: Knowledge

Tutor/Assessor Guidance:

This activity provides an introduction prior to learning about how to communicate effectively with individuals in an end of life care setting.

By completing the online e-learning 03 03

<http://www.e-lfh.org.uk/projects/end-of-life-care/> learners will develop or review their understanding of the underlying principles of 'Communicating with ill people'. The material will give them guidance on how they can make their conversations with individuals with an illness more effective. It will also provide learners with the opportunity to reflect on how they communicate with others

Points that should be covered in the discussion:

- Factors that can make it challenging to communicate with ill people in end of life care
- Recognising when there is a need to stop a conversation
- Strategies for making communication with ill people more effective
- Challenges that may be encountered whilst communicating with ill people
- How priorities and ability to communicate may vary over time

Activity 9: Communicating with ill people



Approximately 1 hour



Complete the Free ELCA e-learning module – Communicating with ill people <http://www.endoflifecareforall.com/> (once you have completed this module print and put the certificate in your portfolio)

Make notes on key points from your reading and e-learning module below:

Notes:

Having read the e-learning module, learners key points should include:

An individual's ability to communicate may be affected by how their illness is making them feel at that time. If they are in pain, feeling nauseated, tired, lack energy or have problems concentrating they might not wish to communicate.

Certain conditions also can directly affect communication such as stroke, ear infections and deafness, dysarthria (slurred speech) and depression.

There may be other factors that affect their ability to communicate such as cultural issues, language barriers, learning disabilities, educational attainment, noisy environment, lack of privacy.

To help individuals who are ill communicate more effectively you can

- Assess the individual's ability to communicate before you go to individual - get to know a little about the person and if they are likely to have any difficulties communicating
- Provide the right environment, quiet and private if possible
- Introduce self and check they know who you are and why talking with them
- Ask them if they are happy to talk with you
- If you some-one is hard of hearing check out ability or understanding by asking questions such as: 'can you hear me well enough'
- Adapt your normal style of communication to meet individual's needs – to take on board any barriers or effects of illness
- Talk at a normal or slower pace than usual
- Use straightforward language and keep sentences short.
- Give individuals time to understand
- Only give small chunks of information – give time to absorb and then ask questions
- Even if people say they understand look out for non verbal cues – puzzled expression
- Pick up on verbal and non verbal cues that they may wish to stop talking such as loss of eye contact, inappropriate questions, looking disinterested or distracted
- Summarise information

End conversation, explain why you think it is best to stop and tell individual when you will come back, ask if ok to come back or that you will come back with a colleague to help with you the conversation.



Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 9 - Resources

Web resources

Activity Sheets

Power Points/ Lesson Plans

Use as a pre-requisite for workshop Effective Communication in End of Life Care Lesson Plan and PowerPoint – Fundamentals of communication and what affects ability to communicate effectively. Common Emotions and Responses to end of life care illness.

E- Learning Resources

ELCA e-learning module 03 03 – Communicating with ill people
<http://www.e-lfh.org.uk/projects/end-of-life-care/> needs registration (Free)

Or

<http://www.endoflifecareforall.com> open access site
Communication Module

Further Reading

Booklet - Effective Communication Skills in End of Life Care

Activity 10 – Communication Quiz

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Quiz

Assessment Type: Knowledge

Tutor/Assessor Guidance:

Effective Communication Skills are considered a Core Competency in End of Life Care (DoH, SfH, SFC 2009). They are vital in ensuring that the needs of people nearing end of life, their families and carers are identified, responded to and met with respect and compassion.

Hence, learning about essential communication skills will boost a support worker's confidence and competence in helping individuals identify and meet these needs (NEoLC Programme 2010).




Learners are asked to read the recommended communication skills booklet to gain an introduction to the principles of communication within end of life care. They can then test their knowledge by completing the quiz.

This activity can be undertaken independently or within or at the end of a communication skills' teaching session. On completion, the learner can be provided with the answer sheet for their reference.

Points that should be covered in the discussion:

- Principles of the communication process
- Observing an individual's body language and understanding the implications
- Effective Listening Skills and signs of a poor listener
- Recognising emotional responses to illness, loss and grief in end of life care

Activity 10: Communication Quiz

	<p>Approximately 1 hour and 30 minutes</p>
	<p>Read the booklet: 1. Effective Communication Skills in End of Life Care</p>
	<p>Following the reading you should now complete the communication quiz below but you may want to make some notes here first.</p>
	<p style="text-align: center;">QUIZ</p> <ol style="list-style-type: none"> 1. Why is it important to be an effective listener in end of life care? It allows individuals to talk about their needs and any concerns which they may have. It will help them to psychologically cope better with their terminal illness 2. What types of body language show you are listening? <ul style="list-style-type: none"> • Eye contact, • Facing individual and leaning towards them, • Nodding, • Attentive facial expression 3. List five actions that would demonstrate you were not listening? <ol style="list-style-type: none"> 1) Asking questions which do not respond to individual's words 2) Not giving individual eye contact 3) Appearing distracted or looking bored – looking out the window, at clock, responding to phone, yawning, reading someone else's, notes, fidgeting. 4) Have a dreamy expression – we are giving eye contact but eyes have glazed over because we are thinking of something else 5) Not picking up on cues and changing the subject 6) Talking about our own experiences – 'oh yes I remember when' or 'that has happened to me' 7) Start giving advice 8) Placate – say things like right, absolutely, I know, of course. 4. Describe three emotional responses, or stages, individuals may experience when they are facing a terminal illness. <i>May include:</i> <ul style="list-style-type: none"> • Loss of control • Loss of identity • Distress Exhaustion & Fatigue • Fear & Confusion • Sadness • Anger & Frustration • Withdrawn • Revulsion • Guilt • Acceptance • Relief • Inadequate / helpless



5. How would you respond to a person who was:

- Crying? Offer them a tissue, reassure them by giving them permission to cry – ‘it’s ok to cry’, sit quietly beside them, be aware of personal space but use gentle non invasive touch - hand on elbow, shoulder, hand. Give them time.
- Anxious? Observe and listen - establish what they are really afraid of. Be alongside, be truthful and reassure where able. Provide explanations, When no more to say or do, just have the courage to be quietly there.
- Angry? Listener absorbs anger. Remain calm. Acknowledge their anger but do not apologise if they are angry about something that has happened or not happened. Do not agree or disagree if they are angry about someone’s behaviour.
- Not wanting to say anything but looking scared or sad? Allow silences but if goes on too long can empathise to prompt. Acknowledge struggle – it’s very hard. Avoid glib responses as this trivialises and it’s important to stay with patient’s mood. Don’t just assume situation is making them sad – may be clinically depressed so may need to be assessed and treated by a Doctor.

6. How would you respond to someone who you know is terminally ill saying to you ... “Do you think I’m getting better, I don’t seem to be in so much pain”?

Why would you respond in that way?

Answers should include points such as:

- Try not to panic, ignore or change subject because I think I don’t know what to say.
- Show them you are happy to listen – give them full attention, sit down with individual.
- Reflect back question to them.
- Use gentle and calm tone to say something like:
- “Is that what you think (say their name) – if you are not in pain you may be getting better?”
- Stay quiet and give them time to respond
- Would not want to give them a dishonest reply which would be disrespectful and would not be picking up on a cue that they want to talk about their illness, concerns etc.
- Own fears often prevent us from allowing individuals talk about their difficulties.

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 10 - Resources

Web resources

Activity Sheets

Communication Skills Quiz Sheet

Listening skills self assessment

Power Points / Lesson Plans

Workshop Lesson Plan & PowerPoint – Effective Communication in End of Life Care

Communication Skills Answer Sheet

E- learning Resources

Further Reading

Booklet - Effective Communication Skills in End of Life Care

Communication Skills Module 03 - ELCA e-learning module <http://www.e-lfh.org.uk/projects/end-of-life-care/> needs registration (Free)

Activity 11 – Communication Scenario

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Scenario

Assessment Type: Knowledge

Tutor/Assessor Guidance:

This activity will enable learners to put what they have learnt into practice by working through a communication scenario. Although it may not be set in their specific care setting, it is a typical scenario that could be easily transferrable as the skills utilised will be comparable

Following the role-play, learners will be asked to consider the skills they used, how the individual responded to them and how they responded to the individual. This will allow them to evaluate the impact of different strategies and consider their responses when asked questions regarding sensitive and emotional issues. It aims to enable the learner to effectively support individuals to express their preferences, needs and concerns.

The learner is advised to refer back to what they have learnt in previous activities to support them through this activity.



Facilitator notes and guidance notes for role players have been provided which are applicable for independent study or a group teaching setting.


It is advised that the learner be given some guidance and reassurance regarding the ground rules of role-play prior to undertaking the activity.

Points that should be covered in the discussion:

- Principles of the communication process
- Observing an individual's body language and understanding the impact
- Empathy
- Effective Listening Skills and signs of a poor listener
- Recognising emotional responses to illness, loss and grief in end of life care
- Strategies for responding to an individual's emotions

Activity 11: Communication Scenario

	Approximately 3 hours and 30 minutes
	<p>Ask a friend, colleague or your mentor to help you with this activity. Think about how to respond to 'difficult questions' by working through the following scenario.</p> <p>In this scenario you will be a health care worker and your partner should act as Vera.</p>
	<p>The scenario</p> <p>Vera is an elderly lady who has been in hospital for two weeks with a chest infection. She has chronic obstructive airways disease and this is her third hospital visit this year.</p> <p>She is getting better and is waiting to hear if she can go home. However she still gets very tired and can still be breathless just while she is resting. Talking can also make her breathless.</p> <p>She doesn't like being in hospital as everyone looks ill and it makes her worry that she is more ill than she wants to believe she is. She doesn't like to talk to the doctors because she is afraid she will hear something she doesn't want to hear. She also tries to talk to her daughter but she always seems in such a rush when she visits that Vera doesn't like to keep her too long. It also seems to upset her if she tries to talk about her worries, particularly when she wants to talk about where she wants to be when she is too unwell to look after herself or what should happen with her house and money when she dies.</p> <p>She also has lots of other questions she wants to ask. Vera decides she will talk to that friendly care worker who will be helping her this morning.</p> <p>The Activity: Remember to ask someone to play Vera for you.</p> <p>Your role</p> <p>Just be yourself but imagine you are caring for Vera in a hospital ward.</p> <p>Don't Panic! - Just try to remember what you have learnt about how to effectively listen (refer back to the booklet in activity 7) and keep focused on her words and feelings. You could respond by saying something like – “why do you say that Vera”?</p> <p>You don't really know the answers but rather than agreeing, disagreeing or offering your opinion, try to use your active listening skills to encourage Vera to do all the talking.</p>

	<p>(Tip: read over the effective communication skills booklet to remind you of the different techniques if required).</p> <p>It is your role to support Vera and encourage her to talk about her concerns and feelings.</p> <p>You come into the ward to help Vera have her morning wash and she catches you off guard as she starts to talk about how she is feeling breathless and asks the questions on her mind.</p> <p>Vera: “I don’t think I’m going to get any better nurse. “</p> <p>Vera: Why does my breathing not get any better – does it mean I could be dying?</p> <p>Vera: Who is going to look after me when I get home?</p> <p>Vera: Am I going to be put in a nursing home?</p> <p>Vera: How can I make sure that my daughter will not give all my money to that no good boyfriend of hers?</p>
	<p>Now you have acted out the scenario, how do you feel it went? What went well, what did not go quite so well?</p> <p>Briefly answer the following:</p> <ol style="list-style-type: none"> 1. What was it like being asked the difficult questions? 2. How did you first respond? 3. Did you portray a sense of time and calm? 4. Did you consider Vera’s privacy? 5. Did you listen and observe Vera’s non-verbal communication and respond by saying what you were seeing e.g. did Vera look sad, distressed, did it sound as if it was difficult for Vera to ask questions or say certain things? 6. Did you use non-verbal and verbal communication such as eye contact, posture, nods, expressions, light touch, lean forward? 7. Did you use encouraging prompts or open questions such as how, when, where, what, why? 8. Did you use reflection to support the speaker, ask her to clarify meaning, repeat her words to help her reflect on what she was saying and how she was feeling?

9. Did you summarise what she was saying to show you understood and had a sense of what she was saying or feeling?
10. Did you help Vera think about why she was asking the questions or why she felt the way she did?
11. Did you empathise, acknowledge her feelings, paraphrase and reflect back her words?
12. Were you supportive, calm and quiet – did you allow for silences?
13. Did you avoid giving your opinion or practical advice?
14. Did you avoid clichés?
15. What have you learnt and how would you do things differently now?

Learners should demonstrate an understanding that if they have answered 'no' to some of the questions they asked themselves, following the scenario, they should be thinking about appropriate responses and listening skills to change their practice.

Knowledge should include:

Awareness of own non-verbal communication skills and reasons why own fears and opinions can impact upon listening and emotionally supporting someone at end of life.

- Portrayed a sense of time and calm
- Respected privacy
- Listened and observed Vera's non-verbal communication
- Responded by saying what was being seen or heard (e.g. did Vera look sad, distressed, did it sound as if it was difficult for Vera to ask questions or say certain things?)
- Used non-verbal and verbal communication – eye contact, posture, nods and expressions, light touch, lean forward
- Used encouraging prompts – open questions – how, when, where, what, why?
- Used reflection e.g. support Vera, ask her to clarify meaning, repeat her words to help her reflect on what she was saying and how she was feeling
- Summarised what Vera was saying to show understanding and had a sense of what she was saying or feeling.
- Helped Vera think about why she was asking the questions or why she felt the way she did?
- Used empathy – acknowledging Vera's feelings, paraphrase and reflect back her words.
- Was supportive, calm and quiet and allowed for silences
- Avoided giving opinion or practical advice
- Avoided clichés

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 11 - Resources

Web resources

Activity Sheets

Communication Scenario Observers sheet or assessment sheet

Power Points/ Lesson Plans

Workshop Lesson Plan & PowerPoint – Effective Communication in End of Life Care

Facilitator Notes – Responding to difficult questions

Support Worker Participant notes – Responding to difficult questions

Vera Participant notes - Responding to difficult questions

E- Learning Resources

Further Reading

Booklet - Effective Communication Skills in End of Life Care

Holistic common assessment of supportive and palliative care needs for adults requiring end of life care (2010) – National End of Life Care Programme in partnership with Cancer Action Team.

Activity 12 – Sharing Information Acceptable or Unacceptable?

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Written tasks and research

Assessment Type: Knowledge

Tutor/Assessor Guidance:

This activity enables support workers to apply the principles of Data Protection Act (1988) to end of life care. They will be taught that the same principles apply as in all areas of Health and Social care when recording, reporting and discussing an individual's personal care situation.

All work settings will have their own Data Protection and Best Interest policy and process in place. The following activity has been designed so that learners have the opportunity to read and understand them. This is a very important aspect of care so they should discuss anything they don't understand with their manager, colleagues or tutor/assessor.

Learners have been provided with some key learning resources that can be selected according to their level of experience and understanding. Facilitator notes and guidance notes for role players have been provided and are applicable for independent study or a group teaching setting.

Points that should be covered in the discussion:

- Seeking Consent
- Mental Capacity and Best Interest Decision Making
- Confidentiality
- Permitted Disclosure
- Written and verbal communication
- Documentation

Activity 12: Sharing Information acceptable / unacceptable



Approximately 2 hours



Read your organisations Data Protection Policy and a resource describing the Data Protection Act such as <http://www.dataprotectionact.org>/The Data Protection factsheet (Dec 2011 www.nvqmadefsimple.com) is also helpful.

Look at the three statements below regarding confidentiality and data and state whether you think the statements are acceptable or not.

- A. Someone calls your place of work saying they are a relative of one of your service users and they want to know how long they have to live. You tell them they have a prognosis from the medical staff of 6-8 weeks.

Acceptable Unacceptable

What is the reason for your answer?

- a. This information is confidential to individual, you did not have permission or consent to give relative this information.
- b. Policy is cannot disclose information over the phone as you do not actually know individual is who they say they are.
- c. It is not your responsibility to discuss medical information to relatives – you should have referred to Senior Carer or Doctor.

- B. You are just writing up Mrs Andrews’ care plan when Mrs Smith calls into the office to ask you to help her father back to his room. She notices you writing the notes and says ‘Oh have you been looking after Mrs Andrews today, I see she’s not so well, did she have a bad night?’ Which of the following would be acceptable for you to reply? Tick as many as you think may be acceptable.

- 1. Yes I’m afraid she isn’t feeling so well today. Did you say you wanted help with your father?
- 2. Yes unfortunately she has had a really bad episode of back pain. Did you say you wanted help with your father?
- 3. I’m sorry Mrs Smith, I appreciate your concern but you know we cannot discuss other service user's situations. Did you say you wanted help with your father?
- 4. Yes I’m afraid I’ve had to call in her family because she’s been really confused all night. Crying out and everything. Perhaps you would like to sit with her until her daughter arrives.

What is the reason for your answer?

Acceptable:

Reply 1: Yes I'm afraid she isn't feeling so well today. Did you say you wanted help with your father?

You have replied in a polite caring way in response to Mrs Smith's concern but you have provided a broad statement that does not disclose any confidential medical information to Mrs Smith. However you have politely moved the conversation on to her father that implies you are not able to discuss anything further.

Reply 3: I'm sorry Mrs Smith, I appreciate your concern but you know we cannot discuss other resident's situations. Did you say you wanted help with your father?

You have replied in a caring way in response to Mrs Smith's concern however you have politely moved the conversation on to her father which implies you are not able to discuss anything further. This would also demonstrate to Mrs Smith that confidentiality is taken seriously and respected in the care setting.

Not Acceptable:

Reply 2: Yes unfortunately she has had a really bad episode of back pain. Did you say you wanted help with your father?

The reply gives too much detail regarding Mrs Andrews. Back pain is confidential as it is referring to a detail about her illness. Mrs Smith is not a relative or named Next of Kin.

Reply 4: Yes I'm afraid I've had to call in her family because she's been really confused all night. Crying out and everything. Perhaps you would like to sit with her until her daughter arrives.

The reply gives too much detail regarding Mrs Andrews and discloses confidential information about her illness. Mrs Smith is not a relative or named Next of Kin.

HOWEVER it may have been a consented arrangement that Mrs Smith does have involvement in Mrs Andrews in this way. This therefore may have been acceptable. Consent should always be obtained by the individual concerned or through a best interest consent process if an individual has incapacity.

C. Dr Johnson (GP) is visiting Fred Thomas to prescribe him some analgesia. Whilst he is in the office he notices that Jack Matthews is listed as a new admission. "Oh I see Jack has been admitted he's a great old gentleman. He's full of interesting tales especially when he's enjoying a swift whiskey. Is he not so well? The wife and I wondered why we hadn't seen him in the Legion lately". He picks up and starts to read the referral letter from Jack's GP, Dr Alan (a colleague from another practice in the town).

Is this

Acceptable

Unacceptable



What is the reason for your answer?

Jack is not Dr Johnson's patient. Occasionally doctors share patient caseloads but Dr Johnson does not share a practice with Jack's GP and therefore has not been given consent to have access to his medical records.

Information should only be shared with staff providing health or social care for the named individual and only as much as that person needs to know to play their part in the individual's care.

Consent should be sought from the individual being assessed for their records to be shared if primary carers are handing over care to colleagues i.e. to manage caseloads.

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 12 - Resources

Web resources

<http://www.dataprotectionact.org/>

Activity Sheets

Sharing information activity sheet

PowerPoint's/ Lesson Plans

E- learning Resources

<http://www.endoflifecareforall.com> open access site
Assessment Module – Session Assessment Values

Further Reading

The Data Protection factsheet (Dec 2011) www.nvqmadefsimple.com)

Data Protection Act 1998 Guidance to Social Services (March 2000) Department of Health

Holistic common assessment of supportive and palliative care needs for adults requiring end of life care (2010) – National End of Life Care Programme in partnership with Cancer Action Team

End of Life Care Co-ordination (March 2012) – Record Keeping Guidance – National End of Life Care Programme

Activity 13 – Reflective Account

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones you will cover when you have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Reflective account

Assessment Type: Knowledge

Tutor/Assessor Guidance:

This activity brings all previous key learning points together.

The learners are also asked to reflect upon their practice to consider if, having gained knowledge through this module, they would implement changes to an individual's care.

The learner's personal account will be subjective but should demonstrate their knowledge of communication factors and key principles of effective communication skills in end of life care

Learners should be advised to revisit their key learning notes and review the Effective Communication Skills booklet to support them with this activity.

The ELCA Communication module <http://www.endoflifecareforall.com> Open access site also provides learners with a blended approach to develop their skills.

Points that should be covered in the discussion:

- Enabling individuals to discuss priorities, needs and concerns
- Factors that affected the individual's ability to communicate, such as prior experience, understanding, capability and capacity to communicate, cultural, spiritual and religious beliefs, environmental issues
- Effective listening skills
- Picking up cues
- How to respond to difficult or sensitive questions
- Supporting individuals to express emotions

Activity 13: Reflective Account



Approximately 2 hours and 30 minutes



Write a reflective account of how you have been involved in an end of life care discussion with an individual or their carer.

Think about:

- What issues, priorities or needs did the individual wish to discuss?
- Were there any factors that affected the individual's ability to communicate?
- What was your role in the discussion?
- How did you respond to questions?
- How did you know they wanted to talk about their feelings?
- Were there any difficult questions and how did you respond to them?
- In what ways did you manage the emotional responses and answers you got from them (e.g. sadness, withdrawn, anger)?
- When you think back to the discussion now, are there any other ways you think you would or could handle their emotions?



A reflective account is about your feelings and thoughts. Think back to how you felt during the discussion and consider the points above.

My Reflective Account

This activity brings all of the previous key learning points together. The learner's personal account will be subjective but should demonstrate their knowledge of communication factors by explaining and describing:

1. What Issues, priorities or needs did the individual wish to discuss?
2. Factors that affected the individual's ability to communicate – may include reference to:
 - Individual's knowledge and understanding of their illness,
 - Previous experience of illness and end of life care symptoms.
 - How they coped previously and their expectations of treatment and condition.
 - Their experience of caring for others or family members who have had advanced illness
 - If they had any unresolved concerns
 - Their spiritual, religious and/or cultural views
 - How they are feeling physically and if they are in pain, feel sick
 - If they had other communication disabilities or cognitive impairment,
 - Environmental issues – privacy,

3. Their role is to provide good support and listening skills – allowing individual to discuss their needs, concerns and emotions. If the learner describes in their account that they needed to share the individual's concerns or the outcome of the discussion this should have been carried out confidentially and with respect to data protection.
4. How did you know they wanted to talk about their feelings – may include a description such as:
 - We were talking about a completely different topic when individual asked a question or made a statement out of context about concerns or needs.
 - Asked a direct question about their illness or prognosis
 - Brought up worries by mentioning worries indirectly such as: 'can I have something for my headache, they seem to have got worse since I went to my last clinic appointment?'
5. Were there any difficult questions and how did you respond to them?

Answers should include points such as:

- Didn't panic, ignore or change subject
 - Showed them happy to listen – gave them full attention, sat down with individual.
 - Reflected back question to them.
 - Used gentle and calm tone and asked them why they asked a certain question or a response similar to raised in question 6 of quiz: "Is that what you think (said their name) – if you are not in pain you may be getting better?"
 - Stayed quiet and gave them time to respond
 - Did not give a dishonest reply which would have been disrespectful and would not have picked up on the cue that they wanted to talk about their illness, concerns etc.
6. In what ways did you manage the emotional responses and answers you got from them (e.g. sadness, withdrawn, anger)?
Answers such as:

Emotion	Response
Anger	Listened to absorb anger. Remained calm. Did not apologise.
Fear	Observed and listened to establish what they are really afraid of. Stayed alongside, was truthful, and reassured where able. Provided explanations, When no more to say or do just had the courage to be quietly there.
Alienation / Denial – avoiding truth	Honesty - being lied to is a lonely place to be, explanation, good body language, give time to talk - shows individuals they are respected.
Sadness & Depression	Allowed to cry. Talked to doctors or nurses re: assessing for clinical depression and gave treatment as appropriate. Helped them sleep, relax, massage, medication etc. Avoided glib responses. Stayed with patient's mood.
Loss	Listened and do the small things / practical things to reduce feelings.
<p>Should provide an account of good listening skills in their response to individual</p> <ul style="list-style-type: none"> • Portrayed a sense of time and calm • Respected privacy • Listened and observed person's non-verbal communication • Responded by saying what was being seen or heard (e.g. did individual look sad, distressed, did it sound as if it was difficult for individual to express their emotions?) • Used non-verbal and verbal communication – eye contact, posture, nods and expressions, light touch, lean forward? • Used encouraging prompts – open questions – how, when, where, what, why? • Used reflection – asked individual to clarify meaning, repeated their words to help them reflect on what they were saying and how they were feeling? • Summarised what the individual was saying to show understanding and had a sense of what they were saying or feeling. • Used empathy – Acknowledged individual's emotions or feelings, paraphrased and reflected back their words. • Was supportive, calm and quiet and allowed for silences? • Avoided giving opinion or practical advice? • Avoided clichés? 	

	<p>7. <i>When you think back to the discussion now, are there any other ways you think you would or could handle their emotions. The learner should give an account of any positive changes they should make to their supportive or listening skills.</i></p>
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Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 13 - Resources

Web resources

Activity Sheets

Listening Self Assessment

Power Points/ Lesson Plans

E- Learning Resources

Communication module <http://www.endoflifecareforall.com> Open access site

Communication Skills Module 03 - ELCA e-learning module <http://www.e-lfh.org.uk/projects/end-of-life-care/> needs registration (Free)

Further Reading

Booklet - Effective Communication Skills in End of Life Care

Holistic common assessment of supportive and palliative care needs for adults requiring end of life care (2010) – National end of life care programme in partnership with cancer action

Activity 14 –Support Services

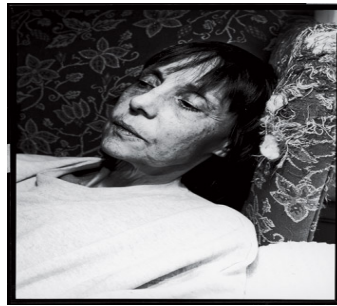
Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Assessment Method: Written tasks and research

Assessment Type: Knowledge



How people die will remain in the lasting memory of relatives, carers, and the health and social care staff who have cared for the dying person and so it is important that all staff recognise their responsibility to provide the best possible care at the end of life.” (DOH 2008)

Tutor/Assessor Guidance:

These activities will ask the learner to consider what support services are there to assist them manage EOL care. This will enable them to have a better understanding of the roles of others and so aid team working at EOL.

It is important that as a carers they know what support services and facilities are available to support people at EOL

Activity 14: Support Services	
	Approximately 2 hours
	Think about all the different services and identify all the people you think would support someone at EOL, write them in the bubbles below

A grid of 12 empty thought bubbles arranged in 4 rows and 3 columns. Each bubble is white with a green outline and has three small circles leading to it from the bottom left.

Look at the people you have identified – how many of them are:

1. Health Staff:
2. Social Care Staff:
3. Working for a Charity:
4. Family:

Others (state here):

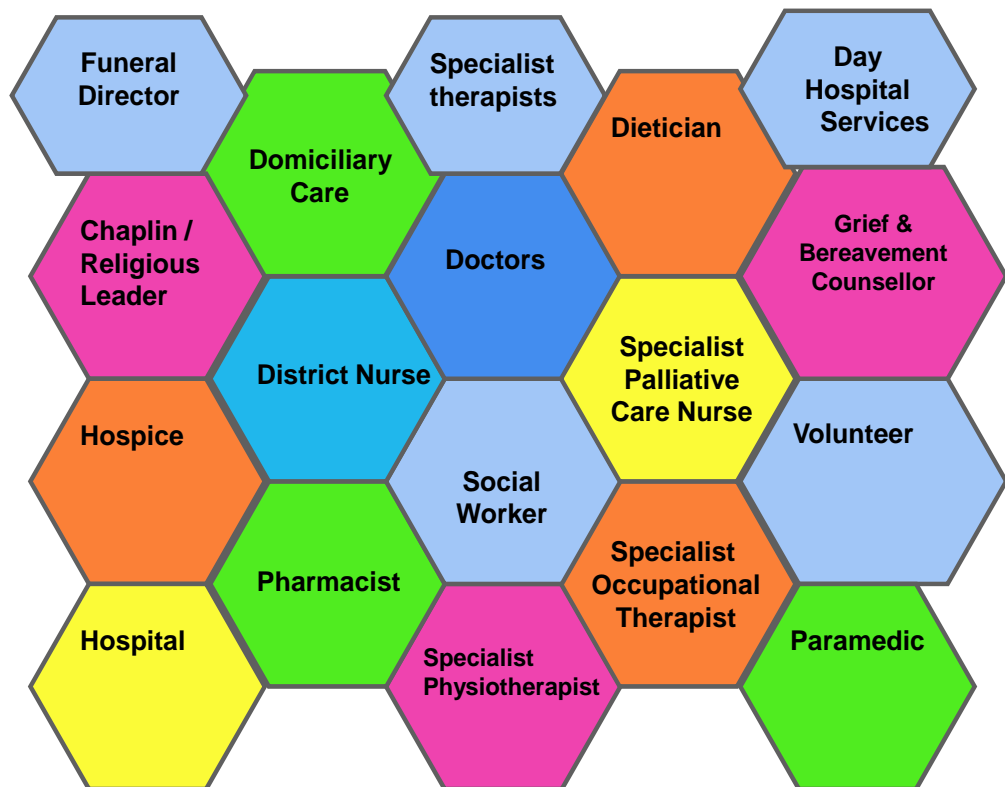
Support Services the Learner may identify are:

- Chaplains/ Religious leaders
- District Nurses
- Specialist Palliative Care Nurses
- Doctors

- Pharmacists
- Occupational Therapist
- Physiotherapists
- Hospital
- Hospice
- Social worker
- Co-ordination centres
- Dietician
- Volunteers



Now look at the following picture with all the names of health and social care professionals and other staff and places. Match the names to the text in the arrow below and write the correct name in the box next to it



They visit people in their own homes or in residential care homes, providing nursing care for individuals and supporting family members

District Nurses

These professionals help individuals, families, groups and/or communities with their social and physical health needs and work as part of the interdisciplinary teams. They provide support with discharge from the hospital to the person's home or hospice care by creating packages of social care.

Social Worker

<p>These professionals provide specialist palliative care nursing and are specialist in terminal /EOL care. They work in hospitals, hospices and in the community visiting the individual at home.</p>	<p>Specialist Palliative Care Nurse</p>
<p>These professionals help individuals maintain movement and improve mobility and address safety concerns in the home.</p>	<p>Physiotherapist</p>
<p>Provide their patients with general medical care and will do home visits. In addition there are some who specialise in palliative medicine, give expert medical advice on managing people with advanced disease. They work closely with palliative care nurses.</p>	<p>Doctor</p>
<p>These are an important member of the health and social care team and assume varied functions ranging from supplying medicines to patients and working with doctors to ensure the best treatment for patients.</p>	<p>Pharmacist</p>
<p>These people are often affiliated with a specific religion and are trained to listen to the person and family members who have concerns or interests in discussing faith-related and spiritual matters, especially in the context of a serious illness.</p>	<p>Chaplain or Religious Leader</p>
<p>These help the individual and family members address any nutritional concerns, such as planning healthy meals, providing practical tips for nutritional supplements, and recommending specialised eating plans</p>	<p>Dietician</p>
<p>This is a professional with social work or psychological training who counsels family members after a death occurs.</p>	<p>Grief and Bereavement Counsellor</p>

	<p>These visit people in their own homes to assist with household tasks, some personal care and occasionally accompanying the individual on visits such as to the doctor or hospital. They may also work nights, offering assistance to clients who require around the clock care.</p> <p>These provide care in emergency situations and often treat people at the scene of an accident or at home. If needed, they will take people to hospital</p> <p>This is a place where people with terminal illness can go to get specialist help to manage their symptoms. Some people choose to die in this place.</p> <p>These people help individuals with upper body mobility and daily tasks/functioning and often organise for specialist equipment to go into their home.</p> <p>This place is where people go when they require nursing or consultant care and operations.</p> <p>People go here during the day to meet people, to have baths, lunches and some therapies.</p> <p>These people provide specialist therapies such as massage, aromatherapy and other treatments such as lymphoedema care.</p>	<p>Domiciliary Care</p> <p>Paramedic</p> <p>Hospice</p> <p>Occupational Therapist</p> <p>Hospital</p> <p>Day Hospital</p> <p>Specialist Therapist</p>
	<p>Multi-disciplinary Teams</p> <p>As we have seen, end of life care often involves a number of health and social care services. If these fail to work together successfully, the result is likely to be unsatisfactory care and distress for the person and their family.</p> <p>Effective co-ordination of a range of services is a crucial aspect of care for people moving towards the end of life but achieving it can be difficult. Some people use a Directory of Key Contacts to help them remember all the contact details of people they will need as EOL approaches</p>	



Look at Directory of Key Contact Sheet your tutor will give you and complete the form with contact numbers for your local area.



Some areas have EOL care co-ordination centres to help co-ordinate all the services that provide care to someone at EOL

Look at the following video clip from SCIE

<http://www.scie.org.uk/socialcaretv/video-player.asp?v=coordinationofcare>



Now you have completed these activities, in the box below identify the key people who may be involved within a multi-disciplinary end of life care team.

Main EOL care multidisciplinary team are:

- Specialist Palliative Care Doctors
- GP
- Chaplains/ Religious leaders
- Specialist Palliative Care Nurses
- Occupational Therapist
- Physiotherapists
- Social worker
- Co-ordination centres
- Dietician
- Volunteers

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 14 Support EOL Resources

Web resources

Look at the following video clip from SCIE

<http://www.scie.org.uk/socialcaretv/video-player.asp?v=coordinationofcare>

Activity Sheets

1. Support at EOL worksheet
2. Support Services Quiz
3. EOL Sculpting Exercise Instruction sheet
4. Directory of Key contact

Power Points/ Lesson Plans

Lesson Plan 3: Supporting EOL care

- Support at EOL

E-learning resources

E: ELCA modules that support the 201 unit can be found in the following document
EOL 201-1.doc

Further Reading

National EOL Strategy (DH 2008)

Activity 15 – Barriers to End of Life Care

Learning outcomes and assessment criteria

This activity links to the following learning outcomes and assessment criteria (page 5). Those highlighted green are the ones learners will cover when they have successfully completed it.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			




Assessment Method: Written tasks and research

Assessment Type: Knowledge

Tutor/Assessor Guidance:

Unfortunately there are some people who face barriers when trying to access good EOL care. The following activities will help learners to identify the groups of people who can face difficulty getting EOL care. These activities will then become more aware of the barriers people face so they can try and ensure that the EOL care and EOL services are open to all. The groups concerned are:

- Lesbian, gay, bisexual and transgender (LGBT)
- Homeless People
- People with Learning Disabilities
- People who have Dementia

Activity 15: Barriers to EoL	
	Approximately 2 hours
	<p>Below are some groups who may often face barriers to end of life care.</p> <p>Lesbian, gay, bisexual and transgender (LGBT)</p> <p>A report by the National Council for Palliative Care (NCPC) and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations highlighted that lesbian, gay, bisexual and transgender</p>
	

(LGBT) people often feel let down by end of life care service. With more than 3.7 million lesbian, gay and bisexual people and at least 12,500 transgender people in Britain, the report expresses concerns that a significant proportion of the population are not accessing appropriate care when they are dying because of their sexuality or gender identity (Ref : National End of Life Care Programme (2012) The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people)

Reluctance to access services for fear of being judged by others, because they are (LGBT) – delays in getting treatment

Reluctance to talk openly or have EOL conversations with others who do not know they are LGBT, so often true EOL wishes are not known

The significance of 'friend' relationships is not recognised before and after death. This could result in a person or group, and their relationship with the dying person and their grief being unrecognised

Family members 'taking over' all arrangements as their partner is not recognised

Relationship not being recognised by employers, leading to difficulties getting compassionate leave to spend time with their dying partner and attending the funeral

An individual may find it difficult to be open and assertive about their needs at EOL and who they want to spend their time with.



Some of these examples are now illegal under the Equality Act 2010. Discuss which they are.



Now watch the LGBT video clip by accessing the following website <http://www.dyingmatters.org/page/lgbt-people-let-down-end-life-care-services>

Ways we can minimise the barriers facing LGBT people in their EOL care.

1. Ensure all health and social care staff are trained in the needs of LGBT people. Ensure equality and diversity policies are known by all.
2. Ensure staff respond sensitively to any cues the individual may give, allow time to talk in private, encourage them to talk about EOL care wishes.
3. Ensure staff do not assume that people are heterosexual, ensure they enquire about who significant others are and how they might like to feel supported. Be aware of family dynamics and what people know, do not assume that the LGBT person has 'come out' to family members.
4. Support LGBT individuals to make Advance care plan stating their wishes, advice them about lasting powers of attorney if capacity will be lost. Encourage them to seek legal advice if they are concerned about their partner. Encourage them to talk to their family about their wishes if they can.
5. As a society, ensure that employers recognise the rights and needs of LGBT people and that policies are not discriminatory.
6. Support the LGBT person to meet their EOL wishes in a sensitive way, acting as their advocate if required.

Homeless People



early and have significantly higher levels of mental and physical health problems. Many have learning disabilities, drug and alcohol abuse problems.

The 'National End of Life Care Programme (2012) End of Life Care Achieving quality in hostels and for homeless people - a route to success' report notes that there is evidence that people who are sleeping, or have slept, rough and/or are living in hostels and night shelters are more at risk of dying

Sleeping rough can affect their ability to look after their own health due to the poor environments they live in e.g. lack of shelter, lack of hot meals, lack of privacy

Supporting homeless people with bereavement issues can be difficult as relationships can be short lived as they move from place to place

Death can appear sudden as there is often poor communication between health and hostel staff during the last 6 months of life

Staff in homeless hostels find it difficult to know an individual's EOL care wishes, as many tend to deny what is happening to them, so they rarely have time to prepare for their death

Many homeless people often refuse to access health services

Obtaining the right help and treatment can be difficult due to the attitudes of some health professionals who see the homeless as difficult and unreliable people

Many have memory problems linked to alcohol and drug problems

Ways we can help the homeless have better access to EOL care and ensure their EOL choices are known

1. Encourage the homeless to use hostels and shelters.
2. Ask them to keep a blue book with them, identifying who is important to them and where that person is likely to be.
3. Educate care staff about the needs of the homeless and set up field workers who can support the homeless get to appointments. Set up health screening programmes and treatment sessions in hostels and shelters.
4. Try and find opportunities to have EOL care conversations when the person is able to have the conversation and listen for cues from the person e.g. "I know I will die if I carry on drinking like this".
5. Educate hostel staff in spotting the signs of EOL. Ensure there is good communication between care staff and hostel staff.
6. Try to find out the underlying reason why they do not want to use the service and try to address this. Ensure hostels have GPs who understand the homeless communities needs
7. If a homeless person has died, ensure the hostel staff encourage residents to talk about the deceased person. Be aware of who was close to them and offer support. Look in the blue book for family/ friends contact details etc.
8. Encourage the homeless person to make an Advance Care Plan when they are able, to be kept at the hostel to let other agencies know.

Learning Disabilities



People with learning disabilities are likely to have all of the major life threatening diseases at least 5-10 years earlier than the rest of the population and their survival rates are much shorter.

A person with learning disabilities access to general health care has traditionally been very poor and many suffer from a range of different illnesses that makes their care highly

complex.

People with learning disabilities often do not realise there is something wrong with them, so they often seek medical help too late

People with LD often struggle to remember appointments

Many people with learning disabilities may not have experience of making choices or controlling their own lives and they may not be able to understand the decisions they are making

Historically people with learning disabilities have lived in places (both professional and with family) where it has been considered not to be in their best interests to tell them about serious illness or death, so not to upset them.

Where people with LD live, in their own homes or under the care of social care staff, staff may not be trained in physical health care or care of the dying and may not see end of life care as part of their role

Many hospitals and hospices do not have experience of caring for people with learning disabilities who are dying

Many people with LD have difficulty expressing themselves and feelings of pain or anxiety can often be misunderstood as 'challenging behaviour'. This can affect their access to pain relief and other treatment

Previous bad experience of Health and Social care may make the person with LD reluctant to use these services or trust people they do not know



Dying Matters and the National End of Life Care Programme have produced several films called 'We're living well but Dying Matters'. The films show how people with learning disabilities need to be able to acknowledge their loss and mourn when someone close to them dies. They need to be included in important decisions around end of life, especially their own, be able to ask questions and have their emotional needs and dying wishes recorded.

Click on the link below to watch the films

<http://www.dyingmatters.org/page/were-living-well-dying-matters>

Ways we can help people with LD to have better access to EOL care and ensure their EOL choices are known

1. Ensure that information leaflets are easy to read and that care staff are aware of the needs of LD clients and some of their common health problems.
2. Ensure that someone is allocated to co-ordinate the care for the person with LD.
3. Encourage and train staff to have EOL discussions with the person they are caring for.
4. Ensure Advance Care Plans and tools are in a format that is accessible to the LD person. Give the person plenty of time and check understanding. If you suspect they do not understand, report to your manager.
5. Ensure that staff who work with LD clients receive good EOL care education so they are aware of the needs of their LD client as they approach EOL. Ensure they are aware of the quality markers they are required to comply with.
6. Ensure that hospice staff are trained in the needs of LD clients and there is good liaison with LD services.
7. Ensure that staff know how the individual expresses themselves in various situations ask relatives etc. Encourage the use of 'All about Me books' to highlight to others communication needs, likes and preferences etc. Use appropriate pain assessment tools etc.
8. Try and find out the reason why they are reluctant to use services and try to address their concerns.

Dementia



About half a million people die each year in England, a third of them from frailty or dementia. Most people with dementia die in residential or nursing care homes or in hospital. Although some receive excellent care at the end of life, many do not.

The last few months of life may often be dominated by pain and distress, physical deterioration and malnutrition, frequent, ineffective and costly admissions to hospital and an absence of dignity and choice.

High quality care towards the end of life for people with dementia can support vulnerable individuals to live comfortably and as well as possible until they die. It can also be of great help to families that care for them and help to avoid the distress of unnecessary, repeated, often lengthy and costly hospital admission

(Ref: National End of Life Care Programme: End of Life for people with dementia an online resource guide.)

The deterioration in communication skills with dementia prevents people from expressing their views and wishes – particularly on how and where they wish to be cared for and where they want to die

It can be hard to recognise when someone with dementia is at EOL, as dementia has a slow decline. Often carers of people with dementia commonly underestimate the likelihood that a person will die in the next few months.

People with dementia have difficulty expressing themselves and feelings of pain or anxiety can often be misunderstood as 'challenging behaviour'. This can affect their access to pain relief and other treatment

Dementia is often diagnosed too late. People with dementia often do not realise there is something wrong with them, so they often seek medical help too late, many reach crisis point before they are known to services

Many people with dementia lose the mental capacity to make choices and often they are not able to understand the decisions they are making. Many fail to make Advance care plans

Many people with dementia have more than one medical condition and their care can be complex, however referrals to specialist palliative care services are often not made as there is a lack of knowledge of how to manage complex care and the referral process

Now watch a film produced by the Social Care Institute for Excellence. SCIE The film is about supporting a person with dementia to die well. Click on the link below to watch the film



<http://www.scie.org.uk/socialcaretv/video-player.asp?guid=6cddd9aa-041e-446e-b637-d47ab7b37643>

Ways we can help people with Dementia have better access to EOL care and ensure their EOL choices are known

1. Encourage people with dementia to make Advance Care Plans while they are still able to communicate their wishes
2. Recognise when the dementia signs and symptoms have increased or condition has deteriorated and they may be at EOL.
3. Know the person's body language and how they express themselves, possibly asking relatives. Write it down for other care staff in an 'All about Me' book. Use appropriate pain assessment tools.
4. Everyone needs to be dementia aware and know how to spot the early signs of dementia.
5. If someone with dementia has lost capacity to make decisions then the Mental Capacity Act (2005) should be followed including consulting with any Powers of Attorney and holding best interest meetings
6. Ensure that referrals are made to specialist palliative care services to manage complex symptoms.



Now you have read about some groups who face barriers to end of life care, choose one group of people and identify 4 barriers they may face and how you might overcome these.

Identified Group :

No	Barrier	Ways to help minimise barrier to EOL care
1		
2		
3		
4		



Further Reading and useful web pages

National End of Life Care Programme: End of Life for people with dementia an online resource guide, accessed link below

http://www.opaal.org.uk/Libraries/Local/1013/Docs/Dementia_resource_final_20101025.pdf

Dying matters people with dementia

<http://www.dyingmatters.org/page/people-dementia>

Dying matters web site

<p>http://www.dyingmatters.org/</p> <p>National Association for Palliative Care www.ncpc.org.uk</p> <p>My Home Life Programme http://myhomelife.org.uk</p> <p>National End of Life Programme http://www.endoflifecare.nhs.uk/care-pathway.aspx</p> <p>Leaflets: 'How would I know' Published by The National Council for Palliative Care 2012</p> <p>'Time to talk' Published by The Dying Matters Coalition</p>
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Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.

Activity 15 - Barriers to EOL Care Resources

Web resources

Learning Disability: Dying Matters

<http://www.dyingmatters.org/page/were-living-well-dying-matters>

Dementia Film: SCIE

<http://www.scie.org.uk/socialcaretv/video-player.asp?guid=6cddd9aa-041e-446e-b637-d47ab7b37643>

LGBT people Dying Matters Film

<http://www.dyingmatters.org/page/lgbt-people-let-down-end-life-care-services>

Activity Sheets

1. Barrier Quiz
2. Reducing barriers sheet
3. My life my choices

Power Points/ Lesson Plans

Lesson Plan : Barriers to EOL care

Barriers to EOL PowerPoint.

Further Reading

National End of Life Care Programme: End of Life for people with dementia - an online resource guide, accessed via link below

http://www.opaal.org.uk/Libraries/Local/1013/Docs/Dementia_resource_final_20101025.pdf

Dying matters people with dementia

<http://www.dyingmatters.org/page/people-dementia>

Dying matters website

<http://www.dyingmatters.org/>

National Association for Palliative Care

www.ncpc.org.uk

My Home Life Programme

<http://myhomelife.org.uk>

National End of Life Programme – Route to Success Guides

<http://www.endoflifecare.nhs.uk/care-pathway.aspx>

E-learning resources

E: ELCA modules that support the 201 unit can be found in the following document
EOL 201-1.doc

Summary

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

You have had the chance to explore the people's views on death and dying and you have seen that this can be affected by a number of factors.

You have studied communication issues and have had a chance to think about how you might respond to some difficult questions, by listening and picking up verbal and non verbal communication issues. You have also explored the issue of confidentiality and when to share information.

You have read a summary of the national EOL policy and considered how this has helped develop the local policy in your area. In addition you have seen the roles of other professionals and how they support those at EOL.

You have thought about the common symptoms of EOL and how these might be managed and have considered the role of the national and local EOL pathway.

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

Confidence level	1	2	3	4	5
Understanding the various factors that affect people's views about death and dying					
Your knowledge about what an advance care plan is					
Understanding the national EOL care policy					
Knowing how to respond to difficult questions					
Recognising verbal and non verbal communication cues					
Understanding confidentiality and sharing of information					
Knowing what services support EOL care					
Knowledge of how to provide comfort at EOL					

CONGRATULATIONS!

You have now undertaken all the activities in this unit.

You now need to meet with your tutor/assessor – to discuss how you might present these completed activities as evidence towards meeting the unit learning outcomes.

1.1	1.2	1.3	1.4			
2.1	2.2	2.3	2.4	2.5		
3.1	3.2	3.3	3.4	3.5		
4.1	4.2	4.3	4.4			

Appendix

- Continuation sheets for photocopying as required
- Glossary of Terms
- Template Support Agreement
- Lesson Plans

Continuation sheets

Continuation sheets

Glossary of terms

Term	Definition
Best Interest decision	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.
Cognitive ability	Is able to think, concentrate, formulate ideas, reason and remember.
Cognitive impairment	This is when an accident or illness affects the ability to think, concentrate, formulate ideas, reason and remember.
Culture	The shared knowledge, behavioural norms, values and beliefs that help people to live in families, groups and communities
Consent	Permission for something to happen or agreement to do something
Factors	The things, events or circumstances which will affect something e.g. what is affecting an individual's ability to cope with an illness
A 'good death'	A term used in the National End of Life Care Strategy (2008) to describe a death where everything was as the dying individual wished for. The comfort and dignity of the individual was maintained.
Holistic	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.
Informed consent	When an individual gives permission to have an assessment, treatment or procedure with full knowledge of the risks involved, probable consequences and the alternatives.
Mental Capacity	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.
Multi-disciplinary Team	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.
National End of Life Care Programme	This is a national programme funded by the NHS which works across health and social care in England to improve end of life care and support people to live and die well.
Palliative Care	Palliative care is a holistic approach that improves the quality of life of individuals and their families facing problems associated with incurable and life-threatening illness. It aims to control symptoms to provide relief from pain and other distressing or debilitating symptoms.

Picking up cues	Noticing when a person needs or wants to talk about needs, concerns, fears, loss etc. They may do this from the things they say or through non-verbal communication.
Person centred care	Person centred care is providing care that is responsive to individual personal preferences, needs and values and assuring that the individual's values guide all clinical decisions.
Signposting	Directing people to support services or information they require

Support Agreement

Learners Name:	
Tutor / Assessor:	
Unit / Qualification Title:	
Date:	

Due to the sensitive nature of End of Life (EOL) care, topics may be covered that can cause upset 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. Before you begin learning activities, spend some time with your Tutor / Assessor to complete the boxes below:

Lone study – Identify support networks (these could be friends, family, colleagues) if you are upset by topics:

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One to one – Outline how you would like to be supported if you are upset by topics:

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Work based learning- Identify a mentor or supervisor to whom you can go if you are upset by topics at work:

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Class room based learning - Outline how you would like to be supported if you are upset by topics (take i to account that your tutor / assessor will not be able to leave the classroom):

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Lesson Plan 1: Factors that can affect an individual's views on death and dying. Approx 3-4 hours

Time	Learning Objective	Activity	Resources
	Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	
		Introduce the sessions and outline the aims	Slide 1
15 min	Outline the factors that can affect own views on death and dying.	Group work : Personal experiences Split into groups, ask individual to complete sheet and discuss in their group most popular answer to question 3.	Slide 2 Personal experiences worksheet
20 min	Outline the factors that can affect an individual's views on death and dying.	Group work : Social Influences What was most popular answer to Q 3 Show slide 3, explore how much impact the following have on people's attitudes – ask group to rank them in terms of influence	Slide 3
15 min		Cultural Influences Discuss each aspect.	Slide 4 Background reading 1. Read Introduction cultural issues 2. S.M. Carey, J.F. Cosgrove. <i>Cultural issues surrounding end-of-life care</i> . Journal Current Anaesthesia & Critical Care (2006) 17, 263–270.pub Elsevier accessed on line 09/02/2013

Lesson Plan 2: Factors that can affect an individual's views on death and dying.

Time	Learning Objective	Activity	Resources
10 min	Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	
15 min		<p>Spirituality Discuss handout</p> <p>Ask if anyone has ever identified a spiritual need in somebody – how did they help them meet this.</p>	<p>Slide 5 Spiritual Handout</p>
30 min	Outline how the factors relating to views on death and dying can impact on practice.	<p>Religious Beliefs</p> <p>Split group into different faith groups. On flipchart ask them to consider how the religious beliefs can affect how they would care for that person at EOL. Feedback to other groups</p>	<p>Slide 6</p> <p>Religious practice wall chart http://www.cumbria.gov.uk/elibrary/Content/Internet/536/656/3838485955.pdf</p>
30 min		<p>EOL discussion Role play - 3 characters</p> <p>Mrs Delgado Mr Delgado Dr Jones</p> <p>Play out the scene in the scenario. After role play ask group to consider the questions</p>	<p>Slide 7</p> <p>Mrs Delgado Role play</p>
30m min	Define how attitudes of others may influence an individual's choices around death and dying.	<p>Influence of others on EOL Choices – Ron Role play</p> <p>3 characters Ron Mary Dr Brown</p> <p>Play out the scene in the scenario. After role play ask group to consider the questions</p>	<p>Slide 8</p> <p>Ron Role play</p>
		Q& A and Summarise session	Slide 9

Lesson Plan 3: Maintaining Comfort and well being at EOL care

Time	Learning Objective	Activity	Resources
10 min	Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	Comfort and wellbeing PowerPoint
		<p>Introduce the sessions and outline the aims</p> <ul style="list-style-type: none"> • Maintaining comfort and wellbeing at EOL • Introducing the Liverpool Care Pathway • Care after Death 	Slide 1
10 min		Split into groups and the ask the groups to come up with a group definition of palliative care	Slide 2
		Discuss definition how close were they?	Slide 3
		Play the video from help the hospice –adding life to days	Slide 4
		In their groups get them to discuss society’s attitude to the dying – Words like pity, avoidance, burden, brave etc might come up. Why do people avoid people who are dying? Dying people want to be treated like normal people. Play video Dying for a Laugh	Slide 5
		In groups ask them to consider what the most common EOL symptoms are. Discuss the ones they have highlighted show slides	Slide 5 Slide 6-13

Lesson Plan 4: Care in last Days of Life

Time	Learning Objective	Activity	Resources
10 min	Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	Care in the last Days of life Session
20 min		Split into groups and give them Maud scenario Discuss in small groups first then larger group	Maud Scenario
50 min		Give Lecturer re LCP and other pathways Q&A	LCP PowerPoint slides 1-29

Lesson Plan 5: Advance Care Planning. Approx 2 hrs

Time	Learning Objective	Activity	Resources
10 min	Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	
5 min		Introduce Aim and ACP process	Slides 1-3
15 min		Give the group the Planning your Future Care document Discuss this document. Talk about Preferred Priorities for Care. Give out support sheet.	Slide 4 Slide 5
15 min		What about those who cannot make ACP decisions. Ask the group which type of people these may be. Introduce the Mental Capacity Act	Slide 6-8
15 min		Discuss Lasting Power of Attorney and Best Interest. Ask the group if anyone has attended a best interest meeting, what happened, who was present (no actual names, only roles)	Slide 9-10
15 min		Introduce and discuss Advance Decisions to Refuse Treatment. Ensure to clarify this is legally binding document. Give out ADRT sheet.	Slide 11
10 min		Watch the video clip of Peter Ashley- internet access required	Slide 12
20		In groups get member to spend 10 minutes One person to be the care worker One to be the individual – answer the questions How did this feel ? Q&A Summary and Close	Slide 13 Slide 14

Lesson Plan 6: Care after Death

Time	Learning Objective	Activity	Resources
10 min	Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	PowerPoint Care after Death
		Introduce sessions aims	Slide 1
		Discuss the National policy	Slide 2-3
15 minutes		Split into small groups ask them to reflect on what care is given to individuals after death.	
		Show Care after Death Slide. Did the groups miss anything?	Slide 4
		Split into small groups- ask them to reflect on what care is given to relatives/ partners after someone has died	
		Discuss Support family/partner slide - Did the groups miss anything? Give out support sheet SS 09 What to do when someone dies V2	Slide 5
		Discuss transfer of the body slide	Slide 6
		Ask groups to reflect on their feelings after someone has died, how do other staff react – what are the coping strategies used	Slide 7
		Talk about personal coping - what are the coping strategies people use	Slide 8
		Q&A Summary	Slide 9

Lesson Plan 7: Effective Communication Skills in End of Life Care - 4 hour Session

Duration	Learning Objective	Activity	Resources
30 mins	To know how to respond and support patients discuss their end of life experience	Welcome, Intros – round robin, name, role, workplace Introduction to workshop Present relevance & Context of Communication in EoL Learning outcomes & programme Ground rules – sensitivity & confidentiality, non judgemental, safety Ice-breaker – Exercise 1 in pairs – 3 mins avoiding the D word – dying matters.org.uk (refer to how in society death is a taboo)	<ul style="list-style-type: none"> Attendance List, Refreshments, Fire regs, handout post session Facilitators Slide 1 – 7 Icebreaker – list of phrases or euphemisms for death and dying, timer – prize
45 mins	To understand the communication process and what affects the ability to communicate effectively	Review fundamentals of communication Definition – two way process Exercise 2 – divide the communication pie – discuss RSVPPP Exercise 3 – testing non verbal communication – discuss which ones used Exercise 4 – Ability to communicate – Pairs, circle back to back – 1 to describe a diagram, 1 draw – discuss what helped or inhibited ability Exercise 5 – retaining information – read out – participants to answer – discuss - % of retaining info post conversation	<ul style="list-style-type: none"> Slide 8, 9, 10, 11,12, 13, 14,15, 16 Paper and pens – Flip Any picture of diagram Flip to list barriers Instructions to read - pen / paper
45 mins	To recognise the emotional impact of terminal illness, loss and bereavement	Exercise 7 - Identifying common emotions and responses to end of life care illness. Overview of grief processes to understand common emotional responses	<ul style="list-style-type: none"> Slide 17-26 Flip Chart Effective communication skills in EoLC booklet
15 mins	Break		
30 mins	To outline strategies to help individuals cope with their emotional responses - Picking up cues, responding to difficult questions, listening and supporting patient	Exercise 6 – in pairs why difficult to communicate in emotional situations – reflect on challenging communication scenarios – feedback and discuss key points raised. Compare with slide 18 by way of summary and discuss different strategies (refer to booklet)	<ul style="list-style-type: none"> Slide 27 – 30 Questionnaire Effective Communication Skills in EoLC booklet
50 mins	To know how to become a more effective listener and how to respond appropriately to difficult questions	Exercise 9 – Are you a good listener? Discuss barriers to listening, blocking tactics – habits of ineffective listeners – (refer to booklet) Tips on effective listening - SOLER & OWL Exercise 10 – Vera Scenario Discussion re exercise - summarise by supporting others – be there quote	<ul style="list-style-type: none"> Slide 31 - 35 Listening questionnaire Effective Communication Skills in EoLC booklet Slide 36 - Scenario & Task sheets – observer, listener, talker Quote & tips
15 mins	To know how to respond and support patients	Looking after yourself Support systems, boundaries, time for you, sustainability	<ul style="list-style-type: none"> Slide 37 – 38
10 mins	Evaluations, Questions and close		Slide 39

Lesson Plan 8: Supporting EOL Care

Time	Learning Objective	Activity	Resources
10 min	Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	
		Introduce the sessions and outline the aims	Slide 1
20		Who supports at EOL Hand out Support at EOL worksheet and get groups to try and identify which professionals etc gives support at EOL	Slide 2 Support at EOL worksheet
20		Ask groups how many did they identify. Get them to complete the Support Services Quiz. Which team scored the most?	Slide 3 Support services Quiz
30		EOL Sculpting Exercise Refer to EOL Sculpting Exercise Instruction sheet Complete activity and hand of Directory of Key Contacts, instruct the group to try and find out their own local area contacts	Slide 4 EOL Sculpting Exercise Instruction sheet Directory of Key contact
10		The importance of Co-ordinating EOL care	Slide 5
10		Q& A Summary	Slide 6

Lesson Plan 9: Effective Communication Skills in End of Life Care - 4 hour Session

Duration	Learning Objective	Activity	Resources
30 mins	To know how to respond and support patients discuss their end of life experience	Welcome, Intros – round robin, name, role, workplace Introduction to workshop Present relevance & Context of Communication in EoL Learning outcomes & programme Ground rules – sensitivity & confidentiality, non judgemental, safety Ice-breaker – Exercise 1 in pairs – 3 mins avoiding the D word – dying matters.org.uk (refer to how in society death is a taboo)	<ul style="list-style-type: none"> Attendance List, Refreshments, Fire regs, handout post session Facilitators Slide 1 – 7 Icebreaker – list of phrases or euphemisms for death and dying, timer – prize
45 mins	To understand the communication process and what effects the ability to communicate effectively	Review fundamentals of communication Definition – two way process Exercise 2 – divide the communication pie – discuss RSVPPP Exercise 3 – testing non verbal communication – discuss which ones used Exercise 4 – Ability to communicate – Pairs, circle back to back – 1 to describe a diagram, 1 draw – discuss what helped or inhibited ability Exercise 5 – retaining information – read out – participants to answer – discuss - % of retaining info post conversation	<ul style="list-style-type: none"> Slide 8, 9, 10, 11,12, 13, 14,15, 16 Paper and pens – Flip Any picture of diagram Flip to list barriers Instructions to read - pen / paper
45 mins	To recognise the emotional impact of terminal illness, loss and bereavement	Exercise 7 - Identifying common emotions and responses to end of life care illness. Overview of grief processes to understand common emotional responses	<ul style="list-style-type: none"> Slide 17-26 Flip Chart Effective Communication Skills in EoLC booklet
15 mins	Break		
30 mins	To outline strategies to help individuals cope with their emotional responses - Picking up cues, responding to difficult questions, listening and supporting patient	Exercise 6 – in pairs why difficult to communicate in emotional situations – reflect on challenging communication scenarios – feedback and discuss key points raised. Compare with slide 18 by way of summary and discuss different strategies (refer to booklet)	<ul style="list-style-type: none"> Slide 27 – 30 Questionnaire Effective Communication Skills in EoLC booklet

50 mins	To know how to become a more effective listener and how to respond appropriately to difficult questions	<p>Exercise 9 – Are you a good listener? Discuss barriers to listening, blocking tactics – habits of ineffective listeners – (refer to booklet) Tips on effective listening - SOLER & OWL Exercise 10 – Vera Scenario Discussion re exercise - summarise by supporting others – be there quote</p>	<ul style="list-style-type: none"> • Slide 31 - 35 Listening questionnaire • Effective communication skills in EoLC booklet • Slide 36 - Scenario & Task sheets – observer, listener, talker • Quote & tips
15 mins	To know how to respond and support patients	<p>Looking after yourself Support systems, boundaries, time for you, sustainability</p>	<ul style="list-style-type: none"> • Slide 37 – 38
10 mins		Evaluations, Questions and close	Slide 39

Lesson Plan 10: Barriers to EOL Care

Learning Objective	Activity	Resources
Attendance recording	Arrival, welcome, registration, housekeeping, ground rules.	
	Introduce the sessions and outline the aims	Slide 1
	Some of the problems at EOL	Slide 2,3,4,5,6
	Barrier Quiz Hand out barrier Quiz and get groups to see which of the barriers belong to what group	Slide 7 Barrier Quiz
	Minimise barriers Give out Reducing barriers sheet and discuss at each slide	Slide 8 Reducing barriers sheet
	Learning Disability : Minimise barriers (requires internet and sound) Show PCLD web page full of resources to support clients and staff. Look at Dying Matters film, choose short film or other chapters Short film 5 minutes - Discuss	Slide 9
	Homeless : Minimise barriers My life my choices – in resource folder as PDF is you want to show learners- distribute electronically	Slide 10 My life my choices
	Dementia : Minimise barriers (requires internet and sound) SCIE film good care for Dementia at EOL	Slide 11
	LGBT : Minimise barriers (requires internet and sound) Dying Matters film	Slide 12
	Q& A Summary	