UNIT 303: Understand Advance Care Planning

Learner’s Workbook

Learning Activities
Acknowledgements

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

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

This unit of learning has been developed and written by

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**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</th>
<th>Assessment criteria</th>
<th>Own evidence log (optional)</th>
<th>Assessment Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>The learner will:</td>
<td></td>
<td>Page No</td>
<td>Type of evidence presented</td>
</tr>
<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>
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<td></td>
<td>1.2. Explain the purpose of advance care planning.</td>
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<td>1.3. Identify the national, local and organisational agreed ways of working for advance care planning.</td>
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<td>1.4. Explain the legal position of an Advance Care Plan.</td>
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<td>1.5. Explain what is involved in an ‘Advance Decision to Refuse Treatment’.</td>
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<td></td>
<td>1.6. Explain what is meant by a ‘Do Not Attempt Cardiopulmonary resuscitation’ (DNACPR) order.</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>The learner will:</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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<tr>
<td></td>
<td>2.2. Outline who might be involved in the advance care planning process.</td>
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<td></td>
<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>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>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>2.6. Explain the meaning of informed consent.</td>
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<td>2.7. Explain own role in the advance care planning process.</td>
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<td>2.8. Identify how an Advance Care Plan can change over time.</td>
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<td>2.9. Outline the principles of record keeping in advance care planning.</td>
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<td>Learning outcomes</td>
<td>Assessment criteria</td>
<td>Own evidence log (optional)</td>
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<td>The learner will:</td>
<td>The learner can:</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>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>
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<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>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>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>
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<td>Knowledge</td>
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<td></td>
<td>3.5. Explain how an individual's care or support plan may be affected by an Advance Care Plan.</td>
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<td>Knowledge</td>
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</tbody>
</table>
Section 1: Introduction to EOL Unit 303

General Introduction

As people approach the end of life it is important that those caring from 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 module 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 module 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, sometimes learners can become upset whilst completing the learning activity. For example you may be asked to consider your thoughts about your own death, or watch video clips that include the views of people who are actually dying.

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

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

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

Learning Activities

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

Table 2: Type of learning activities and symbols

<table>
<thead>
<tr>
<th>Activity Symbol</th>
<th>Explanation</th>
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<tbody>
<tr>
<td><img src="image" alt="Symbol" /></td>
<td>This symbol means you will need to access the internet *</td>
</tr>
<tr>
<td><img src="image" alt="Symbol" /></td>
<td>This symbol means you will be reading something</td>
</tr>
<tr>
<td><img src="image" alt="Symbol" /></td>
<td>This symbol means you will be asked to talk about something with friends, colleagues, your tutor or assessor</td>
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<tr>
<td><img src="image" alt="Symbol" /></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="Symbol" /></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="Symbol" /></td>
<td>This symbol means you will be asked to write something in a work book 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="Symbol" /></td>
<td>This symbol means you will be asked to research some information. This might be through the internet, books, and articles or from talking to people you know</td>
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<tr>
<td><img src="image" alt="Symbol" /></td>
<td>This symbol means your assessor will plan to conduct an observation of your practice or will examine a work product</td>
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</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 reporting guidelines of the website concerned.
For each activity you will see a clock symbol, which will provide you with a guide to how long the activity will take you. Remember this is a guide and the activity may not take as long as it says!

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

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

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</table>

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

The table also provides you with an optional ‘own evidence log’. This is so you can keep your own record to help discuss your learning and evidence with your tutor and/or your assessor. Keeping your own learning log can be a useful tool to help you keep track your own learning and progress.

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

**Plagiarism and Confidentiality**

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

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

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

End of Life Care for All (e-ELCA)

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

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

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

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

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

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

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

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

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

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

Table 3: Suitable Evidence

<table>
<thead>
<tr>
<th>Evidence methods</th>
<th>Explanation</th>
<th>Suitable for evidencing Competence</th>
<th>Suitable for evidencing Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct observation of you by assessor</td>
<td>You will be observed by your Assessor carrying out your everyday work activities in your workplace</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 workplace 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 ongoing 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 workplace, including evaluation and reflection</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Written and pictorial information</td>
<td>Written answers and completed activities set by your Tutor or Assessor</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>A scenario or case study</td>
<td>Written or verbal account of how you would respond to specific events set down by your Tutor / Assessor</td>
<td>NO</td>
<td>YES</td>
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</tbody>
</table>
Reflective Practice and Reflective Accounts

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

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

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

**Pre-learning assessment** – Rate how confident you feel about understanding the principles and process of person centred approach to advance care planning. 1 being not very confident and 5 very confident

If you are not sure about completing this table please discuss with your tutor/assessor.

<table>
<thead>
<tr>
<th>Confidence level</th>
<th>1</th>
<th>2</th>
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<tbody>
<tr>
<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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<td>Knowing how to record advance care plans and when information can be shared</td>
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Section 2: Activities
Activity 1 – Advance Care Planning Introduction

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

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Assessment Method: Information question and answer
Assessment Type: Knowledge

It is important you understand what an advance care plan is and how it differs from a general care plan. It is also important to understand why advance care planning is useful to the person, their family and the professionals involved in their care.

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 that 150 words, about what you have learnt about the importance of discussing end of life care issues and making plans in advance and what is the purpose of them.
For further information, click on the following links and read the document.

Planning for your Future Care:
http://www.nhs.uk/Planners/end-of-life-care/Documents/Planning-for-your-future-care.pdf
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 form 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 an example 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 form from the link above, search on the internet for more forms so you can see a range of forms and how these 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 Place of 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 to 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 Advance Care Planning?

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 the ways in which your workplace provides an environment where people are supported 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 about where individuals and their families can get help
- Display board with information
Describe in a short paragraph one change you would introduce into your workplace to encourage end of life discussions.

**One change I would make is:**

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

- A _________ care plan can cover any aspect of health and social care
- A _________ care plan can cover any aspect of future health and social care
- A _________ care plan provides the multidisciplinary team with a plan of action
- A _________ 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 _________ care plan to aid care
• The individual has the final say over who can see their __________ care plan

• A __________ can be completed for an individual who lacks capacity in their best interests

• A __________ care plan cannot be written if the individual lacks capacity to make these statements

• A __________ 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 Advance Care Plans?

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

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

**Learning outcomes and assessment criteria**

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

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**Assessment Method:** Professional Discussion  
**Assessment Type:** Knowledge

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.
## Activity 2: Professional Discussion

**Approximately 8 hours (including preparation time)**

For this activity you will 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 your tutor or assessor.

You should also gather any evidence you feel appropriate to support your discussion, this could include references to websites, films, TV programmes or books.

## Informed Consent or Decision Making

**Consent to treatment** is the principle that a person must give their permission before they receive any type of medical treatment.

Consent is required from a patient regardless of the treatment, from blood tests 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 and risks, whether there are alternative treatments and what could happen if treatment does not go ahead.

• **Capacity:**

The person must have the **mental capacity** to make that decision. Mental Capacity means that individuals can:

- Understand the information given to them
- Remember that information
- 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, for example because they have dementia, then there is a process to follow. This will be discussed later on.

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

Consider something in your care setting that would require an individual to give informed consent and discuss the following:

- What would be your role in this?
- What information would you give them to ensure they are fully informed to make a decision?
- 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
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 Care 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 had 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?
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?

What other aspects might the care worker discuss with Fatima now that the conversation has been opened?
Further information can be found by reading “Advance decisions to refuse treatment: A guide for health and social professionals.


### Decisions about Resuscitation

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

The doctor will complete a form, it is very important that the information is available to all those concerned with the individuals care.

Think about and answer the following questions.

If during an Advance Care Planning discussion, or even in a quiet moment after supper as often happens, a client confided they were worried that attempts would be made to restart their heart if it stopped, what would you do?
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.

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<tr>
<td>Where would a completed form be kept and where else would this information be recorded?</td>
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<td>What would be your role if the person were admitted to hospital?</td>
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<tr>
<td>What would be your role if the ambulance were called to the individual?</td>
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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:**

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?
### 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 worker’s 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.

### Further reading

[http://www.resus.org.uk/pages/dnarpdf](http://www.resus.org.uk/pages/dnarpdf)

### 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 deciding 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 by other agencies as lacking capacity. 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 decisions 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 individual 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. It is important to 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?
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?

1. 
2. 

3. When making decisions for someone who lacks capacity, in order to be protected by the Mental Capacity Act, name two things that must happen.

1. 
2. 

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

true  false

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?

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?

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
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

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**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.

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- 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.
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 below)

**Avoid restricting an individual’s rights**
Consider any other options which 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 themselves.

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 individual’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 individual 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 was 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.

Having recognised that John is dying, the care home staff called his daughter to see if she wanted to be with him that evening. John’s daughter stated that she did not want to come and that she expected the care staff to call for an ambulance and admit him to the local hospital.

Should the care home staff call an ambulance and seek admission to the local hospital for John?
How would you assess John’s capacity in relation to this decision?

What would you need to consider, who would you need to talk to, where would more information (if required) come from?
How would the Best Interests principles be applied? Weigh up the risks and benefits of each decision. Who would be involved in the discussions? Would you have a formal Best Interests Meeting?

What is your outcome for this decision? Will John stay at the care home or will you call an ambulance and seek hospital admission?
**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 you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 3 “Case Study - Betty”

Learning outcomes and assessment criteria

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

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Assessment Method: Case study  
Assessment Type: Knowledge

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.

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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 she receives.

Betty’s sons visit on a regular basis and are less involved with her care. Following the recent hospital admission Elizabeth has told you she feels her mum “has had enough”. Mary and Margaret however were very pleased with the hospital treatment and feels 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 yesterday she commented to you that 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 plan discussion? How would you respond to this opportunity and what would be the right environment and time to have this discussion?

Q: Who would be the most appropriate person(s) to undertake and lead on this discussion? Consider: the knowledge and skills required.
Q Who else might you involve in this discussion?  
Consider everyone’s needs and the Mental Capacity Act

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

Q Explain what can be done if Betty does not have the capacity to make decisions for herself
Q Where would you record this information?

Q When and how would you communicate the outcome of this discussion? Consider who needs to know and how would you review?
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 care 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.

You should be aware of where care planning documents including: advance decisions to refuse treatment; DNACPR forms; preferred place 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....
Summary of Advance Care Planning guidelines
Adapted from:
Capacity, care planning and advance care planning in life limiting illness (NEoLCP, 2011)

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 only make or share records of any discussion with the person’s permission. In the case of individuals who lack capacity, only if it is felt to be in their 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 you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 4 – Reflective Account

Learning outcomes and assessment criteria

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

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

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

<table>
<thead>
<tr>
<th>Activity 4: Reflective Account</th>
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<tr>
<td>Approximately 5 hours</td>
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<tr>
<td>Before you have the conversation, consider the factors you need to take into account before undertaking an advance care planning conversation. These should include:</td>
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<tr>
<td>What things might indicate an individual is ready to undertake advance care planning</td>
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<tr>
<td>The environment where the conversation is conducted</td>
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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? |
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 you have completed this activity we recommend you go back to your own evidence log on page 4 and fill in the page number and type of evidence (e.g. case study or reflective account) for the assessment criteria you have completed in this activity. Remember – these are highlighted green in the grid at the start of each activity.
Activity 5 – 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 4). Those highlighted green are the ones you will cover when you have successfully completed it.

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**Assessment Method:** Work product  
**Assessment Type:** Knowledge

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

Now produce your care plan on the template you have identified and place a copy in your portfolio
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 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...
Completed Activity

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

Learning outcomes and assessment criteria

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

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

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

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 this 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:
Scenario 2:
Scenario 3:

Scenario 4:
Scenario 5:

Completed Activity

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

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

• 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.

<table>
<thead>
<tr>
<th>Confidence level</th>
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<tr>
<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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<tr>
<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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</table>
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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# Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Best Interest decision</td>
<td>This has to occur if someone does not have the mental capacity (see below) to make a legal, healthcare, welfare or financial decision for themselves. This is one of the principles of the Mental Capacity Act (2005). The decision can only be made after an assessment has deemed the individual does not have capacity. Strict principles and codes of practice should be followed to carry out the assessment and to make the best interest decision, these are set out in the Mental Capacity Act (2005).</td>
</tr>
<tr>
<td>Consent</td>
<td>Permission for something to happen or agreement to do something</td>
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<tr>
<td>Futile treatment</td>
<td>Treatment which is deemed unlikely to be of benefit to an individual. The most senior healthcare worker is ultimately responsible for making the decision that a treatment is futile. e.g. attempting cardio-pulmonary resuscitation in the last days of life may be deemed futile.</td>
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<tr>
<td>A “good death”</td>
<td>A term used in the National End of Life Care Strategy (2008) to describe a death where everything 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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<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 who 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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<tr>
<td>DNACPR</td>
<td>Do Not Attempt Cardio-Pulmonary Resuscitation. A decision made by the doctor in charge of an individuals 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>
</tr>
<tr>
<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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<tr>
<td>Advance Decision to Refuse Treatment (ADRT)</td>
<td>An advanced 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 lost the capacity to give or refuse consent to treatment.</td>
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</table>
**Advance Care Planning (ACP)**

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.

**Lasting Power of Attorney (LPA)**

- **For personal welfare**  
  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.

- **For property and affairs**  
  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.

**Individual**

The person who is receiving care or support in any domiciliary or care setting

**Social Care Worker**

The person delivering care in a professional capacity in any domiciliary or care setting

**Carer**

The non professional relative or friend caring for the individual