UNIT 303:
Understand Advance Care Planning

Tutor’s / Assessor’s Handbook
Acknowledgements

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

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

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The purpose of this tutor book

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

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

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

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

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

All the resources to support this learning can be found on the following website:
### Table 1: Learning Outcomes and Assessment Methods

**EOL 303: Understand Advance Care Planning**

**Unit level 3**  
**Credit value 3**  
**Study/activity hours 25**

**Unit aim** The purpose of this unit is to assess the learner’s knowledge and understanding of advance care planning.

<table>
<thead>
<tr>
<th>Learning outcomes The learner will:</th>
<th>Assessment criteria The learner can:</th>
<th>Own evidence log (optional)</th>
<th>Assessment Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Understand the principles of advance care planning</td>
<td>1.1. Describe the difference between a care or support plan and an Advance Care Plan.</td>
<td>Page No</td>
<td>Type of evidence presented</td>
</tr>
<tr>
<td></td>
<td>1.2. Explain the purpose of advance care planning.</td>
<td>Knowledge</td>
<td></td>
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<td></td>
<td>1.3. Identify the national, local and organisational agreed ways of working for advance care planning.</td>
<td>Knowledge</td>
<td></td>
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<td></td>
<td>1.4. Explain the legal position of an Advance Care Plan.</td>
<td>Knowledge</td>
<td></td>
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<tr>
<td></td>
<td>1.5. Explain what is involved in an 'Advance Decision to Refuse Treatment'.</td>
<td>Knowledge</td>
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<tr>
<td></td>
<td>1.6. Explain what is meant by a ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR) order.</td>
<td>Knowledge</td>
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<tr>
<td>Learning outcomes</td>
<td>Assessment criteria</td>
<td>Own evidence log (optional)</td>
<td>Assessment Type</td>
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<tr>
<td>2. Understand the process of advance care planning.</td>
<td>2.1. Explain when advance care planning may be introduced.</td>
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<td>Knowledge</td>
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<td>2.1.</td>
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<td>2.2. Outline who might be involved in the advance care planning process.</td>
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<td>2.2.</td>
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<tr>
<td>2.3. Describe the type of information an individual may need to enable them to make informed decisions.</td>
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<td>Knowledge</td>
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<td>2.3.</td>
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<tr>
<td>2.4. Explain how to use legislation to support decision-making about the capacity of an individual to take part in advance care planning.</td>
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<td>Knowledge</td>
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<tr>
<td>2.4.</td>
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<tr>
<td>2.5. Explain how the individual's capacity to discuss advance care planning may influence their role in the process.</td>
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<td>Knowledge</td>
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<td>2.5.</td>
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<td>2.6. Explain the meaning of informed consent.</td>
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<td>2.6.</td>
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<tr>
<td>2.7. Explain own role in the advance care planning process.</td>
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<td>2.7.</td>
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<td>2.8. Identify how an Advance Care Plan can change over time.</td>
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<tr>
<td>2.9 Outline the principles of record keeping in advance care planning.</td>
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<td>2.9</td>
<td></td>
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<td>2.10. Describe circumstances when you can share details of the Advance Care Plan.</td>
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<td>Knowledge</td>
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<td>2.10.</td>
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<tr>
<td>Learning outcomes</td>
<td>Assessment criteria</td>
<td>Own evidence log (optional)</td>
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<tr>
<td>The learner will:</td>
<td></td>
<td>Page No</td>
<td>Type of evidence presented</td>
</tr>
<tr>
<td>3. Understand the person centred approach to advance care planning.</td>
<td>3.1. Describe the factors that an individual might consider when planning their Advance Care Plan.</td>
<td></td>
<td>Knowledge</td>
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<tr>
<td></td>
<td>3.2. Explain the importance of respecting the values and beliefs that impact on the choices of the individual.</td>
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<td>Knowledge</td>
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<tr>
<td></td>
<td>3.3. Identify how the needs of others may need to be taken into account when planning advance care.</td>
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<td>Knowledge</td>
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<tr>
<td></td>
<td>3.4. Outline what actions may be appropriate when an individual is unable to or does not wish to participate in advance care planning.</td>
<td></td>
<td>Knowledge</td>
</tr>
<tr>
<td></td>
<td>3.5. Explain how an individual’s care or support plan may be affected by an Advance Care Plan.</td>
<td></td>
<td>Knowledge</td>
</tr>
</tbody>
</table>
Section 1: Introduction to EOL Unit 303

General Introduction

As people approach the end of life it is important that those caring for them know what the individual’s wishes and decisions are so that appropriate care can be given.

This unit helps you develop an understanding of what Advance Care Planning involves. Talking to people about their wishes is a sensitive area. This unit will help you to understand how to deal with these conversations. The unit covers the importance of people expressing and recording their wishes and preferences for the future. Legal aspects are considered so that we can ensure an individual's wishes and preferences are carried out.

The unit will also include information about the Mental Capacity Act (2005). The Mental Capacity Act is important where individuals are not able to make decisions for themselves and have to rely on others to act in their best interests.

Learning Support

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

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

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

Learning Activities

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

Table 2: Type of learning activities and symbols

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

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

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

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

Learning outcomes and assessment criteria

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

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<th></th>
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</thead>
<tbody>
<tr>
<td>1.1</td>
<td>1.2</td>
<td>1.3</td>
<td>1.4</td>
<td></td>
</tr>
<tr>
<td>2.1</td>
<td>2.2</td>
<td>2.3</td>
<td>2.4</td>
<td>2.5</td>
</tr>
<tr>
<td>3.1</td>
<td>3.2</td>
<td>3.3</td>
<td>3.4</td>
<td></td>
</tr>
<tr>
<td>4.1</td>
<td>4.2</td>
<td>4.3</td>
<td>4.4</td>
<td></td>
</tr>
</tbody>
</table>

Assessment Method: Reflective account
Assessment Type: Knowledge

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

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

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

Table 1 (page 5) shows you and learners what learning outcomes will have to be achieved to pass this unit and what the assessment criteria will be. The table also identifies whether it is a skill or knowledge competency.
Each section will outline the activity and provide guidance on how to do the activity. Look for this symbol to help you with ideas, further learning and suggestions on completing the activity.

**Plagiarism and Confidentiality**

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

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

**Portfolio of Evidence of Learning**

We have recommended that learners keep a portfolio to record all the learning they have collected for this unit. This portfolio will demonstrate their understanding on the subject and will help you assess how the learner is meeting the relevant learning outcomes.
End of Life Care for All (e-ELCA)

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

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

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

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

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

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

There are twelve sessions which are freely available to everyone, including volunteers and clerical and administrative staff on an open access website: www.endoflifecareforall.org.uk. For further details see 'Access the e-learning'.

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

a. Competence / Skill – This is where they need to demonstrate something about their practice.

b. Knowledge – This is where they need to demonstrate that they have learned and understood some new information.

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

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

Learners have been provided with the following information:

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

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

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

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

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

<table>
<thead>
<tr>
<th>Confidence level</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>The difference between advance care plan and a care or support plan</td>
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<tr>
<td>Understanding when advance care planning should happen</td>
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<tr>
<td>Knowing who else should be involved in advance care planning</td>
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<tr>
<td>Understanding what needs to be discussed when considering advance care planning</td>
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<td>Understanding mental capacity and advance care planning</td>
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<td>Knowing how to record Advance Care Plans and when information can be shared</td>
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Section 2: Activities
Introduction to Understanding Advance Care Planning

Although each individual may have a different idea about what would constitute a good death for them, for many people this would involve:
- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

End of Life Care Strategy 2008

Looking at this statement it tells us that end of life care is an individual experience. Many people facing the end of life worry that their particular wishes will not be carried out, especially if they become unable to tell others what they want.

Making plans for the future - Advance Care planning is important because:

- Advance care planning means that the individual can be involved in making decisions about their future care.
- Making Advance Care Plans ensures that future care given is appropriate to the individual
- Advance care planning enables the carers to work with that individual to provide care that is appropriate for that individual.
- Advance Care Plans need to take into account the physical, psychological, cultural, spiritual and social needs or wishes.
- Being able to plan enables a person to feel they have some control over what is happening to them and can give them confidence about their future. Making plans can give a sense of peace.

You may recognise these aspects as part of any holistic care planning.

Things that may be discussed when talking about advance care planning include the following:

1. The person’s wishes and preferences for care as they approach their end of life.
2. Identifying the person they would like to be consulted in relation to their wishes and preferences if they are unable to express these in the future.
3. Appointing someone to make decisions for them using a lasting power of attorney.
4. Refusing specific treatments in certain circumstances.
5. Decisions about where they would like to be cared for at end of life.
6. Any plans about funeral arrangements.

Making plans in advance means everyone can be aware of that individual’s wishes.

This module will look at all these aspects of advance care planning. There will be opportunities to think about your role in advance care planning.
Activity 1 – Advance Care Planning Introduction

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

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<th>1.6</th>
<th>2.1</th>
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**Assessment Method:** Information question and answer

**Assessment Type:** Knowledge

**Tutor/Assessor Guidance**

In this section the learners will start to think about what is meant by advance care planning.

The first video clip they are asked to watch shows how planning in advance can make it easier for both individuals and their families or friends as end of life approaches. Detailed information about the learning points from this clip is given in the answer book.

The clip shows people being open about expressing their wishes and how it brings a sense of peace to the individual and those close to them to know that their plans are in place and that major decisions will not need to be made at difficult times as they have already been communicated.

The learner should be encouraged to think about how the taboo of talking about death has been overcome and that rather than causing distress it has brought comfort to those concerned. The comment from the lady with dementia that her son 'will know what the old girl wants' is particularly telling.

The next section compares and contrasts the differences between advance care planning and general care planning.

The learner is encouraged to start thinking about how information is gathered in the care setting in order to prepare Advance Care Plans. The carer should be starting to think about their role in relation to this and the importance of knowing the individual wishes and needs of each person they care for. Knowing these wishes can improve the quality and individuality of care given.

There is then an exercise that asks the learner to start looking at the environment in which care takes place and see what is in place to encourage understanding of advance care planning and encourage individuals and their families to take part in these. Suggestions are given in the answer book.

The next activity asks the learner to write a paragraph about one change they...
would make in their workplace to promote the use of advance care planning. The learners are reminded about ensuring that the change is either within their sphere of responsibility or that they identify how to take their suggestion forward.

The learners are reminded that making an Advance Care Plan is voluntary and that there should be no outside pressure for them to do so. If an individual declines to talk about or plan for the future then that decision should be respected.

The learners are then asked to access a web link to further information about the differences between Advance Care Plans and general plans. The next part of this section is a quiz to consolidate their learning about the differences between general and Advance Care Plans.

The final part of this section is questions about the difference in legality between an Advance Care Plan and a Last Will and Testament.
### Activity 1: Advance Care Planning Introduction

**Approximately 3 hours**

Watch the following video clip about advance care planning [http://www.advancecareplanning.ca/](http://www.advancecareplanning.ca/) on the homepage.

Write a short paragraph (no more than 150 words) about what you have learnt about the importance of discussing end of life care issues and making plans in advance and what the purpose of them is.

The learners are asked to write a short paragraph about what they have learnt about the importance of discussing end of life issues and making plans in advance.

- They may have noticed that the individuals and their relatives are quite calm when talking about the issues.
- They may have noted that one lady says that talking about death was a ‘taboo’ in her generation.
- They may notice how well the son supports his mother (who appears to have dementia), reminding her they have had discussions and what decision she made at the time and giving her the opportunity to confirm or change those decisions.
- They may notice that the relatives feel it will be easier to make decisions knowing that they can follow their relative’s instructions.

This is not an exhaustive list but covers the main points that should be drawn out of the learning activity.

For further information, click on the following links and read the document.

**Planning for your Future Care:**

This is written for the public and is a good introduction to advance care planning conversations.

**Preferred Priorities For Care**

This is a version written for people with learning disabilities.

Also read Advance Care Planning –A guide for Health and Social care staff:

This document was published to offer guidance relating to ACP for health and social care professionals which recognised their different contributions to an individual’s care.
Advance Care Planning is different from general care planning

General Care Planning
A care or support plan is designed to describe the care to be given to an individual at that time. It reflects their present abilities and identifies where they need care or support.

Advance Care Planning (ACP)
The process of ACP is to make clear what a person’s future wishes may be.

Advance Care Planning (ACP) is a process of discussion between an individual and their care provider. That care provider does not need to be medically qualified to be involved in Advance Care Planning. It may be any member of staff or it may be family or friends. Individuals may also decide to write their own plans down.

It is recommended that, with the individual’s agreement, the Advance Care Planning discussion is written down so that everyone involved in that person’s care is aware of their wishes.

As their illness progresses the person may change their mind so plans need to be regularly reviewed.

Many care areas have their own forms for recording Advance Care Plans. These plans may be part of the initial assessment process or form part of the information gathered prior to someone entering a care setting. If there are no forms in your work area then look at some examples by going to http://www.sayitonce.info/download-forms/139-download-advance-care-plan-forms
and click on Advance Care Plan (V9)

In addition to the forms in your workplace and/or the forms from the link above, search on the internet for more forms so you can see a range of how these forms may be used. Put copies of these in your portfolio.

Key elements

- The ACP process is voluntary and should not be as a result of pressure from anyone else. Some people may not wish to plan. If this is the case their wishes should be respected. It should be written in the care plan that the conversation has been offered so that everyone knows.

- The Advance Care Plan is a statement of an individual’s wishes and preferences for care. This may include a choice about where they would like their care to be provided. This is often referred to as
‘Preferred Priorities for Care’

- All health and social care staff should be prepared to be involved in ACP discussions if an individual expresses a wish to discuss their future care

- Discussions focus on the views of the individual although they may make a request for a carer, friend, partner or relative to be involved

- An Advance Care Plan can only be made if the individual has the capacity to discuss and understand the options available to them and agree what is then planned

- The wishes expressed during ACP are not legally binding but should be taken into account when professionals are required to make a decision about an individual’s care.

ACP gives an opportunity for an individual at the end of life to think about any treatments they do not want to have in the future. This could be that they do not want to go back into hospital or that they do not want to have further treatment but maybe would accept antibiotics if they developed an infection.

However ACP is not just concerned with the big decisions about treatment. It is also about the things that are important to the individual. This might include having their favourite music played as they near the end of life. It could be about making arrangements for their pets or it might be about ensuring they are not alone as they approach death.

**What is the role of the care worker in relation to ACP?**

Talking about their future wishes and facing the end of life is a difficult time for individuals and their families.

There are clear benefits to planning ahead to ensure that the care given is appropriate for that individual and so that their wishes are known and can be taken into account.

Knowing what a person’s wishes are before their condition worsens means that family members are not faced with making difficult decisions when they are feeling upset about losing their relative.

If a person has dementia, it is particularly important that discussions are started early so that they are still able to make their own decisions.

As a social care worker you will develop close working relationships with individuals and their families so you are in a position to gain their trust and support them in thinking about the future.

As you progress through this module you will gain information that will help to answer questions about how they make their wishes known and some of the choices they have.
Think about how your work setting encourages an environment where people are encouraged to make their end of life plans. Make a list in the box below of what is in place to encourage people to talk about their end of life plans. This could include:

- Leaflets and written information for individuals and their families
- Special events such as a coffee morning held to talk about advance care planning
- Information on who individuals and their families should approach
- Display board with information

Suggestions are made in the text e.g. presence of information leaflets, special events such as coffee mornings to talk about Advance Care Planning, people and organisations who individuals can approach, display board. Other things they may highlight could include:

- Keyworker system to allow relationships to be built with individuals and their families.
- Letters in advance or on admission outlining the process of making advance care plans
- That the care planning documentation includes a section to consider advance care plans

Describe, in a short paragraph, one change you will introduce into your workplace to encourage end of life discussions.

**One change I will make is:**

Learners are asked to outline one change they will introduce to encourage advance care planning conversations. Encourage the learners to be inventive but ensure it is within their sphere of authority to implement the change they suggest or that they know how they can take their suggestion forward.

NB the learners must understand that making an Advance Care Plan is a voluntary decision and there should be no pressure from others to do so.
Click on the link below to access “The differences between general care planning and decisions made in advance”
http://www.endoflifecare.nhs.uk
Click on ‘search resources’ in the menu and then in the search box enter “The differences between general care planning and decisions made in advance” – the link to this document will appear in the list.

Read the leaflet and complete the sentences below by writing either advance or general in the blank spaces.

• A General care plan can cover any aspect of health and social care
• An Advance care plan can cover any aspect of future health and social care
• A General care plan provides the multidisciplinary team with a plan of action
• An Advance care plan makes the multidisciplinary team aware of an individual’s wishes and preferences in the event the person loses capacity
• All members of the multidisciplinary team can see the General care plan to aid care
• The individual has the final say over who can see their Advance care plan
• A General care plan can be completed for an individual who lacks capacity in their best interests
• An Advance care plan cannot be written if the individual lacks capacity to make these statements
• An Advance care plan is not legally binding but must be taken into account when acting in an individual’s best interests

Answer the following questions:
What is the legal standing of ACP plans?

An ACP has no legal standing. An individual can change the plan at any time while they have capacity to do so – this is why the plan should be reviewed on a regular basis. The plan is only active if the individual does not have capacity and then will be taken into consideration so that the individual’s wishes can be taken into account when making a decision in that person’s Best Interests.

What is the legal standing of a Last Will and Testament?

A Last Will and Testament, once it is correctly drawn up and witnessed, is a legal document. The executor(s) named in the will assume authority over that person’s affairs and make decisions about the affairs of the individual who made the will once that person dies. Wills can be adjusted but must be with agreement of those who inherit and following legal process.
Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 1 - Resources

Web resources

Speak up “Start conversations about end-of-life care”
http://www.advancecareplanning.ca/

Information Sheets/booklet

1. EoLC planning your future care booklet
1a Preferred Priorities for Care (easy read version for learning disabilities)
3. My Advance Care Plan
4. Support sheet 3 ACP
4a ACP factsheet002
5. Differences between ACP and ADRT
6. Support sheet 18 PPC
9. ACP fact sheet

PowerPoints/ Lesson Plans

PP ACP activity 1

E- learning Resources

E: ELCA modules that support the 303 units can be found in the following document
E ELCA EOL 303.doc

Further Reading

Further Reading
1. Advance Care Planning. A guide for health and social care staff (DH 2008)
2. National EOL Strategy (DH 2008)
3. Matters of life and death (RCGP, RCN 2012)
Activity 2 - Professional Discussion

Learning outcomes and assessment criteria

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

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Assessment Method: Professional Discussion
Assessment Type: Knowledge

Tutor/ Assessor Guidance:

1. What informed consent means and the information an individual may need to enable them to make informed decisions.

The learner is asked to identify an example of where they may need to support an individual to make a decision and give ‘informed consent’

Suggested examples are given such as decisions concerning medical treatment or where they wish to be cared for. Other examples have been given under the learning for Activity one.

The learners need to realise that they personally, can help the person by giving information but that often they will need to involve others. This may be talking to family and friends, spiritual representatives or in the case of decisions about treatment then the medical doctor in charge of the care needs to be consulted.

2. What is involved in an ‘Advance Decision to Refuse Treatment’?

• The learner should be able to describe how an individual makes their wishes known.
• The learner should understand that advance decisions do not become valid until the individual has lost the capacity to make their own decisions. If the individual is able to make their own decisions they should always be consulted as they may wish to change their mind.
• The learner should understand that advance decisions are not legally binding but should be taken into consideration when deciding an individual’s care and acting in that person’s best interests.

3. What is meant by a ‘Do Not Attempt Cardio-Pulmonary Resuscitation Order’?

• The learner should be aware of who is involved in making a decision about DNACPR
• Consultation should be had with individual (where possible) and relatives or someone who holds Power of Attorney. The ultimate decision is based on the
clinical assessment of the doctor in charge of care after consultation as above.

- The learner should be aware of the correct procedure for recording a DNACPR order.
- The learner should be aware of the system in place in their particular part of the country as this may vary.
- In some parts of the country the DNACPR is only valid in a particular setting for instance if it is made in hospital it will not be valid in the ambulance or in the community unless a new DNACPR is made by the doctor.
- The learner should be aware that if the DNACPR is not valid (and this may include not being signed by the doctor) that the staff attending, such as ambulance staff, must carry out attempts at resuscitation.

3. How the Mental Capacity Act supports making decisions about the capacity of an individual to take part in advance care planning

- The learner should be aware that any decisions made on behalf on an individual who lacks capacity should be made in the ‘best interests of that person’
- They should be aware of the process of acting in best interests such as finding out if there is a Power of Attorney in place.

4. What to do if a person lacks capacity

- The learner should be aware of the process of determining mental capacity.
- The learner should be aware of the initial screening process that can be carried out by social work carers which should include the individual’s ability to understand information, retain long enough to make decisions and to make their own decisions.
- The learner should understand that if after the initial screen the person appears to lack capacity then health care professionals need to be involved.
- The learner should be aware that in the absence of relatives or in dispute about decisions then an Independent Advocate might be appointed.

5. Understanding the role of Power of Attorney

- The learners should be aware that under the present regulations Power of Attorney is divided into two parts;
- Property and financial affairs – decisions about paying bills, collecting benefits, selling the private home.
- The learner should know that there is a charge to register a power of attorney.
- The learner should understand that the person who is appointed power of attorney is nominated by the person concerned.
- The learner should know who can hold power of attorney – must be over 18. Can be a relative, friend, professional such as a solicitor, husband, wife or partner.
In this section we will look at some particular aspects of Advance Care Planning that are important to consider when discussing an individual’s future care.

Advance Care Planning discussions may lead to a variety of decisions including:

- Refusing further treatment now or under certain circumstances in the future
- Appointing someone to have power of attorney
- Completion of a Do Not Attempt Cardio-Pulmonary Resuscitation order
- Decisions about who should be consulted about the individual’s care
- Where care should take place in the future
- Special religious spiritual and cultural beliefs the individual wishes to be respected

These are big decisions.

Before making decisions about their future care the individual must know all the facts so that they are able to make informed decisions. Once a person has all the information they are able to give informed consent. We will explore the meaning of informed consent and what information an individual will need in order to make decisions about future care.

An individual can only make an Advance Care Plan if that person has the mental capacity to make the decision concerned. We will also discuss the Mental Capacity Act (2005).

The Mental Capacity Act (2005) describes the process to be followed where an individual lacks the capacity to understand information and make decisions, e.g. through illness such as dementia. We will examine how to determine mental capacity and explore your role in this.

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For this activity you will be need to book and plan a discussion with your tutor/assessor. You will be required to talk about the following topics:

1. What informed consent means and the information an individual may need to enable them to make informed decisions.
2. What is involved in an “Advance Decision to Refuse Treatment”
3. What is meant by a “Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) Order”
4. How the Mental Capacity Act supports making decisions about the capacity of an individual to take part in advance care planning
5. What to do if a person lacks capacity
6. Understanding the role of Power of Attorney

Before your discussion you should complete the tasks below and write down your answers. Your answers will form part of your discussion with
Informed Consent or Decision Making

Consent is required from a patient regardless of the treatment, from blood test to organ donation.

Defining consent

For consent to be valid it must be voluntary. The person must have been given all the information they need to make an informed decision. The person must have the mental capacity to make the decision. These terms are explained below.

• Voluntary:
The decision to consent or not consent to treatment must be made by that person. They make take advice from others such as medical staff, friends and family but should not be put under pressure to make a particular decision.

• Informed:
The person must be given full information about what the treatment involves. This must include the benefits; the risks; whether there are alternative treatments and what will happen if treatment does not go ahead.

• Capacity:
The person must have the mental capacity to make that decision. Mental Capacity means an individual can:
  o Understand the information given to them
  o He or she can remember that information
  o He or she can use it to make an informed decision.
What happens if a person does not have mental capacity?

If a person does not have the mental capacity to make their own decisions because for example they have dementia then there is a process to follow. This will be discussed later on.

You will now be asked to give an example of supporting an individual to make an informed decision and give informed consent.

Describe something in your care setting that would need an individual to give informed consent, consider the following:
  o What would be your role in this?
  o What information would you give them to ensure they are fully informed to make a decision?
  o Who else would need to be involved in that decision?

Some examples could include:
1. Decisions relating to their medical treatment
2. Decisions regarding where they are cared for at the end of life
What would be your role in this?

To decide if their initial screening indicates that the person has capacity to make decisions.

To give information as far as they are able to and recognising their limitations, to involve others as appropriate.

What information would you give them to ensure they are fully informed to make a decision?

This will vary on the decision to be made and the points above should be taken into consideration. The learners should be aware that an individual may be able to make some decisions such as what to eat, what to wear but may not have the capacity to make other decisions such as those about treatments.

Who else would need to be involved in that decision?

The learner should consider the Best Interests of the individual under the Mental Capacity Act. Who is involved will again depend on the decision but should include any known views of the individual, family or close friends (ie those who know the person best), anyone who holds power of attorney for that person, anyone involved in the care of that individual and for medical decisions must include the doctor caring for that individual. The learner should be aware when an independent mental capacity advocate may be appointed.

The learner should be aware that in their role they may be involved asked to give information to support decisions made at a Best Interests meeting.
Advance Decision to Refuse Treatment (ADRT)

We have looked at making Advance Care Plans. We can think of these as the wishes of an individual for their future care.

An Advance Decision to Refuse Treatment (ADRT) can be used to formalise some areas of the plan relating to treatment. It will come into effect if the individual loses the capacity to give or refuse consent for certain treatments. The individual writes an ADRT, often with support from professionals, relatives or care workers. An ADRT cannot be prepared if the individual lacks capacity.

To be valid an ADRT must be in writing, signed and witnessed.

Remember an individual can only refuse treatments. They cannot request specific treatments or insist on a treatment that is pointless.

If the person has capacity and makes a voluntary and informed decision to refuse a particular treatment, their decision must be respected. This is still true even if their decision would result in their death.

An individual cannot make an Advance Plan asking to stop basic care such as food and fluids by mouth – though they may refuse these at the time.

Individuals cannot request that health or social care workers end or intentionally shorten their life.

Key elements

- Making an ADRT is entirely voluntary and this should not be undertaken as a result of external pressure
- An ADRT can only be made by someone over 18 years of age
- An individual making an ADRT must have the capacity to do so
- The ADRT should specify the treatment which is to be refused and may specify the circumstances in which the refusal applies
- The ADRT must be applicable to current circumstances
- If the ADRT is to apply (even if the person’s life is at risk) it must be in writing, signed and witnessed
- An ADRT can only be used to refuse treatment not to demand treatment or to request procedures which are against the law e.g. assisted suicide
- Professionals can only respect the ADRT if they know about it. A copy should be retained by the patient and (with consent) be retained in all relevant patient records
Consider the 2 case studies below:

- Freda lives at home and is in the early stages of dementia. She tells her domiciliary care worker she has been thinking about the future and feels that if she loses the ability to make future decisions about her care she would like it written down that she would not want to be fed artificially if she can no longer swallow properly. Her domiciliary care worker says “Don’t worry about that, it’s a long way off and I’m sure that won’t happen”

- Fatima has suffered a stroke and is being cared for in a nursing home. She is worried about the future and says to her care worker that if she were to have another stroke in the future and no longer has the ability to make or communicate her decisions relating to her care she would not want to be kept alive by artificial feeding. Her care worker replies “This is something you might want to discuss further with your GP as there are things you can put in place to ensure that we can follow your wishes”

Which is the correct response from the care worker to ensure a conversation about Advance Care Planning can happen and why?

The care worker should take the opportunity to discuss what the person’s wishes are. The correct response is to suggest they discuss their wishes further and that this will involve the doctor if the wishes relate to medical treatments.

Why is it important that the care worker acts now to have this conversation with Freda even though she has no problems with eating and drinking at the moment?

Advance Care Planning means that plans should be made as far in advance of an event as possible. If Freda is no longer able to eat and drink it may also mean she has difficulty communicating her wishes at that time. By making the plan now while this is not an urgent issue, Freda will be in a better position to weigh up the positives and negatives or risks involved with her decisions and make rational choices. It is always more difficult to make decisions when you are feeling unwell or have to make a decision quickly - especially if you are facing several big decisions in a short time when you and your family are feeling emotional.
What other aspects might the care worker discuss with Joan now that the conversation has been opened?

The care worker could take the opportunity to discuss other wishes Joan may have for her treatment such as:

- Discussions about what to do if her heart stops or about other treatments apart from artificial feeding so that the doctor is aware of her thoughts when he discusses treatments with her
- Discussions about whether she would like to make an Advance Decision to Refuse Treatment
- Discuss where she would like to be cared for at end of life, explain Preferred Priorities for Care form
- Discuss who she would like consulted about her care e.g particular family members of friends
- Ask if she has considered Power of Attorney and briefly describe the two types
- Discuss any special wishes for her end of life care such as special music, spiritual or cultural observances
- Consider writing a will/financial planning
- Possibility of organ donation
- Funeral planning

Further information can be found by reading Advance Decisions to Refuse Treatment; A guide for health and social professionals.

Click on the link below to access it

Decisions about Resuscitation

One decision that an individual may make is that they do not want attempts made to restart their heart if it stops. This decision should be made only after decision with the doctor and wherever possible, the family.

As care worker, it can be hard to accept that no attempts will be made to prolong life but these decisions are made on an individual basis and only where there is little or no possibility of success.

Once the doctor has completed the form, it is very important that the information is available to all those concerned with the individual’s care.
Think about and answer the following questions.

What would you do if during discussion of Advance Care Planning or in a quiet moment after supper as often happens, a client told you they were worried attempts would be made to restart their heart if it stopped?

Listen carefully to their concerns. Explain about Advance Care Plans and if ask they would like you to make sure their wishes were known so they could be respected if this happened. Explain that you would need to involve their GP. Suggest it would be a good idea to involve the family in these discussions and explain that you can help with these discussions if they are finding it difficult.

Where would a completed form be kept and where else would this information be recorded?

This may vary – the important thing is that the correct form is used, it is signed by the doctor and is readily available and that all those caring for the person are aware it exists including out-of-hours carers and outside agencies such as ambulance services.

What would be your role if the ambulance were called to the individual?

To bring the form to the attention of the ambulance staff
You may not have been sure about the answers to the last two questions. Until recently a DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) order was only valid in the place where the person was. It stopped being valid if the individual was moved.

For instance, if the form was completed in the hospital it would not be valid in the community. A GP would have needed to complete a new form for that person. Until the new form was in place then attempts would have to be made to restart the person’s heart if it stopped.

As you can imagine, this can be a very distressing for the individual, the family and all those involved in the care of that individual.

More recently, partnership working is being done all over the country to ensure that once a form has been completed and signed by the doctor then it remains valid wherever the individual is.

Research and ask in your place of work what happens in that setting. Make notes below:

**Notes:**

How is a DNACPR recorded in your area? If the individual is admitted to hospital and a DNACPR order is put in place there what happens about this when they return to the home?

If the learner is not clear about this they should seek advice from the manager in their work area.
If the DNACPR is a separate form, the learner should find out how other treatment decisions and wishes are recorded and communicated to those involved in the care of that individual e.g. a letter from the GP or discharge instructions – if the latter then how are these acted upon by the GP to keep all carers informed?

Also, look at examples of the forms used in your area for DNACPR. In some areas there will be a form that relates only to the decision not to resuscitate. However, in other parts of the country a Treatment Escalation Plan (TEP) has replaced this. This form contains additional information about what treatments are and are not appropriate for this person.

What forms are being used in your area?

The learner should find out if there are Treatment Escalation Plans in their area. If so, they should be prepared to discuss what information is recorded on this; where the forms are held, whether there are systems in place to make sure they follow the individual wherever they are cared for. The learner should be aware of their role in ensuring a TEP is in place, contacting the GP to complete and who is responsible for obtaining blank copies of the forms (normally this is the GP).

Validity of the forms
- The form is only valid if it is signed by the doctor looking after the individual’s care
- Only the original document is valid, photocopies are not accepted

The care workers role in the completion of a DNACPR or TEP form
A care worker is not able to complete either of these forms but they may be the one who asks the doctor to look at the care of a person who is nearing the end of life.

Looking again at the questions above, if the individual went to hospital then your role may be to make sure the form went with them. It is also important to note that the hospital must be told the form is there and the individual must return from hospital with the form.

Again with the ambulance, your role may be to show the paramedic the completed form. Without this form then resuscitation would have to be started if the person’s heart stopped. The ambulance staff would have no choice even though you know what the wishes of that person were.
Thinking about people who are unable to make their own decisions.

So far we have considered decisions made by individuals who are able to make their own decisions. However many of the people we care for will not have the capacity to make these decisions. This may be because of dementia, other illness or learning disability. In the next section we will look at how people who lack capacity can be supported and plans made.

A person who does not have the capacity to make the bigger decisions about their future care may still retain capacity to make smaller decisions. This may be about how they are cared for day to day such as the food they wish to eat or the clothes they wish to wear. They may give information that shows what they would like in the future.

Some of the people you meet in your caring role will already have been assessed as lacking capacity by other agencies. Some of the people you care for may develop loss of capacity.

Some people may lose capacity for a short time due to acute illness. If this is the case the decision that social care staff need to make is whether the decision is urgent or can wait until the person regains capacity. You may need to take advice from others such as the doctor.

Assessing Capacity

Although judgements about whether someone has the mental capacity to make decisions will be made by medical staff it is useful to be able to screen within your care setting.

Doing this will mean you have information to help outside agencies such as the GP.

Find out whether you have a tool which you use in your work setting and if so provide an outline of how that tool is used below:
The tools may vary slightly but the key principles are:

1. Can the person understand the information?
   You may need to try to give the information in more than one way. Sometimes the words we use or the speed we talk at can make it hard for the person to understand. Avoid jargon

2. Can they retain the information?
   That is, can they remember what has been said for long enough to actually make a decision? You may need to check this out by seeing if they make the same decision when the information is repeated later.

3. Can they use or weigh up that information?
   You need to be sure the person understands the benefits or risks of a particular decision. It is not enough that they say ‘yes’ or ‘no’

4. Can they communicate their decision?
   You need to be sure that the person has had chance to let you know about their decision. This means that you have to take time if they have difficulty speaking or to get them to write something if they are unable to speak.

**Mental Capacity Act (2005)**

The Mental Capacity Act (2005) guides decision making when a person has lost the mental capacity to make their own decisions. The Act will be discussed in more detail below but first see how much you already know.
Quiz

1. What 3 factors would you assess to decide if an individual has capacity

   I. Understand relevant information
   II. Retain the information
   III. Weigh up the information and be able to communicate their decision

2. Under the Mental Capacity Act an individual can appoint someone to hold power of attorney. What two types of power of attorney are there?
   I. Health and Welfare
   II. Financial and property

3. To be protected by the Mental Capacity Act when making decisions for someone who lacks capacity name two things that must happen

   I. Establish the individual lacks capacity
   II. Believe the action taken is in the individual’s best interests

4. If a person lacks capacity to make some decisions they should be assumed to lack capacity to make any decisions

   False – they may often be able to make day to day decisions such as what to wear or what to eat even if they are unable to understand the implications of bigger decisions

5. If there is a disagreement about the right decision to make in a person’s best interests or they have no one to represent them, who may be appointed to represent the individual’s interests?

   Independent Mental Capacity Advocate (IMCA)

6. If a person makes an unwise decision they should be assumed to lack capacity
7. Who is the person responsible for making a resuscitation decision and completing the form

Doctor - It is best practice to discuss it with the patient but if the doctor felt it would be futile to try and resuscitate an individual and it would cause distress to discuss it with them then the doctor does not need to have that conversation. If the patient does not have capacity it may be discussed with the Power of Attorney or as part of a best interests meeting.

The law determines how to support someone who lacks capacity. The guidance the law provides is set out in the Mental Capacity Act (2005). The key principles are summarised below.

The Mental Capacity Act (2005) talks about decisions being made in the Best Interests of that person. We will now consider:

- What does acting in best interests mean
- Who will make these decisions
- What is your role as a social care worker

**Mental Capacity Act (2005)**

- Individuals must be assumed to have capacity unless it is established that they lack capacity.

- Individuals are not to be treated as unable to make a decision unless all possible steps to help them to do so have been taken without success.

- Individuals are not to be treated as unable to make a decision merely because they make an unwise decision.

- Under this Act, any actions or decision taken for, or on behalf of, individuals who lack capacity must be taken in their best interests.

- Any decisions made must take individuals’ rights into account and restrict their freedom as little as possible.
**Best Interests**

Any decision made on behalf of an individual who lacks capacity must be made in that individual’s best interest. This means thinking about what is best for the individual and not what anyone else wants. This applies regardless of who is making the decision or what the decision applies to. We will look at who that might be later in this section. The person(s) making the decision for someone who lacks capacity should:

**Determine that the individual does lack the capacity to make a decision**
Remember that the individual is assumed to have capacity unless it is proved they have not.

**Encourage participation**
Encourage people to talk about their plans. However, respect their right not to talk about these if they do not want to. Even if individuals do lack capacity they may still be able to make some decisions for themselves.

**Identify all relevant circumstances**
Identify anything the individual may have taken into account if they were able to make the decision for themselves. This may involve talking to people who knew the individual best before they lost capacity. Although this will usually be family and friends, care staff may also be consulted if they have known that individual for a long time.

**Find out an individual's views**
An individual’s preferences and wishes may have been expressed previously, verbally or in writing. Religion or culture may have a likely influence.

**Avoid discrimination**
Do not make assumptions based upon someone’s age, appearance or condition.

**Assess whether the individual might regain capacity**
Consider if capacity may be regained e.g. after medical treatment. In this case, it may be possible to wait until the individual is able to make their own decisions.

**Do not make an assumption about the individual's quality of life**
We cannot know for certain what any individual considers a good quality of life. We must never be motivated in any way by a desire to bring about a person’s death.

**Consult with others for their views about the individual’s best interests**
This may be someone involved in caring, a close relative, someone previously named by the individual, someone appointed under a Lasting Power of Attorney or a deputy appointed by the Court of Protection (see
Avoid restricting an individual’s rights

Consider if any other options may be less restrictive of the individual’s rights after carefully considering all of the above.

Anyone can make some decisions about day-to-day care, such as what to eat and what to wear or if anyone else needs to be involved in that individual’s care. These decisions should still be made in that individual’s best interests.

Remember that even someone who has limited capacity may be able to make or be involved in making these decisions. If you are supporting an individual in this way, you could talk to the family or someone else who knows that individual well to see what their preferences are.

If decisions have to be made that are legally binding then the process is more complex but clearly defined. These decisions may involve for example, deciding to stop active treatment, agreeing the person is not to be resuscitated or agreeing they will not have further hospital admissions.

Refusing treatment or stopping active treatment are decisions that have legal consequences so the decision making process is more complex.

While the individual still has capacity they may arrange a Lasting Power of Attorney. A Lasting Power of Attorney means that someone is appointed to act on that individual’s behalf if they no longer have capacity to do so for themself.

Power of Attorney is divided into two sections:

Health and Welfare
- Daily routine
- Medical care
- Moving into a care home
- Refusing life sustaining treatments

Property and financial affairs
- Paying bills
- Collecting benefits
- Selling the private home

An individual can decide to arrange one or both parts of the Power of Attorney.

To be valid these have to be registered and there is a fee for this.
**Who can be a Power of Attorney**

- The person must be over 18
- They can be a
  - Relative
  - Friend
  - Professional such as a solicitor
  - Husband, wife or partner

A Power of Attorney for health and welfare is only valid if a person loses mental capacity but it can be made at any time prior to this.

If an individual has no one to act as Power of Attorney an independent advocate may be appointed to act in their best interests.

Where there is no Power of Attorney in place then all decisions must still be made in that person’s best interests.

The views of those closely involved with the care of that individual will be collected. This may include the family, close friends, social work carers and health professionals.

A Best Interests meeting may be held where everyone can give their point of view. A decision will then be made about what is in the individual’s best interests at that time.

Particular attention will be given to any knowledge of what is known about the person’s wishes before they lost capacity.

In the case of medical treatment the doctor in charge of that individual’s care will make the decision.

Best Interests should be carefully recorded.

This means thinking about what is best for the person and not what anyone else wants.

- What the decision under discussion was
- Who was consulted
- What the outcome of the discussion was
- The action taken
Read the following scenario and then answer the questions.

John is an 85-year-old man who lives in a residential home. He gets occasional visits from his daughter. John has end stage Dementia and has lost quite a lot of weight over a period of months. John has been hospitalised twice previously for chest infections and treated with a course of antibiotics. His weight is now 6 stone. He is very poorly and not taking much food or fluids. John was seen by his GP who prescribed nutritional drinks and advised the care staff on making John comfortable in his last few days. Additionally members of the District Nursing team visit regularly in relation to end of life care.

John has been unable to make day to day decisions about his care for some time and spends most of his time sleeping.

The staff in the care home have recognised that John is dying and phone his daughter that evening to see if she wants to be with him. John’s daughter stated that she did not want to come and she expected that the care staff would call for an ambulance to admit him to the local hospital.

Should the care home staff call an ambulance and seek admission to the local hospital for John?

Any decision should be made in John’s best interests. They should consider if daughter has Power of Attorney.

How would you assess John’s capacity in relation to this decision?

They should look at involving the healthcare professionals for advice about his Best Interests and to enter into a further discussion with the daughter.

What would you need to consider, who would you need to talk to, where would more information (if required) come from?

The staff should consider if there is an Advance Care Plan in place that outlines John’s wishes particularly in relation to where he is to be cared for at the end of life.

They should apply a mental capacity screen (2 stage test) to see if John is able to make this decision for himself ensuring he can meet the criteria outlined above of understanding the benefits or risks of a decision.

How would the Best Interests principles be applied? Weigh up and risks and benefits of each decision. Who would be involved in the discussions? Would you have a formal Best Interests Meeting?
It may be difficult at this stage of his care and at the time of day indicated to have a formal best interests meeting but a record should be made of what decision was made and how it was arrived at.

What is your outcome for this decision? Will John stay at the care home or will you call an ambulance and seek hospital admission?

The learning point is the importance of advance planning rather than crisis decisions. With advance planning the daughter should have been aware of her father’s deterioration and the care plan that was being suggested. In view of the fact she does not visit often she appears unaware of these factors in making her decision that John should be admitted to hospital.

**Further reading**

More details on power of attorney can be found on [www.gov.uk - Power of Attorney](http://www.gov.uk)

More information about the mental capacity act (2005), independent mental capacity advocates and booklets including easy read versions can be found on the following website [http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act](http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act)

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**Completed Activity**

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 2 - Resources

**Web resources**
1. NHS choices website
   [http://www.nhs.uk/conditions/Consent-to-treatment/Pages/Introduction.aspx](http://www.nhs.uk/conditions/Consent-to-treatment/Pages/Introduction.aspx)

**Information Sheets/booklet**
3. Support Sheet 4 ADRT
5. Resuscitation Council DNAR form
6. Resuscitation Council notes to complete DNAR form
7. Support sheet 12 MCA
8. Support sheet 13 Best interests
9. Alzheimers.org.uk Powers of Attorney
15. Best interests Checklist
16. Best interests assessment form
17. MCA Quiz

**PowerPoints/ Lesson Plans**
*PP1 – MCA and best interests*
*Lesson Plan 303 MCA and Best Interests*

**E- Learning Resources**
E: ELCA modules that support the 303 units can be found in the following document
E ELCA EOL 303.doc

**Further Reading**
11. Best interests at end of life (Hutchinson & Foster 2008)
12. ACP booklet 2011 Advance care planning health and social care staff (Capacity, care planning and advance care planning in life-limited illness) DH 2011
13. Mental Capacity Act and End of Life Care Department of Health 2007
14. CQC MCA Guidance for providers.
Activity 3 “Case Study - Betty”

Learning outcomes and assessment criteria

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

| 1.1 | 1.2 | 1.3 | 1.4 | 1.5 | 1.6 | 2.1 | 2.2 | 2.3 | 2.4 | 2.5 | 2.6 | 2.7 | 2.8 | 2.9 | 2.10 |
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| 3.1 | 3.2 | 3.3 | 3.4 | 3.5 |     |     |     |     |     |     |     |     |     |     |     |

Assessment Method: Case study
Assessment Type: Knowledge

Tutor/Assessor Guidance:

The purpose of this case study is to think about Betty and how she may benefit from having an Advance Care Plan.

A variety of questions are asked about the case study. This will enable the learner to consolidate their previous learning and make links to their own workplace.

If meeting the student, this would be a good opportunity to ask if they have encountered situations similar to Betty’s and how they approached the situation.

It is important to ensure that the learner understands that where there are decisions about future treatment an individual can only choose to refuse treatments not to demand specific treatments.

The learners should also be aware that an individual cannot ask the social or health care workers to shorten their life or hasten their death.

This section concludes with learning relating to where Advance Care Plans should be kept and the learner is asked to identify where this in their own workplace.

The learner is directed to further reading about advance care planning and asked to highlight factors that are important in regard to recording Advance Care Plans.

The purpose of this case study is to think about Betty and how she may benefit from having an Advance Care Plan. You will need to consider Betty, her family and all the professions who may to be involved. You will need to have an understanding of the Mental Capacity Act to ensure Betty is fully involved in the process or if she is not able to take part, what the correct process is.

It is also an opportunity to consider how the information is recorded and when/how it is shared.
### Activity 3: Case Study – Betty

**Approximately 3 hours and 30 minutes**

**ACP case study**

Betty is a 76-year-old lady who has lived in your residential/nursing home for 14 months. Betty has a diagnosis of severe chronic respiratory disease and is always breathless and finding it increasingly difficult to care for herself. Betty uses a wheelchair to aid mobility and relies on carers for assistance with her daily needs, such as washing and dressing. Betty’s current physical condition has been deteriorating.

Betty has a large family of 3 daughters Elizabeth, Mary and Margaret and 2 sons Charles and Andrew. Betty’s daughters visit on regular basis and like to be involved in directing the care Betty receives.

Betty’s sons visit on a regular basis and are less involved with her care. Following the recent hospital admission Elizabeth has expressed to you she feels her mum “has had enough”. Mary and Margaret however were very pleased with the hospital treatment and feel she always does well and “bounces back” after each admission.

Betty has recently had a hospital admission for a ‘flare up’ of her condition which was treated successfully. However, on return to your home Betty appears even more dependent on the care staff and her mood appears low.

On attending to Betty one morning she comments to you she “feels tired with her existence” and never wished to live in this way.
Using the case study above, consider and answer the following questions.

Q What clues did Betty give that she may be ready to have an advance care discussion? How would you respond to this opportunity and what would be the right environment and time to have this discussion?

Betty clearly stated she ‘has had enough’ which indicates she may be thinking she is near the end of life and that she no longer wishes to receive active treatment.

Following her recent admission she has had low mood.

She is more dependent on her carers and the statement she has made indicates she is aware of her increased dependency on others.

The learner should explore with Betty what she means by ‘had enough’ (taking into consideration the suggestions above). They should offer to discuss this further in private – if possible at this time as she has indicated she wishes to have the discussion but must ensure that there is time for a discussion.

Q Who would be the most appropriate person(s) to undertake and lead on this discussion? Consider: the knowledge and skills required.

The learner is likely to be the most appropriate person to have this discussion as Betty has chosen to talk to them and they know Betty well. The learner should be prepared to involve others e.g. keyworker, family, manager of area, health professionals as appropriate and with Betty’s permission. It is important that the learner makes clear to Betty that others may need to be involved and why.

The learner should be clear that advance care planning relates only to decisions to refuse treatment. The specific treatment cannot be requested. The learner must be aware that they cannot enter into shortening a person’s life or hastening their death and that Betty needs to know this if she makes any such request.

The learner should acknowledge if they feel they need further development in communication skills. If so they can be guided to QCF communication modules and/or e-Ifh modules.

Q Who else might you involve in this discussion? Consider: everyone’s needs and Mental Capacity Act

Family, friends, anyone involved in Betty’s care, other staff in the area,
health professionals.

It is important for the family to be included as they hold differing views.

Q Explain how you will know that Betty is able to make decisions for herself.

Apply the screening tool as discussed above about understanding information, retaining information and being able to make decisions or apply the screening tool used in their area. Take into account any previous formal assessments of capacity by other agencies.

Q Explain what can be done if Betty does not have the capacity to make decisions for herself.

Best Interests meeting

Q Where would you record this information?

Where information is accessible to all involved in Betty’s care. Include the decision under consideration; who was involved in the discussion and any conflicting views and the decision reached and how this is in Betty’s best interests.

Is there an electronic palliative care register in the area that people who are in their last year of life are recorded on?

Q When and how would you communicate the outcome of this discussion?

Consider: who needs to know, how would you review?

May have specific care plan for end of life or in general notes. Set review date.

Further reading

Click on the link below to access a booklet designed to introduce Advance Care Planning to the general population. Consider how you could use this information leaflet in your setting.

http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/planning-for-your-future-care.aspx
Record keeping
Click on the links below and read the documents:
http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf
http://www.endoflifecare.nhs.uk/assets/downloads/EoLC_Record_Keeping_Guidance_FINAL.pdf

Outline below the key principles of record keeping in advance care planning.

Learners may include other areas as well but should address
- Consent gained from individual to record and share information and who it can be shared with
- Updating the local electronic palliative care coordination system (sometimes referred to as a Gold Standards Framework or palliative care register)
- Review date should be set when record is made – maximum 3 months and if possible, individual should be involved in setting the review date
- Communicate with other agencies to prevent duplication
- All staff responsible for any updates needed and must make sure it reflects the individual's current wishes
- If consent to share is withdrawn then the record must be removed
- Must reflect the Codes of Practice for Social Workers in regard to record keeping
- Should include who has been consulted.
- Should reflect removing any barriers, if possible, to ensure wishes fulfilled eg organ donation

You should be aware of where care planning documents including: Advance Decisions to Refuse Treatment; DNACPR forms; Preferred Priorities for Care; special requests and wishes for end of life care are kept in your work area. They must be easily available for sharing with other health and social care professionals involved in the care of the individual.

Remember to include out-of-hours providers and the ambulance service.
Complete the speech bubble:

In my workplace, care planning documents are kept.... this will vary in the individual workplace but the important point is that the learner is clear about the system of storage and that the forms are available to those who need them, whilst retaining confidentiality.
An individual who wishes to make advance plans for their future care should be guided by a professional who has had suitable training.

Wishes should be documented using the Mental Capacity Act as guidance.

End of life care plans must be discussed with the individual whenever possible.

Staff should make or share records of any discussion only with the person’s permission. In the case of someone who lacks capacity, only if it is felt to be in his or her best interests.

Any choices or advance decisions to refuse treatment are only relevant when a person is no longer able to make their own decisions. Until then, they can be asked about their decision at the time.

Completed Activity

Now learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 3 - Resources

Web resources


Activity Sheets

Power Points/ Lesson Plans

E- learning Resources

E: ELCA modules that support the 303 units can be found in the following document
E ELCA EOL 303.doc

Further Reading

1. End of Life Record Keeping Guidance (NEoLCP 2012)
2. Record Keeping (DH 2010)
Activity 4 – Reflective Account

Learning outcomes and assessment criteria

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

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Assessment Method: Reflection on own practice in real work environment
Assessment Type: Knowledge

Tutor/ Assessor Guidance:

In this section the learner is asked to undertake an Advance Care Planning conversation with an individual of their choice.

Before undertaking the conversation the learner is asked to consider what factors need to be taken into account prior to having a conversation. This includes the environment; who else may be involved; a reminder about confidentiality and seeking permission before information is shared.

The learner is directed to further learning via the ‘dying matters’ website to help them consider the type of issues that may be covered as part of an advance care planning conversation.

The learner is asked to note any particular learning issues in their portfolio. The learner should also note the key aspects of the conversation to enable them to complete the following activities.

The learner is then asked to produce a reflective account. Bullet points are supplied to outline what needs to be included and the account should show the application of theory to practice.

In this section you will be asked to undertake an Advance Care Planning conversation with an individual you care for.

Activity 5: Reflective on practice

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take into account before undertaking an Advanced Care Planning conversation. These should include:

- What things might indicate an individual is ready to undertake Advance Care Planning?
- The environment where the conversation is conducted
- Where the person wishes to be cared for
- Who else might be involved?
- Where the information is to be recorded
- Confidentiality and how the information is shared and who it is shared with
Now visit http://www.dyingmatters.org/page/dying-matters-leaflets read these leaflets:
- ‘5 things to do before I die’
- ‘To do list’
- ‘Putting your house in order’

I expect you may have thought of more things but these are a good check list and can be useful for an individual or their relatives to read before they are involved in making plans for their future.

You should add any notes from your discussion to your portfolio.

Write a reflective account about how you have undertaken an Advance Care Planning conversation with an individual.

You should reflect on:

- What led to the individual having an Advance Care Plan discussion?
- How did you consider all of the factors identified in the puzzle pieces above?
- What your role was in the advance care planning process?
- Why do you think it is important to respect the values and beliefs of that person?
- How the individual’s capacity was assessed?
- Were best interest principles applied?
- Who was involved in the process?
- How were the needs of others addressed during the process?

This is an opportunity for the learner to relate the theory they have to a specific practice example. They should take into account the bullet points given above as guidance for the reflective piece.

Make sure you cover all the points mentioned above – think of them as questions to consider and work through them as you reflect on the conversation you had. You might find it helpful to make notes first on a separate piece of paper.
Completed Activity

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

Web resources

1. Dying Matters website ‘I didn’t want that’
   http://www.dyingmatters.org/page/i-didnt-want-that

Activity Sheets

Power Points/ Lesson Plans

E- learning Resources

E: ELCA modules that support the 303 units can be found in the following document
E: ELCA EOL 303.doc

Further Reading
Activity 5 – Making an End of Life Care Plan based on Advance Care Planning Conversations.

Learning outcomes and assessment criteria

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

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Assessment Method: Work product
Assessment Type: Knowledge

Tutor/Assessor Guidance:

In this section the learner is asked to use the information they have gathered from an Advance Care Planning conversation to draw up an End of Life Care Plan for that individual.

The learner may already have suitable care plan templates in place in the work environment. Where this is not the case they should be guided in developing a suitable template, finding national examples or adapting the care plan templates they already use.

The section is completed by asking the learner to write a short reflective piece to identify how they felt about approaching sensitive issues.

In this section you will look at how to develop a care plan based on the advance care planning conversation you had in Section 5. When presenting the plan you will need to consider the following:

- Do you have an existing way of recording this information or do you need to develop a method to use in your workplace?
- How will you ensure that the information and existence of the plan is communicated to others within and outside your organisation?

Activity 5: Making an EOL Care Plan

Approximately 3 hours and 30 minutes
This information should be anonymous to prevent identification of an individual, relatives or those involved in their care apart from the learner. The plan should include reference to the areas of holistic planning (see section one) relating to End of Life Care. It should clearly state what relevant documentation has been completed e.g. Mental Capacity, DNACPR, Preferred Priorities for Care, wishes regarding organ donation, instructions about funeral arrangements if made, who has been consulted, if a Lasting Power of Attorney is in place and who holds it, last wishes.

To complete this section write a short piece of 150 to 200 words to reflect on how you considered the following issues when developing the care plan

- How the person’s values and beliefs were respected when they made their choices
- How advance care planning was performed in line with your organisational policy and national recommendations
- What documents were completed and by whom to support the decisions made.
- How the care plan will be reviewed to reflect any changes of decisions by the individual
- How the advance care plan will affect the person’s general care plan

My reflection.....
This reflection should show how the carer approached the process of ascertaining the individual’s advance wishes and how the carer felt about discussing sensitive topics. It should show how they included others, as appropriate, in drawing up an End of Life Care Plan including other agencies, family friends. It should show the learner is aware of the importance of sharing the information appropriately with an awareness of local and national guidance as discussed above. It should make clear the process for review i.e timescale and who is involved in review. Advance Care Planning may involve making known wishes that the individual wants to achieve in their remaining lifetime and this should be reflected in the general care plan. Specific spiritual or cultural needs may also be expressed that need to form part of the general care plan.

**Completed Activity**

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

Web resources

Activity Sheets

Power Points/ Lesson Plans

E- learning Resources
Activity 6 – Applying Advance Care Planning

Learning outcomes and assessment criteria

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

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Assessment Method: Reflection on own practice in real work environment
Assessment Type: Knowledge/Competence

Tutor/Assessor Guidance:

The last section of this module asks the learner to view a video clip that highlights what can happen when Advance Care Plans are not made or are not communicated to others.

Some learners may find some of the scenes, for example resuscitation, distressing but it should be emphasised that this clip was made for the general public to consider what is important when looking at the future plans in end of life care.

Each scene contains valuable learning points and these are detailed in the answer book.

It is useful to get the learner to consider the difference between the distresses of the people in this video and the calm and openness of those in the first clip in section one.

Activity 6: Applying Advance Care Planning

Approximately 2 hours

We have now looked at the importance of making Advance Care Plans. The following video shows the distress that individuals can experience if their wishes are not known and the stress caused to relatives as they try to decide on that person’s behalf. It has some scenes that you may find distressing but contrast that with the first clip you watched that showed how calm everyone was when they knew that there were plans in place.
Click on the link below to access 'I didn’t want that'
http://www.dyingmatters.org/page/i-didnt-want-that

Watch the video clip and think about each situation. Write down why you think advance care planning would have been useful in each situation.

Scenario 1:

The gentleman understands what is happening but is unable to communicate. He is distressed that his care plans are causing arguments in the family.
The ‘I didn’t want that’ may refer to the daughters insistence he goes into care or to the arguments he has unwittingly caused.

Scenario 2:

The brother is told that resuscitation will not benefit his brother but he cannot bear the thought of losing him so insists that resuscitation is attempted.

The voice- over tells us the individual who is dying had comes to terms with his death and did not want the pain and indignity of prolonged and ultimately futile treatment but he had not let those close to him know that.

His brother is faced with a difficult decision when he is feeling emotional and trying to understand his brother is dying. The brother feels he is acting in Best Interest but as we learn from the clip he is not following what his relative’s own decision would have been.

Having an Advance Planning Conversation could have saved suffering to all concerned. It could have led to a discussion with doctors about resuscitation and a DNACPR could have been completed.
Scenario 3:

Again the family feel they are acting in the lady’s Best Interests by making sure she is safe and cared for. From the lady’s point of view she is losing all that she values and gives purpose to her life. Given the fact that she is dealing with the removal of all her possessions without family support, it appears that the family live a distance away or certainly do not visit. It appears that the family’s Best Interests have taken priority over the individual’s as they will no longer need to worry about her managing alone and feel responsible for her wellbeing.

It appears the family may have put pressure on the individual to go into care and that by doing so they have removed meaning and purpose from her life.

Scenario 4:

This clip demonstrates the importance of talking to an individual to know what their wishes are and avoid stereotyping them or imposing our own beliefs about their spiritual, cultural or life style choices upon them even if we believe we are doing so with the best of intent.
Scenario 5:

The dog is used as the link between the scenarios. The dog demonstrates the importance of an individual planning ahead for the care of others, be that family or pets, so that plans are in place for when the individual is no longer able to care for them. The dog is used to show that pets can form an important part of life, especially for those on their own and highlights the distress that can be caused if plans are not in place for them to be well cared for.

The situation can also be used to get the learner to think about the importance of the peace brought by knowing advance plans are in place. This can refer back to the previous scenarios such as contact with family and friends or ensuring those left do not have to make difficult decisions without knowing the individual’s wishes.

Completed Activity

Now Learners have completed this activity we recommend they go back to their own evidence log on page 5 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria they have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
# Activity 6 - Resources

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Summary

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

• You have had the chance to look at how holding Advance Care Planning conversations with individuals and their families can ensure that a person’s wishes are known and that care at the end of life can be given to that individual in a way that is personal to them and respects their wishes.

• You have considered the action to take if an individual does not have the mental capacity to make their own decisions and how to ensure you act in their best interests.

• You have looked at how information about end of life care is recorded and shared.

• You have examined several of the decisions that may need to be made, including those in relation to treatment and resuscitation.

• You have considered the legal standing of Advance Decisions to Refuse Treatment, Do Not Attempt Cardio-Pulmonary Resuscitation orders and Power of Attorney.

• You have discussed the importance of having an environment that encourages future plans and wishes to be made known.

• You have explored your role in helping and supporting individuals to make their plans and wishes known.
As a last task, repeat the assessment you completed at the start of the unit to see if your confidence has increased and discuss this with your tutor/assessor.

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<th>Confidence level</th>
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<td>The difference between Advance Care Plan and a care or support plan</td>
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<td>Understanding when advance care planning should happen</td>
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<td>Knowing who else should be involved in advance care planning</td>
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<td>Understanding what needs to be discussed when considering advance care planning</td>
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<td>Understanding mental capacity and advance care planning</td>
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<tr>
<td>Knowing how to record Advance Care Plans and when information can be shared</td>
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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.

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Appendix

• Continuation sheets for photocopying as required
• Glossary of Terms
• Template Support Agreement
• Lesson Plans
## Glossary of terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<td>Best Interest decision</td>
<td>This has to occur if someone does not have the mental capacity (see below) to make a legal, healthcare, welfare or financial decision for themselves.  This is one of the principles of the Mental Capacity Act (2005). The decision can only be made after an assessment has deemed the individual does not have capacity. Strict principles and codes of practice should be followed to carry out the assessment and to make the best interest decision, these are set out in the Mental Capacity Act (2005).</td>
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<tr>
<td>Consent</td>
<td>Permission for something to happen or agreement to do something.</td>
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<td>Futile treatment</td>
<td>Treatment which is deemed to be unlikely to be of benefit to an individual. The most senior healthcare worker is ultimately responsible for making the decision that a treatment is futile. e.g. attempting cardiopulmonary resuscitation in the last days of life may be deemed futile.</td>
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<td>A ‘good death’</td>
<td>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.</td>
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<tr>
<td>Informed consent</td>
<td>When an individual gives permission to have an assessment, treatment or procedure with full knowledge of the risks involved, probable consequences, and the alternatives.</td>
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<tr>
<td>Mental Capacity</td>
<td>The cognitive ability (see above) of an individual to make decisions that may have legal consequences for themselves and/or for others affected by the decision. In particular these decisions involve their health care, welfare and finances. An assessment must be carried out to determine mental capacity.</td>
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<tr>
<td>National End of Life Care Programme</td>
<td>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.</td>
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<td>DNACPR</td>
<td>Do Not Attempt CardioPulmonary Resuscitation. A decision made by the doctor in charge of an individual’s care. Ideally this decision should be discussed with the individual but the doctor can choose not to if (s)he feels it would cause the individual distress. It is best practice to discuss the decision with the family if the individual consents or does not have capacity.</td>
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<td>Preferred Priorities for Care (PPC)</td>
<td>A tool that can be used to guide discussion and record end of life care wishes and preferences.</td>
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<td><strong>Advance Decision to Refuse Treatment (ADRT)</strong></td>
<td>An Advance Decision to Refuse Treatment is a decision that can be made in order to refuse a specific medical treatment in the circumstances that are stated. It will come into effect when a person has the lost capacity to give or refuse consent to treatment.</td>
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<tr>
<td><strong>Advance Care Planning (ACP)</strong></td>
<td>Advance Care Planning is a process of discussion between an individual and their care provider whatever the discipline. It is a discussion to enable the individual to make clear what their wishes are as their condition deteriorates.</td>
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<td><strong>Lasting Power of Attorney (LPA) For personal welfare</strong></td>
<td>A personal welfare LPA allows another (the attorney) to make decisions on their behalf about an individual's personal welfare, eg where they live. It can include the power of attorney to give or refuse consent to medical treatment. It can only be used once it is registered at the Office of the Public Guardian.</td>
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<tr>
<td><strong>Lasting Power of Attorney (LPA) for property and affairs</strong></td>
<td>It gives the ability of another (the attorney) to make decisions on their behalf about an individual’s property and affairs when the individual is no longer able or lacks the mental capacity to take decisions themself. It can only be used once it is registered at the Office of the Public Guardian.</td>
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<td><strong>Individual</strong></td>
<td>The person who is receiving care or support in any domiciliary or care setting.</td>
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<tr>
<td><strong>Social Care Worker</strong></td>
<td>The person delivering care in a professional capacity in any domiciliary or care setting.</td>
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<tr>
<td><strong>Carer</strong></td>
<td>The non professional relative or friend caring for the individual</td>
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Due to the sensitive nature of End of Life (EOL) care, topics may be covered that can cause upset for example you may be asked to consider your thoughts about your own death, or watch video clips that include the views of people who are actually dying. Before you begin learning activities, spend some time with your Tutor / Assessor to complete the boxes below:

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

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

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

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