



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

Learner's Workbook

Learning Activities

Acknowledgements

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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 you with ways to develop an 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 you might get help and support from a range of support services.

Learning Support

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

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









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

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

Learning Activities

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

Table 2: Type of learning activities and symbols

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

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

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

| | | | | | | |
|-----|-----|-----|-----|-----|-----|-----|
| 1.1 | 1.2 | 1.3 | 1.4 | 1.5 | 1.6 | 1.7 |
| 2.1 | 2.2 | 2.3 | | | | |
| 3.1 | 3.2 | 3.3 | | | | |
| 4.1 | 4.2 | 4.3 | 4.4 | 4.5 | 4.6 | |

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

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



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

Plagiarism and Confidentiality

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

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

Portfolio of Evidence

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

End of Life Care for All (e-ELCA)

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

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

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

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

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

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

It is important that you provide the right type of evidence for the outcome you are trying to achieve. Remember there are 2 types of evidence:

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

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

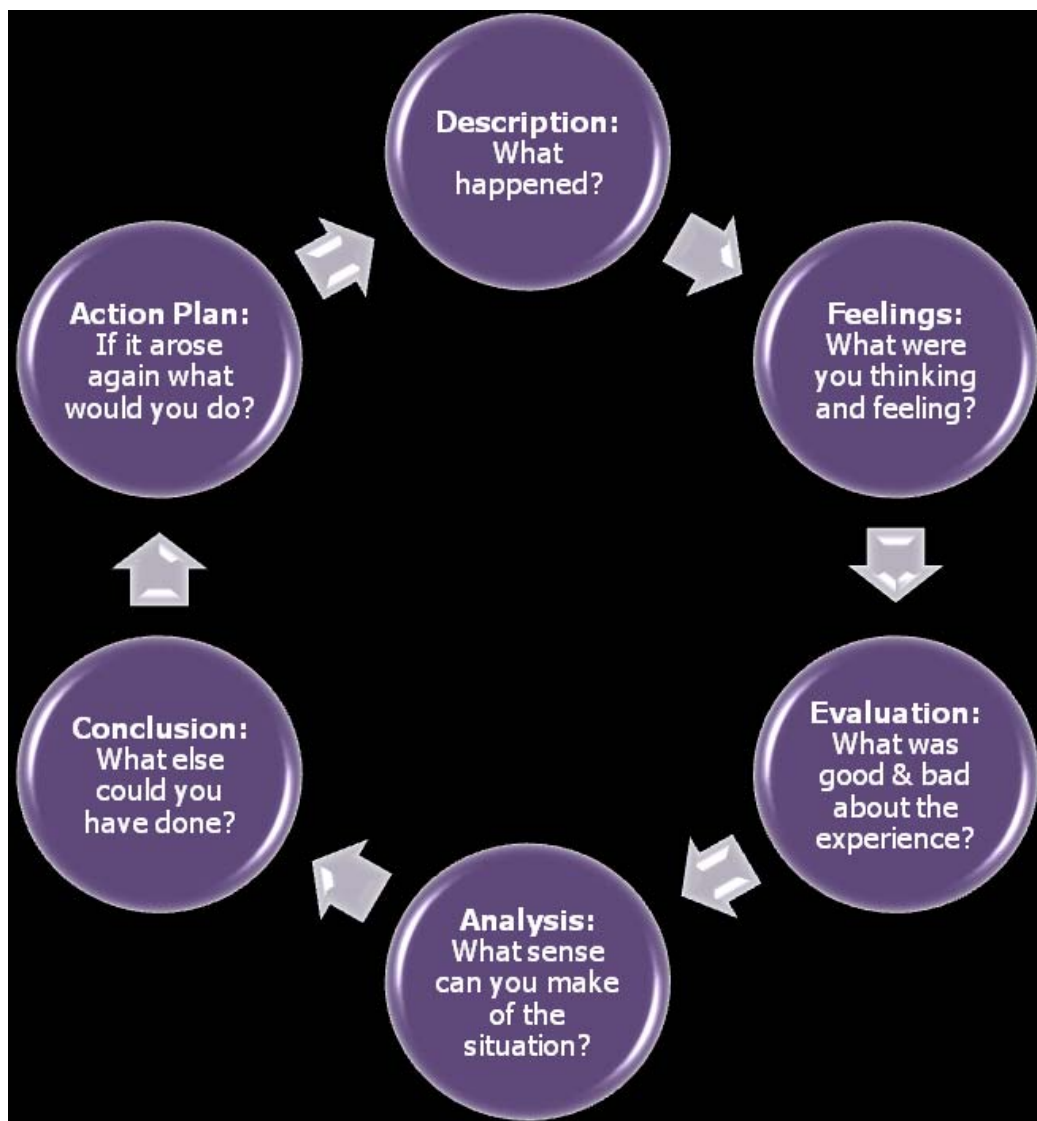
Table 3: Suitable Evidence

| 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

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

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



In some of the activities in this workbook, you will be asked to complete reflective accounts. We recommend that you follow the model above to ensure that you include everything.

Introduction to understanding how to 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!

This unit will help you explore the following 4 key EOL issues

- The different perspectives on death and dying.
- Aims, principles and policies of end of life care
- The communication factors in end of life care
- The range of support services available to individuals and others.

Warning: Please be aware that the activities in this unit will ask you to consider your thoughts and feelings about your death and the death of others. It is important that you pace yourself and complete the activities in your own time.

Before starting the activities please ensure you have completed the support agreement in the appendix with your tutor/assessor and have identified people that you can go to for support if you need to discuss any of the unit activities.

Pre-learning assessment – Rate how confident you feel about your knowledge and understanding about EOL care. 1 being not very confident and 5 very confident

| 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

Activity 1 - 'Let's talk about death'

Learning outcomes and assessment criteria

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




| | | | | | | |
|-----|-----|-----|-----|-----|--|--|
| 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

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.

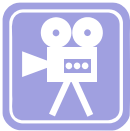
The following activities will help you explore how some of these factors might affect an individual's willingness to talk about the end of their life.

| 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 ctrl 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> |
|  | <i>Notes:</i> |

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

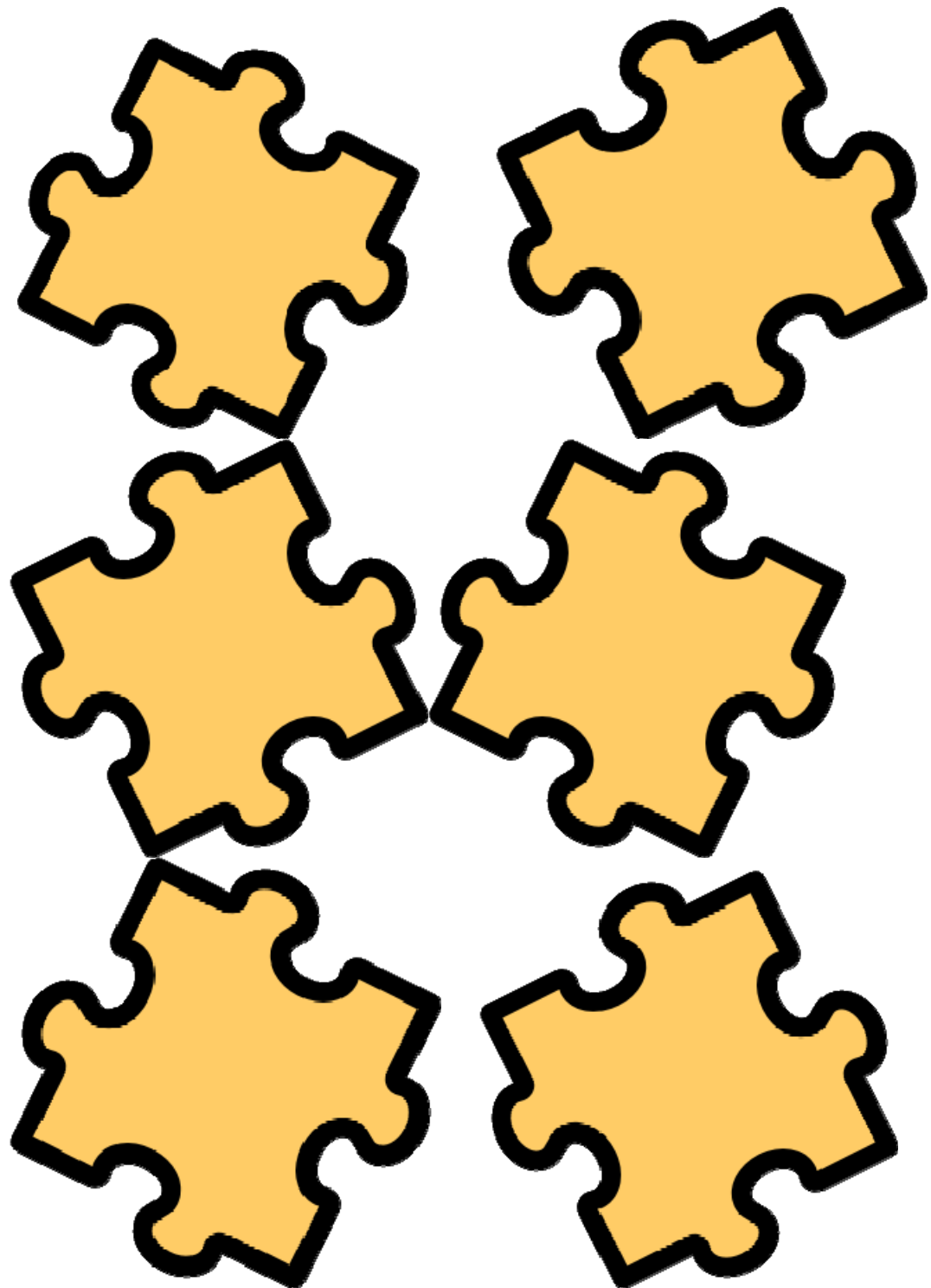
http://www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying/Topic/1201/

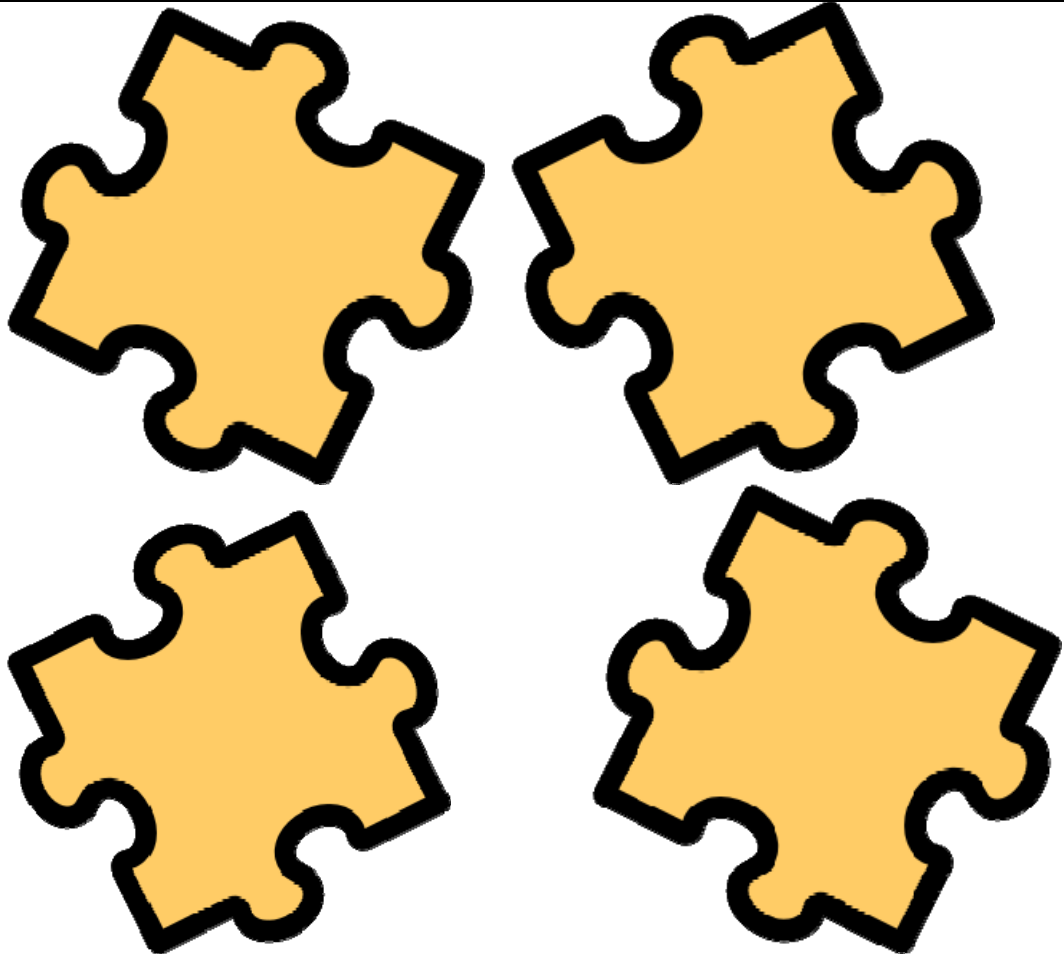


Whilst you are watching and viewing, try and think about the factors that may influence an individual's views about death and dying. Write these down in the space below:

Notes:

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.

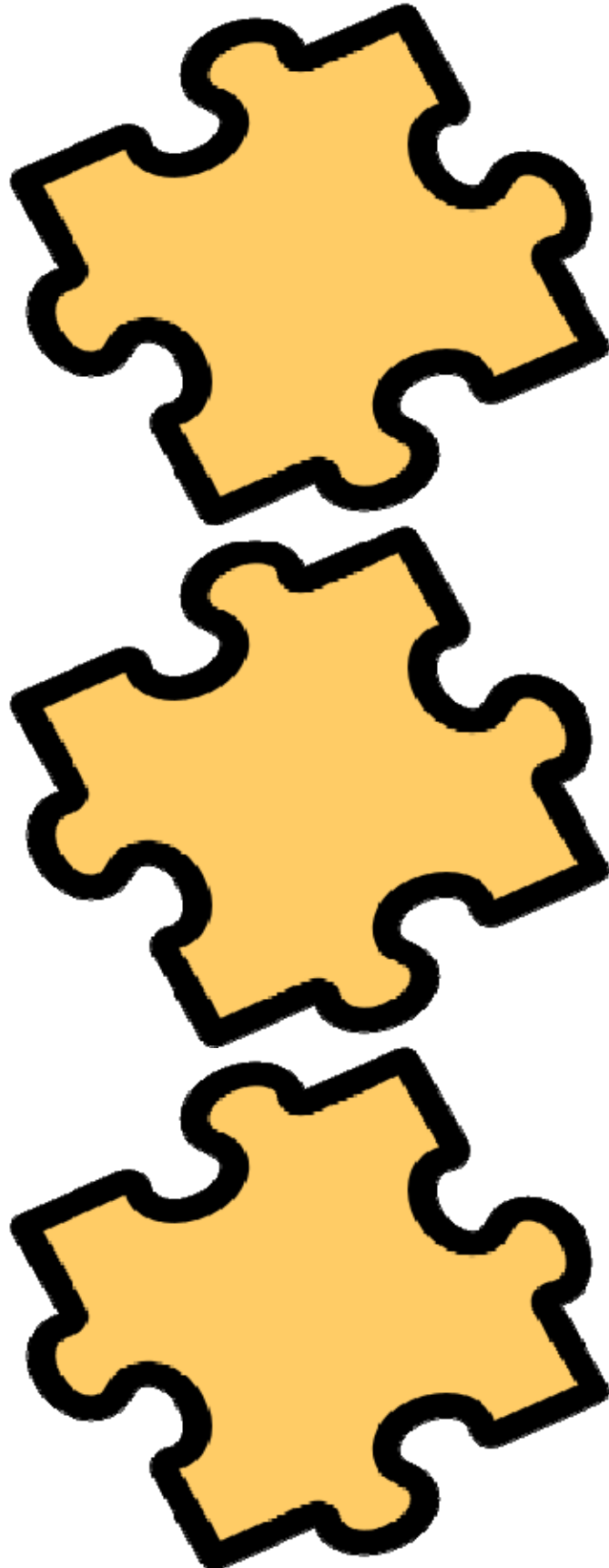


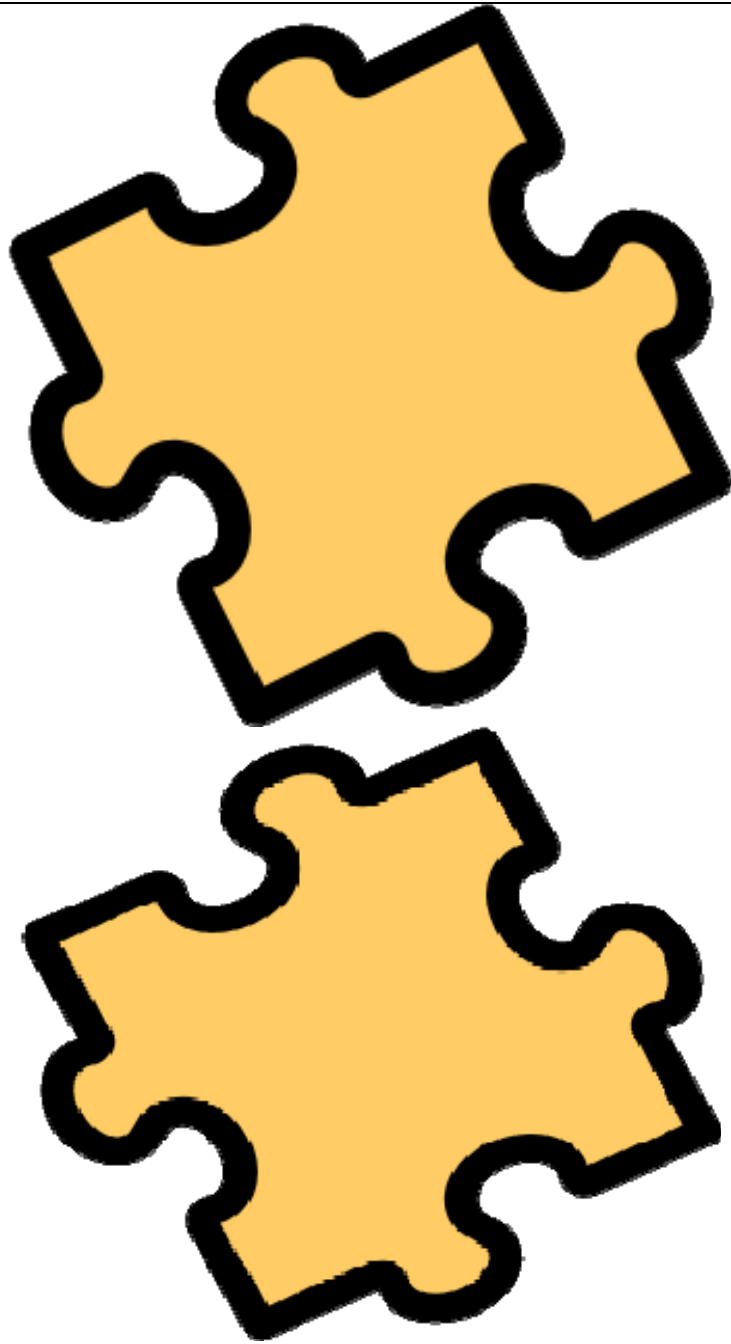
Completing this activity may have got you thinking about your thoughts about death and dying. Write your thoughts down here including:

- 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...

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.

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.

In addition to a broad understanding of beliefs, views relating to handling the body after death, organ donation and autopsy should be considered.

British culture expects calm and controlled mourning which is often different to the natural practice of grief expressed in other cultures.

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.

Source: S.M. Carey, J.F. Cosgrove. *Cultural issues surrounding end-of-life care*. Journal Current Anaesthesia & Critical Care (2006) 17, 263–270.pub Elsevier accessed on line 09/02/2013



Now look back at your answers for Q3 above - what factors do you think influenced the choices you made?

Circle as many as you like

Religious Attitudes

Attitude of the Family & Social Networks

Cultural/ Societal Attitudes

Personal experiences/ Factors

Media Attitude

Others Please State below:



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:

Completed Activity

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

Activity 2 – 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 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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: Scenario

Assessment Type: Knowledge

In Activity 1 you have identified a number of factors that can affect people's views on death and dying, including your own personal views. In this activity we are going to explore how those factors and the views of others can affect the way EOL care is delivered. Before you start this activity it is important that we consider a number of important ethical and legal issues.

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 continuation sheets if necessary.

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

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.

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)?

4. How might Sunita be feeling about this situation?



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

Activity 3 – End of Life Influence




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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: Scenario

Assessment Type: Knowledge

| Activity 3: End of Life Influence | |
|---|---|
|  | Approximately 1 hour |
|  | <p>Read the scenario below and answer the questions following it.</p> <p>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.</p> |
|  | <p>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.</p> <p>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.</p> <p>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.</p> |

1. What were Ron's wishes for his death and why was this important to him?

2. What were Mary's wishes for her father's death and why?

3. What was the outcome for Ron?

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

| | |
|--|--|
| | <p>5. How do you feel about what happened to Ron? What do you think would have helped Mary and Ron agree what was best for him at EOL?</p> |
|--|--|

Completed Activity

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

Activity 4 – Aims and Principles of EOL Care

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |


Assessment Method: Written work and professional discussion

Assessment Type: Knowledge

In the previous activities we explored the various factors that affected an individual's attitudes and values to EOL care and how cultural and society influences shape those individuals beliefs.

In this section we will consider what the aims and principles of end of life care are and how we need to ensure that we treat people with dignity at the end of their lives.

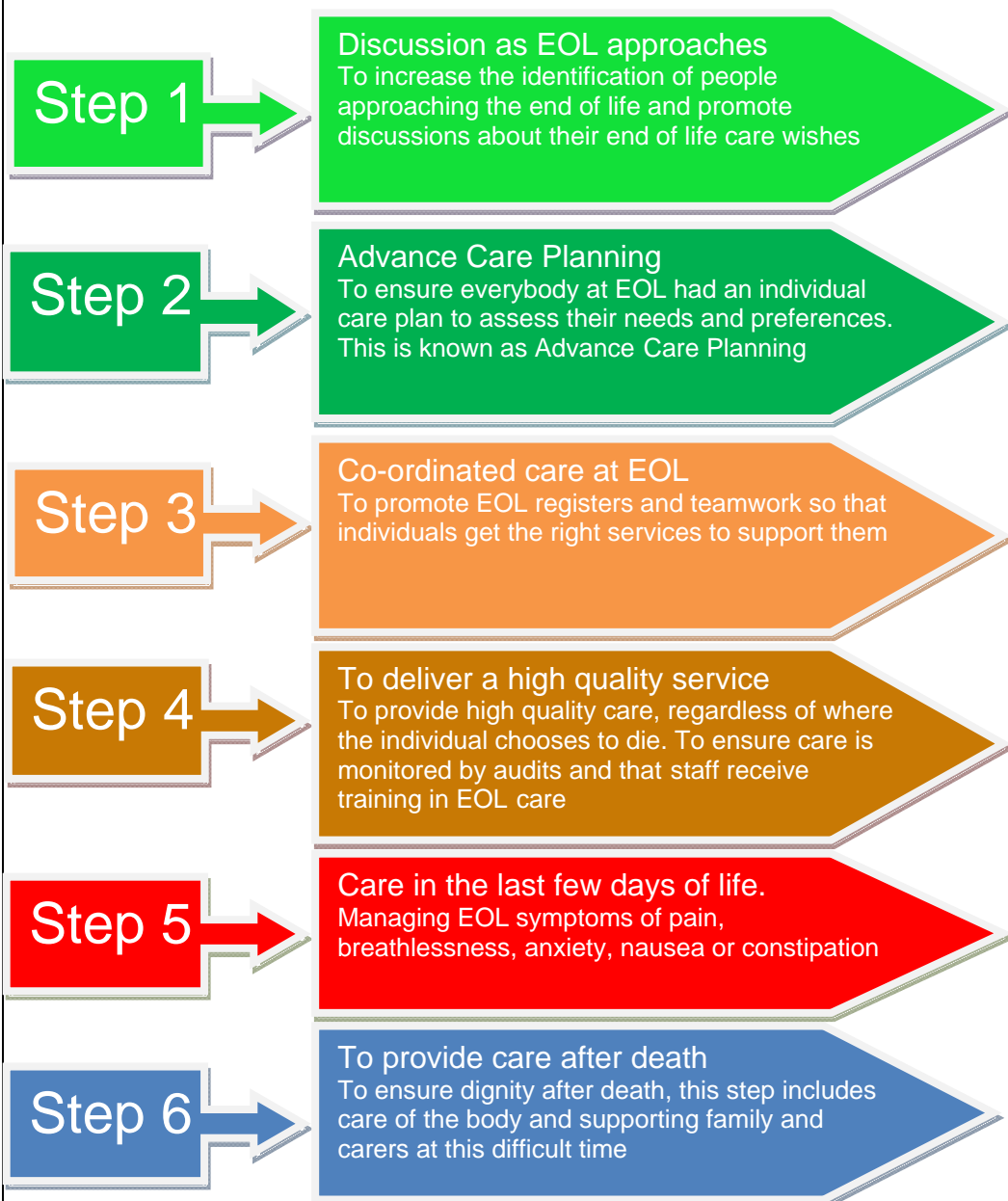
The National End of Life Strategy found that only 30% of the general public have discussed death and dying with anyone. As a result people are not dying in the place they want to.

| 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; margin: 10px 0;"> <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.

Six empty thought cloud shapes arranged in a 3x2 grid, outlined in green, intended for writing thoughts about a good death.

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.

Four empty rounded rectangular boxes arranged in a 2x2 grid, outlined in blue, intended for writing feelings about thinking about one's own death.



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

| 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 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. -----
- 3. -----
- 5.-----

- 2. -----
- 4. -----

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.”



"I'm right there in the room, and no one even acknowledges me."

The New Yorker, 9/18/06

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.

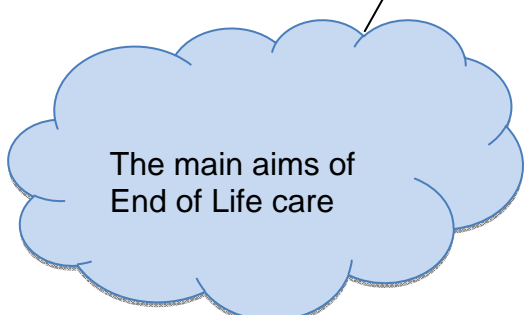
Look back at your answers to where you thought most people died, did you get any of them right? Use the space below to say what you got right and wrong and why you put the answers you did.





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

To meet people's wishes



The main aims of
End of Life care

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 life.



Write your thoughts to the following questions.

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

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

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 someone's dignity at EOL.



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

Activity 5 – Maintaining Comfort and Wellbeing

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: Written tasks and research



Assessment Type: Knowledge

As you have learnt from the activity 4, many people want a 'good death'.

We 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.

| 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; flex-wrap: wrap; justify-content: space-around;"> <div style="border: 2px solid green; border-radius: 50%; width: 30%; height: 150px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 30%; height: 150px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 30%; height: 150px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 30%; height: 150px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 30%; height: 150px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 30%; 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)



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 why it is important to maintain their comfort and wellbeing.

| | |
|---|--|
| |  |
|  | <p>Further reading Tips to Help You Recognise and Manage End of Life Symptoms http://dying.about.com/od/thedyingprocess/tp/Common-Symptoms-At-The-End-Of-Life.htm</p> |
|  | <p>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.</p> <p>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.</p> <p>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 wellbeing.</p> <p>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.</p> <p>http://www.helpthehospices.org.uk/about-us/film/</p> |

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

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

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

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:

Completed Activity

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

Activity 6 – The End of Life Care Pathway

Learning outcomes and assessment criteria




This activity links to the following learning outcomes and assessment criteria (page 3). 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 | | | |

The End of Life Care Pathway, as set out in the National 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.

Assessment Method: Written tasks and research

Assessment Type: Knowledge

| Activity 6: The end of life care pathway | |
|--|---|
|  | Approximately 2 hours and 30 minutes |
|   | <p>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:</p> <div style="display: flex; align-items: center; margin-bottom: 20px;"> <div style="border: 2px solid blue; padding: 10px; margin-right: 10px; text-align: center;"> <p style="font-size: 24px; margin: 0;">Step 6</p> </div> <div style="border: 2px solid blue; padding: 10px; background-color: #4a7ebb; color: white; text-align: center;"> <p style="font-size: 18px; margin: 0;">To provide care after death: Ask the family if they would like a drink and to talk about anything before they leave</p> </div> </div> <p>Then underneath each step write why you think that step is important and what would happen if it wasn’t considered.</p> <div style="display: flex; align-items: center;"> <div style="border: 2px solid purple; padding: 10px; margin-right: 10px; text-align: center;"> <p style="font-size: 24px; margin: 0;">Step 1</p> </div> <div style="border: 2px solid purple; padding: 10px; background-color: #6a3d9a; color: white; text-align: center;"> <p style="font-size: 18px; margin: 0;">Discussion as EOL approaches:</p> </div> </div> |

Step 1 is important because:

Step 2

Advance Care Planning:

Step 2 is important because:

Step 3

Co-ordinated care at EOL:

Step 3 is important because:

Step 4

To deliver a high quality service:

Step 4 is important because:

Step 5

Care in the last few days of life:

Step 5 is important because:

Step 6

To provide care after death:

Step 6 is important because:

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 | | |
| 2 | The LCP was developed by The Marie Curie Palliative Care Institute Liverpool | | |
| 3 | All treatment for somebody on the LCP should be stopped | | |
| 4 | Discussions about placing someone on the LCP should not be discussed with the relatives/ family members due to confidentiality reasons | | |
| 5 | The LCP will ensure the individual is heavily sedated | | |
| 6 | The LCP states that Clinical Artificial Hydration and Nutrition (AHN) such as drips should be stopped | | |
| 7 | The LCP is a form of euthanasia | | |

| | |
|--|--|
| | <p>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.</p> <div data-bbox="359 338 1390 891" style="border: 1px solid black; border-radius: 25px; background-color: #d8bfd8; height: 247px; width: 646px;"></div> |
|  | <p>For information of the EOL Pathway and each step click on the following link http://www.endoflifecare.nhs.uk/care-pathway</p> |

Completed Activity

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

Activity 7 – Advance Care Planning

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |
| | | | | | | |

Assessment Method: Written tasks and research



Assessment Type: Knowledge

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

We are now going to explore something called Advance Care Planning. As we have seen, so many people in the last 12 months of life do not get their EOL choice because they fail to have the discussion about their EOL wishes and what they want to happen to them in the future. The national EOL programme is trying to change this and encourage all of those people who have been identified as EOL to make Advance Care Plans.

For some individuals who have conditions which may affect their ability to make decisions in the future, this process may begin earlier than the last 12 months e.g those diagnosed with Dementia.

| 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 Advance 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. Advance 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 person's behalf.
- Needs to be registered with Office of Public Guardian
- Enduring Powers of Attorney made and signed before October 2007 can continue to 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>



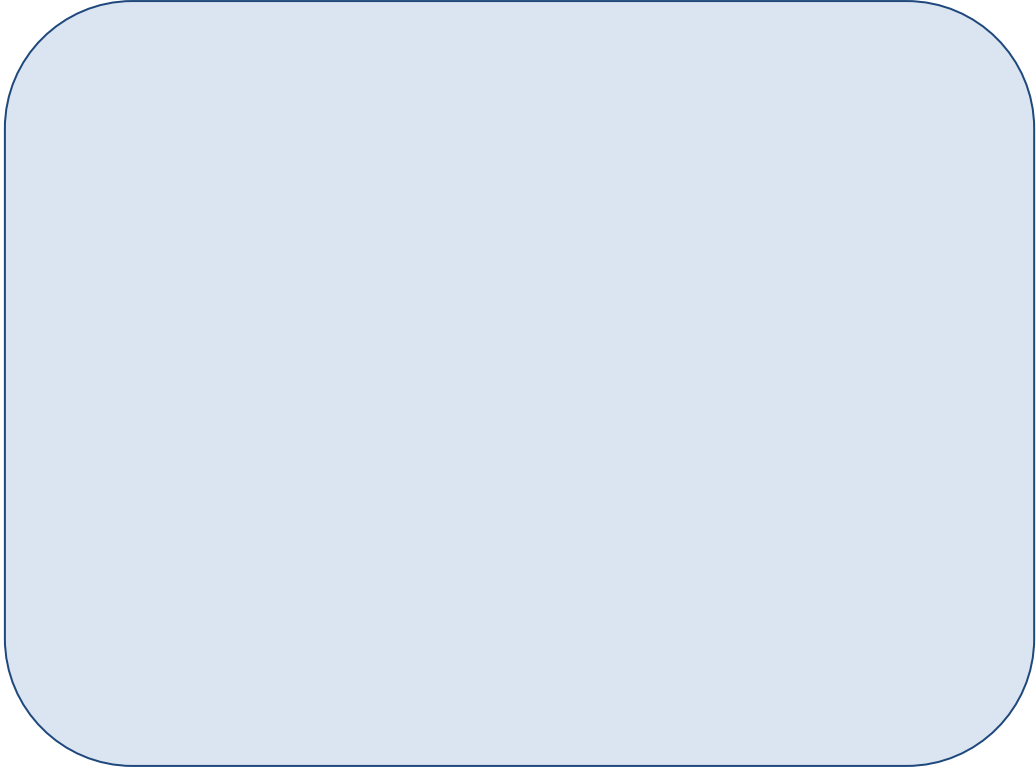
In the box below explain the 3 principles of Advance Care Planning in

your own words.

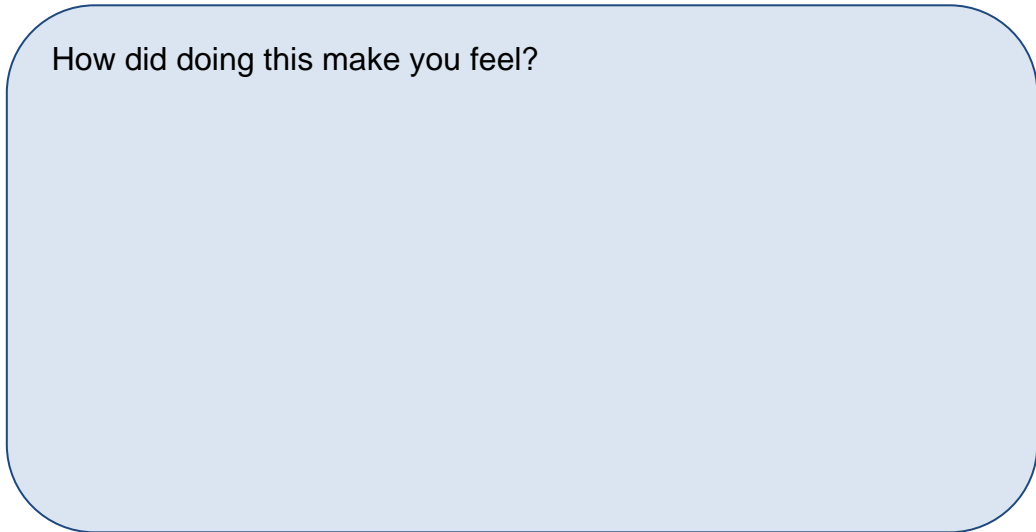
A large, light blue rounded rectangular box with a thin dark blue border, intended for writing.

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

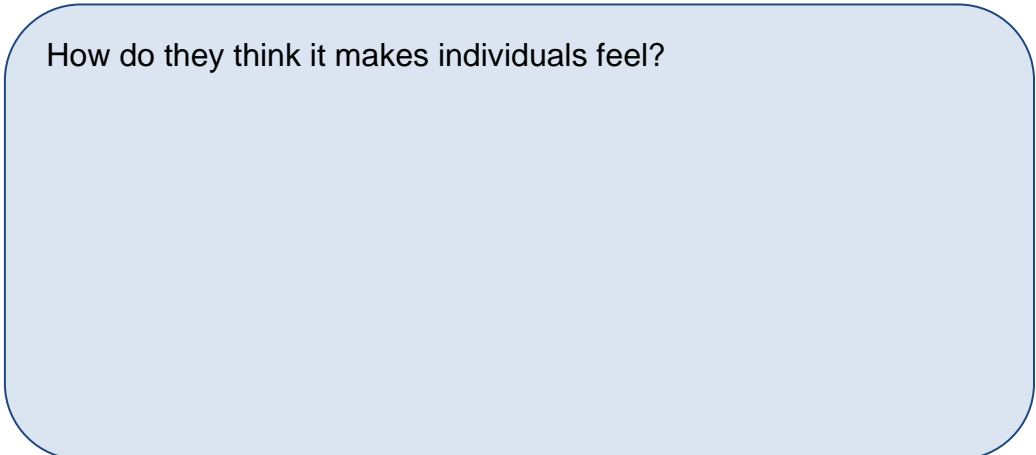
A large, light blue rounded rectangular box with a thin dark blue border, intended for writing.




How did doing this make you feel?



How do they think it makes individuals feel?



| | |
|---|--|
| | <p>Do they think it is important to talk to people about EOL wishes?</p> |
|  | <p>For further information on Advance Care Planning click on this link http://www.endoflifecare.nhs.uk/care-pathway/step-2-assessment,-care-planning-and-review/advance-care-planning.aspx</p> |

Completed Activity

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

Activity 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 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 | 2.6 | |
| 3.1 | 3.2 | 3.3 | 3.4 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

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. The support and care provided to relatives will help them cope with their loss.

Assessment Method: Written tasks and research

Assessment Type: Knowledge

| 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 director's 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:

A large, empty, light red oval shape intended for the student to write their notes on the local policy.

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 to 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:

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

Activity 9 – Communicating with ill people

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: E-learning

Assessment Type: Knowledge

This activity will help you to improve your communication with ill patients in end of life care. It will help you to understand why individuals' priorities and ability to communicate vary over time and to consider the many reasons why communicating with ill patients can be challenging.

When you are talking with individuals who are ill at the end of life, it is important to remember that their ability to communicate may not just be affected by the emotional impact of facing a terminal illness but also by feeling unwell in the same way as any other illness.

Therefore 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 module you will think about some underlying issues and how you might change what you can do to make your conversation more effective.

It will help you to:

- Identify factors that can make it challenging to communicate with ill people in end of life care
- Recognise when you might need to stop a conversation
- Reflect on how you communicate with others
- List some strategies for you to use to make your communication more effective with ill patients

This will help you to understand why individual's priorities and ability to communicate vary over time and to consider the many reasons why communicating with ill patients can be challenging.

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:

Completed Activity

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

Activity 10 – Communication Quiz

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: Quiz

Assessment Type: Knowledge

This activity will help you to consider the different emotions individuals may experience in end of life care. You will think about how individuals' respond and how you can help them manage these emotions. It will explain how you can respond to their cues and difficult questions and how to be an effective listener, which are important factors when communicating in end of life care.

Effective Communication Skills are considered a Core Competency in End of Life Care (DoH,SfH,SFC 2009) because they are vital in ensuring the needs of the dying person, their family and carers are identified, responded to and met with respect and compassion. Hence, learning the essential communications skills will boost your confidence and competence in helping individuals identify and meet EOL needs (NEoLC Programme 2010)

The following activities will help you to recognise the factors that can affect our skills to communicate in general and how this affects people who are coping with, or supporting loved ones to cope with, a terminal illness. As individuals experience their illness and cope differently, it is important that you learn how to recognise the various coping strategies and understand the emotional impact of terminal illness, loss and bereavement.

Part of effective communication in end of life care is to learn how to pick up cues that individuals wish to talk which will be the first step to helping them express their emotions. This requires learning to be an effective listener as individuals explore difficult and sensitive questions and concerns. An important part of being an effective communicator is being aware of the feelings when having end of life care conversations

Thinking about your emotions and how they impact upon the communication process is very much a part of communicating effectively. Therefore, the activity will also help you to consider how to look after your own emotions so that they do not have an adverse effect upon the individuals you are caring for at the end of life.

Activity 10: Communication Quiz



Approximately 1 hour and 30 minutes



Read the booklet:

1. Effective Communication Skills in End of Life Care

Following the reading you should now complete the communication quiz below but you may want to make some notes here first.

Notes:



QUIZ

1. Why is it important to be an effective listener in end of life care?

2. What types of body language show you are listening?

3. List five actions that would demonstrate you were not listening?
 - 1)
 - 2)
 - 3)
 - 4)
 - 5)

4. Describe three emotional responses, or stages, individuals may experience when they are facing a terminal illness.
 - 1)
 - 2)
 - 3)

5. How would you respond to a person who was:
 - Crying?
 - Anxious?
 - Angry?
 - Not wanting to say anything but looking scared or sad?

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?

Completed Activity

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

Activity 11 – Communication Scenario

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: Scenario



Assessment Type: Knowledge

This activity will help you to think about the strategies you can use to help individuals facing end of life discuss their concerns, priorities, needs and emotions.

You have now learnt about the principles so it is time to put them into practice. The following scenario is a typical scenario you may encounter in your work; although it may not be set in your specific care setting it can easily apply to all areas. All individuals and their experiences are different but the types of concerns can be typical therefore thinking about how you would respond to possible questions will provide you with some pointers should a similar situation arise.

It can feel daunting at first knowing how to respond in sensitive situations as we are often afraid we will say the wrong thing. It is therefore tempting to just politely ignore a cue that someone wants to talk or to placate them in some way – e.g. ‘everything will be alright dear’. However it has been shown that this is the worst thing we should do and only makes a situation worse for individuals. Expressing emotions and needs enables individuals to feel supported, develop coping strategies, overcome fears and ultimately help them to feel respected and maintain their dignity.

Although acting out scenarios can feel unnatural, it does allow us to practice and develop our own strategies in a safe way. Don’t worry if it seems to be going wrong just go with it. Practicing in this way will help you to find out how certain listening techniques work better than others. Remember it is about trying to help an individual talk about their concerns and sometimes they need help to do this. Effective listening skills are just the skills you need to help individuals discuss their concerns, priorities, needs and 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> |

The scenario

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.

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.

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.

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.

The Activity:

Remember to ask someone to play Vera for you.

Your role

Just be yourself but imagine you are caring for Vera in a hospital ward.

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”?

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.

(Tip: read over the effective communication skills booklet to remind you of the different techniques if required).

It is your role to support Vera and encourage her to talk about her concerns and feelings.

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>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> |
|  A cartoon character of a yellow notepad with a face, arms, and legs, holding a blue pen and writing on a piece of paper. | <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? |

- | | |
|--|--|
| | <ol style="list-style-type: none">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?

Completed Activity

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

Activity 12 – Sharing Information Acceptable or Unacceptable?

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: Written tasks and research

Assessment Type: Knowledge

This activity will help you to understand how to share information appropriately and the principles of confidentiality and data protection.


As in all areas of Health and Social care, whenever we are discussing, reporting or writing about the end of life care we have provided and whether the communication was with the individuals, their carers or families, or with our colleagues, it is very important that we follow some key rules. These rules or principles are in line with best practice and the Data Protection Act 1988 and protect the rights of individuals within our care.

We should always seek consent from the individual that they agree to a conversation taking place. When storing, sharing information or discussing care we should do so confidentially. In other words, we should not disclose information unless the individual has given us permission to do so.

The exception to this would only be where not sharing the information would place others at risk of death or serious harm.

In the situation where an individual cannot consent, a best interest decision must be in place for them in line with the Mental Capacity Act 2005.

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 you have the opportunity to read and understand them. This is a very important aspect of care so discuss anything you don't understand with your manager, colleagues or tutor/assessor.

| 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?

- 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?

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?

Completed Activity

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

Activity 13 – Reflective Account

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |



Assessment Method: Reflective account


Assessment Type: Knowledge

This activity will enable you to think about how you respond to individuals key questions and cues, how you respond to difficult questions and how you help individuals manage emotionally when they are regarding their end of life experience.

Learning to be an effective communicator in end of life care is an ongoing process and it will take time to feel totally confident and competent in this area. In fact it is important that the most experienced health and social care workers keep their skills up to date. Therefore regular reflection upon our practice and some of the sensitive situations we find ourselves in enables us to be self aware, to make sure we are practicing as we should and to be alert to any gaps in our skills and knowledge.

This activity will enable you to think about how you applied the key principles of end of life care communication when caring for an individual and/or their family and friends. It will help you to think about how you responded to key questions and cues, how you responded to difficult questions and therefore how you helped individuals to manage emotionally when they are regarding their end of life experience.

| Activity 13: Reflective Account | |
|---|--|
|  | Approximately 2 hours and 30 minutes |
|  | <p>Write a reflective account of how you have been involved in an end of life care discussion with an individual or their carer.</p> <p>Think about:</p> <ul style="list-style-type: none"> • 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? |

| | |
|---|--|
| | <ul style="list-style-type: none">• 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? |
|  | <p>A reflective account is about your feelings and thoughts. Think back to how you felt during the discussion and consider the points above.</p> |
| | <h1>My Reflective Account</h1> |

Completed Activity

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

Activity 14 –Support Services

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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |

Assessment Method: Written tasks and research

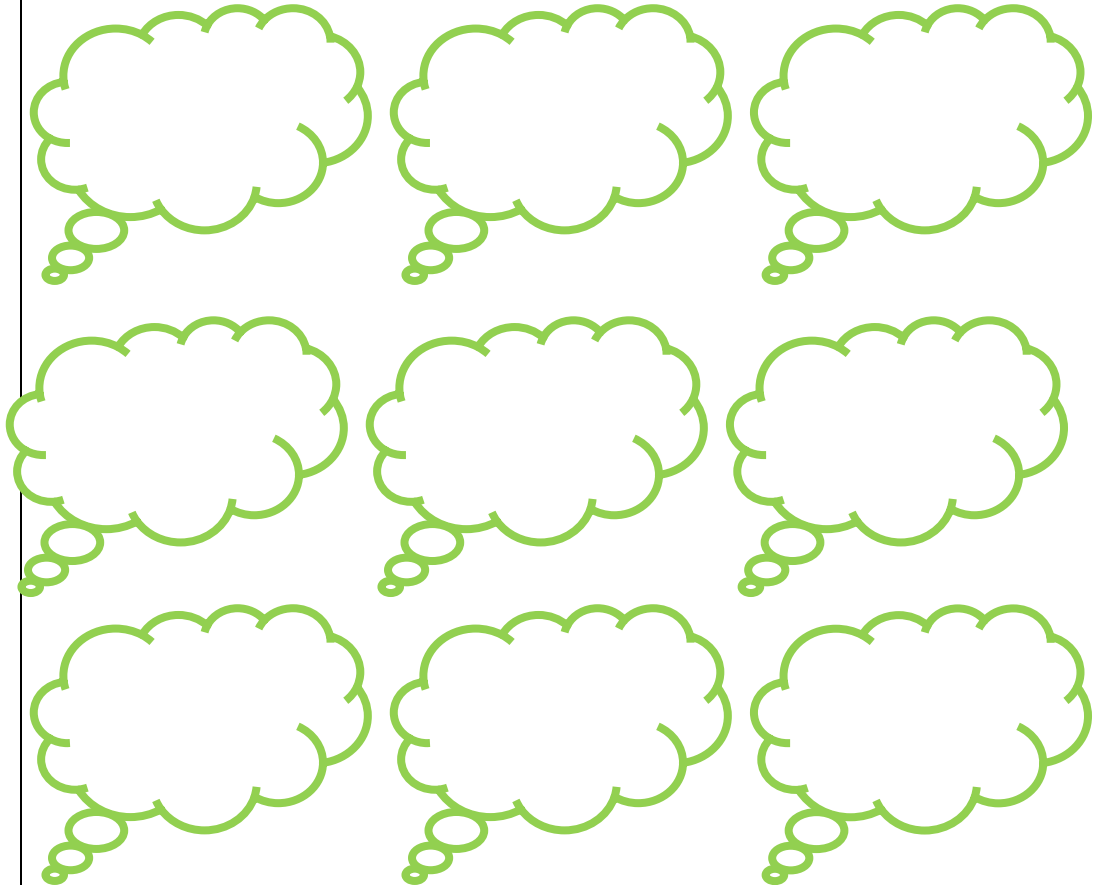
Assessment Type: Knowledge



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)

It is important that as a carer you know what support services and facilities are available to support people at EOL.

| Activity 14: Support Services | |
|-------------------------------|--|
| | Approximately 2 hours |
| | <p>Think about all the different services and identify all the people you think would support someone 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: 150px; height: 100px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 150px; height: 100px; margin: 10px;"></div> <div style="border: 2px solid green; border-radius: 50%; width: 150px; height: 100px; margin: 10px;"></div> </div> |



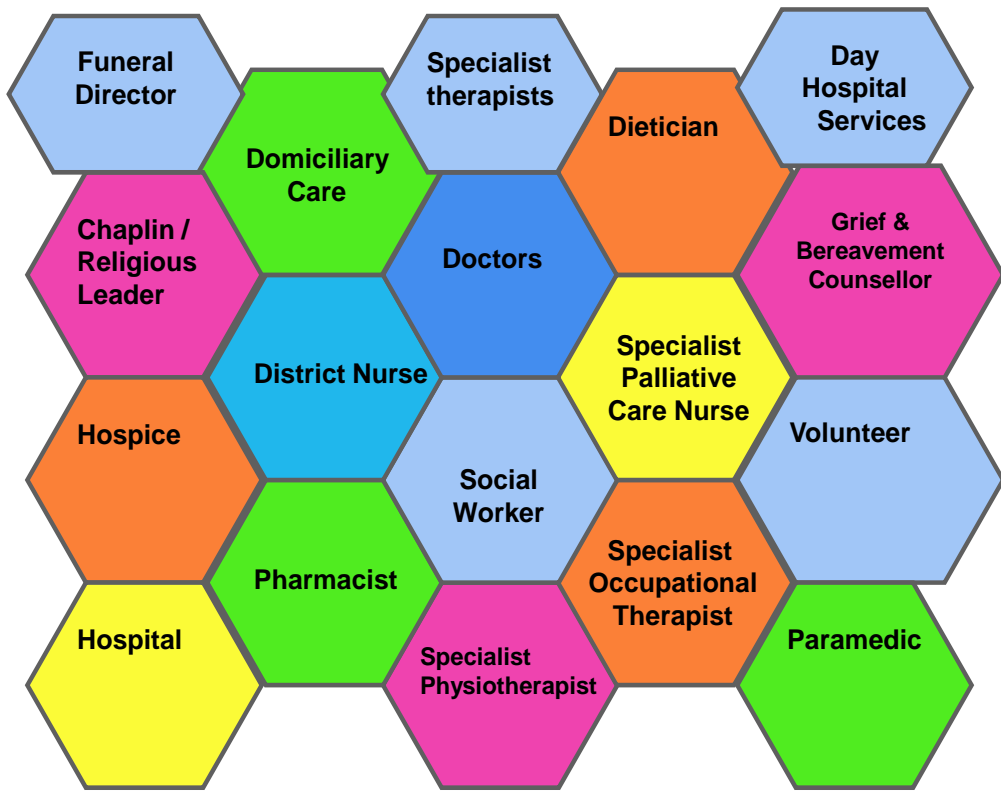
Look at the people you have identified – how many of them are:

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

Others (state here):



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

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.

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.

These professionals help individuals maintain movement and improve mobility and address safety concerns in the home.

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.

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.




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.

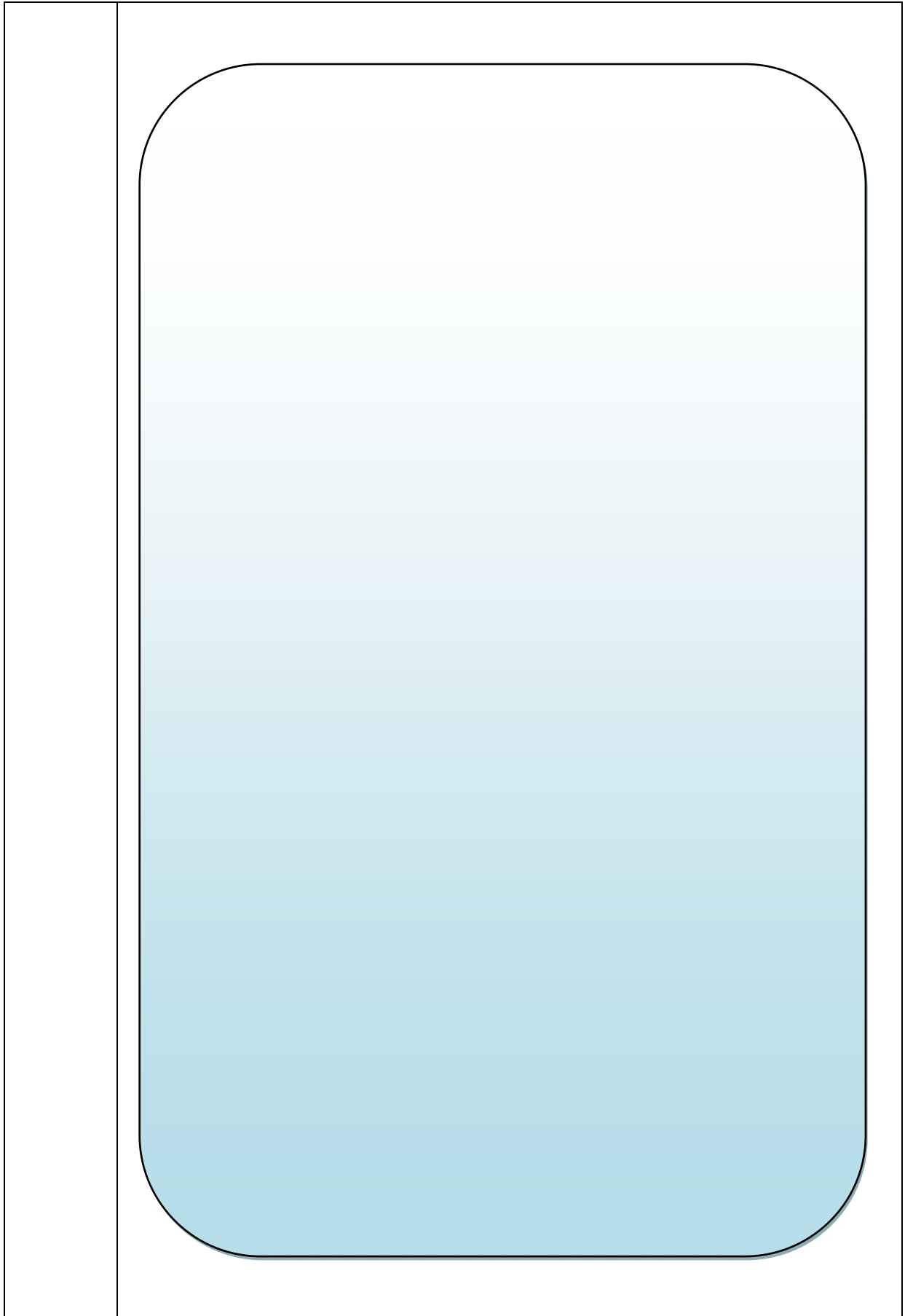
These help the individual and family members address any nutritional concerns, such as planning healthy meals, providing practical tips for nutritional supplements, and recommending specialised eating plans

This is a professional with social work or psychological training who counsels family members after a death occurs.

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.

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>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> | <div style="border: 2px solid blue; height: 40px; width: 100%;"></div> <div style="border: 2px solid blue; height: 40px; width: 100%;"></div> <div style="border: 2px solid blue; height: 40px; width: 100%;"></div> <div style="border: 2px solid blue; height: 40px; width: 100%;"></div> <div style="border: 2px solid blue; height: 40px; width: 100%;"></div> |
|  | <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 individual 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> <p>Look at Directory of Key Contact Sheet your tutor will give you and complete the form with contact numbers for your local area.</p> | |
|  | <p>Some areas have EOL care co-ordination centres to help co-ordinate all the services that provide care to someone at EOL</p> <p>Look at the following video clip from SCIE http://www.scie.org.uk/socialcaretv/video-player.asp?v=coordinationofcare</p> | |
|  | <p>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.</p> | |



Completed Activity

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

Activity 15 – Barriers to End of Life Care

Learning outcomes and assessment criteria

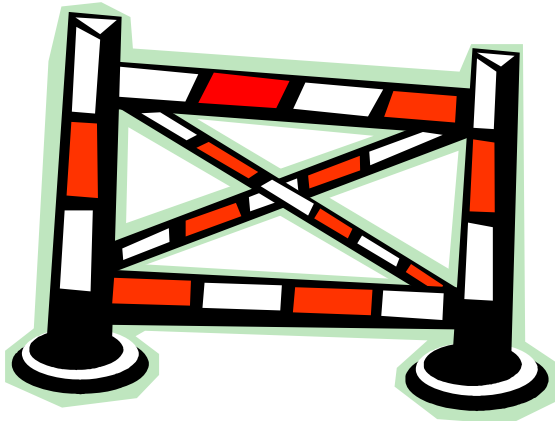
This activity links to the following learning outcomes and assessment criteria (page 4). Those highlighted green are the ones you will cover when you have successfully completed it.

| | | | | | | |
|-----|-----|-----|-----|-----|--|--|
| 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 | 3.5 | | |
| 4.1 | 4.2 | 4.3 | 4.4 | | | |




Assessment Method: Written tasks and research

Assessment Type: Knowledge

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



Barriers to End of Life Care

| Activity 15: Barriers to End of Life Care | |
|---|---|
|  | 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 (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</p> |

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 to 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, advise 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

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

problems.

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 get trained in the needs of LD clients and there is good liaison with LD services.
7. Ensure that staff know how the individuals express themselves in various situations, ask relatives etc.
8. Encourage the use of 'all about me books' to highlight to others communication needs, likes and preferences etc. Use appropriate pain assessment tools etc.
9. 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 website

| |
|--|
| <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> |
|--|

Completed Activity

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

Summary

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

You have had the 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 module 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 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 | | | |

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. |

Continuation Sheets

Continuation Sheets