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Advance Care Planning

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Learning Outcomes

- Explain what is meant by Advance Care Planning (ACP) and why it is Important.

- Describe WHO can undertake Advance Care Planning and WHEN it should occur.

- Identify ways of promoting positive communication around Advance Care Planning.

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Why is Advance Care Planning Important?

- ACP is becoming increasingly important in ensuring that people receive good care and ultimately experience a “good death”.
- ACP can lead to less aggressive or invasive medical care, better quality of life near death, decreased rates of hospital admission, and people being more likely to receive care that is aligned with their wishes and dignity.
- It can be a difficult subject to discuss and can be confusing for health and social care professionals, staff and families, due to a lack of knowledge about ACP and a lack of awareness regarding the legal position.

What is Advance Care Planning?

What is Advance Care Planning?

A general care plan can cover any aspect of **current** care; however an ACP covers any aspect of **future** care, up to and including the person's End of Life wishes as well as after the person has died, such as funeral arrangements.

ACP is a **voluntary** 'process of discussion and review,' to help an individual who currently **has capacity** (has the ability to make their own decisions) to anticipate how their condition may affect them in the future; and, if they wish, to agree and record choices about their care and treatment and/or an Advance Decision to refuse treatment in **specific** circumstances, should they become too ill and lose capacity to communicate in the future.

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The process of Advance Care Planning may lead to a person making:

An Advance Decisions to Refuse Treatment (ADRT)

- ADRTs cover decisions in relation to **specific** future treatment in a **specific** situation. This may include things like: the medication a person would or would not take or the interventions a person would or would not accept, e.g. artificial feeding, intravenous drips, resuscitation, use of respiratory devices etc.

- An ADRT is **legally binding** if it is assessed as complying with the **Mental Capacity Act** and is valid and applicable. It can be written or verbal but if it includes refusal of life sustaining treatment, it must be in writing and must be signed and witnessed and include the statement ‘even if life is at risk’.

The process of Advance Care Planning may lead to a person making:

Advance Statements

- An Advance Statement is different to an ADRT because it can cover any aspect of future health and social care, including care preferences and spiritual or social aspects.

- These are much more holistic in nature and can relate to any aspect of care. Advance Statements may be verbal or written. They are not legally binding but must be **taken into account** when acting in a person's best interests and making decisions on their behalf.

The process of Advance Care Planning may lead to a person making:

DNACPR

- Covers decisions **specifically** about the withholding of future CPR (Cardiopulmonary Resuscitation).

- It is important for care staff to check their local and regional policies regarding whether an ADRT / DNACPR would transfer with a person should they be transferred into hospital.

The process of Advance Care Planning may lead to a person making:

Power of Attorney / Lasting Power Attorney

- An ACP may also include details regarding a Power of Attorney (PA).
- The big differences between the types of PA are the decisions they cover – **financial or health and welfare**.
- The options available depend on whether the person lives in England, Wales, Scotland or Northern Ireland as each country has slightly different terminology.

Describe WHO can undertake ACP and WHEN it should occur?

An **Advance Care Plan** may not be able to address every eventuality that may occur at the end of life, however it is important to think about it in terms of a holistic approach to person centred care. Therefore it can include:

- Choices about legal, financial, psychosocial and administrative issues.
- Personal goals or aspirations for care: whether they would prefer a shower or a bath.
- Who they might want present at the end of their life, such as family members, particular staff or spiritual/religious figures.
- Where they would prefer to be, for example hospital or care home.
- Their environment.
- Particular requests, such as having a favourite pet visit or listening to particular music.

Who are Advance Care Plans for? Everyone should consider Advance Care Planning, regardless of their age or health. But it’s particularly important for people who have on going health problems or conditions that may affect their future capacity to communicate, such as Dementia, Motor Neurone Disease, Parkinson’s, stroke etc.

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Why is Advance Care Planning (ACP) important?

Many conditions may affect a person’s capacity to communicate their wishes towards the end of their life, e.g. progressive conditions (such as dementia) or the final stages of a condition or disease (such as cancer or stroke).

Fundamentally, every person, no matter what their illness, has the right to good care and ultimately a **“good death”.** What each person considers a “good death” will differ, however some of the key components have been identified as:

- Awareness and acceptance of impending death
- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Having time and the ability to settle worldly affairs (peace of mind)
- Making preparations and planning for a death the person would choose and in some cases, what they believe comes after

Advance Care Planning can…

ACP ensures a person’s wishes and preferences are known and made clear to ALL those involved in their care, in order for the person to experience **their** idea of a “good death”.

ACP can:

- Empower and enable the dying person and their family
- Increase ‘realistic hope’ and resilience
- Reduce the potential for confusion, ambiguity and conflict that may arise amongst staff and between family members
- Allow greater time for people to make informed decisions

While decisions made as part of an ACP (e.g. regarding refusal of treatment) may have the potential to result in a person’s death, ACP enables the person to balance the benefit of potentially invasive and distressing interventions that may prolong their life, with their desire for a “good”, “peaceful” or “dignified” death. ACP will never hasten death, rather it allows for a natural death without life prolonging treatments.

Who can undertake Advance Care Planning discussions?

- ACP can sometimes be a difficult subject for a person to discuss with their direct family. It is often those that they are ‘leaving behind’ for whom they feel most concerned. Therefore staff play an essential role in providing comfort and enabling the dying person to have opportunities to discuss their wishes and concerns.
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- Formal discussions about ACP may take place with a GP/healthcare professional or in their home setting with a manager or senior staff.
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- However, the best person to engage in advance care planning and end of life care conversations is not necessarily the most senior staff member, or even a support worker; it can be **any** staff member within the service that the person feels particularly comfortable or at ease with (this may even be an activities coordinator, a member of the domestic team, the gardener, the chef).

When should Advance Care Planning take place?

As early as possible

Ideally ACP discussions should be encouraged at the earliest possible opportunity, so that people have time to consider their wishes. This is particularly important if a person has a diagnosis of dementia, so that they can clarify their wishes while they still have capacity.

It is recommended that the ‘process’ of discussion should be initiated as a standard practice as soon as someone moves into a service. This can be daunting for someone newly arrived so it is important to get across that ACP is more than just End of Life Care and that more sensitive topics can be approached as the person and staff get to know each other.

When should Advance Care Planning take place?

When it suits the person

As with all aspects of care, a sensitive and person centred approach to ACP is essential. It is important to recognise that people will feel differently about the prospect of discussing death and dying.

Some may be eager to have conversations and often feel relieved when issues have been discussed and plans have been made. Others may be reluctant; they may fear death and simply not be ready or willing to engage in the ACP process. It is a voluntary process so people do not have to engage with ACP and should not be pressured to talk about it.

It is an on going process

ACP is not just a single formal discussion or a tick box exercise. It is an on going evolving process that needs to be re-visited regularly. It is also not just about planned meetings; ad hoc conversations are just as valuable.

People need time to think and reflect so they should be offered repeat opportunities and openings to bring up ACP discussions. People who initially feel unable to discuss the subject may change their mind at a later point as they come to terms with their situation

When should Advance Care Planning take place?

An ACP should be regularly re-visited and updated
Even if someone has already completed an ACP, people’s wishes may change over time. An ACP is not set in stone, it should evolve and be routinely reviewed to ensure that recorded preferences for the future are accurate and reflect a person’s **current** beliefs and values.

As well as being reviewed at regular intervals, they should also be revisited when the person’s condition changes or when they voice that they have changed their mind. Any revisions should be shared with those they wish to involve in their care.

When should Advance Care Planning take place?

What format should ACP records take?

- There is no set format for making a record of Advance Care Planning discussions.

- ACP does not always need to be in writing; however a written record is recommended so that wishes may be communicated more reliably and accurately to all professionals involved in a person’s care. Wishes may also be recorded as voice or video recordings.

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Identify ways of promoting positive communication around ACP

- Effective communication, carried out with compassion and sensitivity, is fundamental to the process of person centred Advance Care Planning.
- This means learning how to create opportunities for conversations and becoming comfortable talking about the subject of dying.

Recognise barriers to communication

For staff, barriers may include fear of saying the wrong thing, or making matters worse, or they may feel embarrassed by this kind of emotional intimacy. As carers, natural instincts may also be to preserve life at all costs and therefore it may feel difficult to acknowledge that this may not be what the person wants.

For the dying person it may include denial, trust, fear of upsetting relatives or simply not being at ease talking about such subjects. There may also be cultural/religious perceptions around death and dying that may impact how comfortable a person is discussing the subject.

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Promoting opportunities for discussion and responding to ‘cues’

Opening discussions about death and dying can be difficult, so staff need to look out for appropriate opportunities and cues.

A dying person might sometimes help indirectly by throwing out ‘tester questions’ to check if you are willing to engage with them.

They might, for example, ask you, ‘What do you think happens to you after you die?’ They might ask if you think there is life after death. They might ask, ‘Do you think God really exists?’

Look out for ‘cues’ that may crop up in passing that could indicate that a person has concerns, or that they are feeling open to a conversation about their future.

For example, if they were to express worries over what may happen to them, or concerns about who would care for them.

Promoting opportunities for discussion and responding to ‘cues’

These questions may be directed at any member of staff, often at unlikely or unplanned moments, which is why it is so important to train and encourage ALL staff to be comfortable engaging with these subjects. For example it may be that someone might be up in the middle of the night worrying about death and dying. So it might actually be a member of the night staff who is in a position to comfort and discuss their concerns while it is on their mind.

If staff want to broach the subject but do not quite know how, one way is to ask the person who they would want contacted if they became very seriously ill. This conveys that the staff member knows that they may not recover and is willing to talk about it. It also gives the person the space to decide whether or not to respond.

Try indirect questions, such as ‘I wonder whether there’s anything you want to talk to me about?’ or ‘Perhaps there’s something bothering you which you want to tell me about?’ or ‘What can I do to help you at the moment?’ or ‘When you think of the future, what do you hope for?’ This gives them the choice to respond, or to say no.

Promoting opportunities for discussion and responding to ‘cues’

Leading questions may also work, such as:

‘If you become ill, what medical care would you like?’ or ‘Have you thought about what kind of service you would like at your funeral?’

Again, this provides the person with the choice to respond or not.

Use reassuring statements, e.g. ‘If there ever comes a time when you want to talk about something or you feel frightened, please do tell me’.

Start with the small things like do they want a bath/shower/pets visiting etc. then it may be easier to later broach the more difficult subjects around End of Life Care.

Time and place

Think about time and place for initiating discussions and ensure it suits the person’s preferences. Ensure it is private and somewhere they feel comfortable.

It may be in a person’s bedroom or it may be that someone feels particularly at peace and able to respond while out in the garden, or another location important to them.

Think about the time when they may feel most comfortable and able to respond; for example, if you know someone gets very tired immediately after lunch, do not try to initiate a difficult conversation then as it may be counter-productive.

If you know there are times of the day when a person begins to feel particularly emotional or contemplative, try to be on hand to offer support and discussion if they desire it.

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Communicate and Listen

- Be respectful of other people's cultural, spiritual and religious views around what happens during and after death, it is not a time for responding with your own beliefs or views.

- Use language the person can understand and avoid technical terms or jargon.

- Be honest, do not appear shocked, do not downplay the person's concerns.

- Use engaged open body language and make eye contact.

- Be alert and attentive to what their body language is telling you. Listen to their tone of voice and be aware of changes to their facial colour; their willingness to engage with you; their willingness to meet your eyes. Is what they are saying really what they mean? Are they asking you something with their body language that they are not expressing with words? If so, invite them to tell you what they really want to say.

- Do not fear tears, it is okay for people to cry; crying is a natural response to emotionally charged situations.

- Do not feel you have to talk all the time. It is about listening not advising. Just being there quietly is important, and can often be surprisingly peaceful and reassuring for the person.

Communicate and Listen

Encourage family involvement (if possible)

If appropriate, encourage family members to raise the subject with their loved one and to be involved in conversations. This can afford family members more time to adjust and enables them to hear the person's wishes first hand, which may minimise confusion, conflict or denial at the end of life.

Provide Supporting Information

Staff need to ensure the person is provided with adequate information and supporting resources (in a format that suits them), in order to assist them in making an informed decision. This could mean providing easy read materials about possible medical interventions, or encouraging conversations with suitable professionals like GPs.

Maximising Capacity

Please note, staff need to ensure they follow the principles of the following when assessing a person's ability to make decisions. A person must always be assumed to have capacity until it has been proven otherwise.

Mental Capacity Act (England and Wales) Assisted Decision Making (Capacity) Act 2015 (Northern Ireland)
Note: Northern Ireland legislation is still in draft form and not yet enacted **Adults With Incapacity Act 2000 (Scotland)**

Communicate and Listen

Maximising capacity involves taking every practicable step to support individuals with mental health conditions such as dementia, to make their own decisions, before it is decided that decision-making capacity is an issue. For example, consideration should be given as to whether an individual’s capacity is affected by the time of day or medication regimes. Or it may include:

- Bringing another person to ACP meetings
- Having audio or pictorial information about their condition
- Writing things down
- Using simple language
- Finding out how the person usually communicates
- Giving the person space to think quietly

The aim is to ensure that individuals who are capable of making decisions for themselves, but may need *some* support, are not inappropriately assessed as **lacking** decision making capacity.

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Documenting

ACPs are commonly written from the first hand point of view of the person, for example:

"If 'X' occurs, I would prefer to remain in my home rather than being transferred into hospital or specialist service."
"If I become very ill, I would like to be able to listen to my favourite music 'X'."

If you are making a written record of discussions with the person, read this back to the person so they can confirm if it is accurate. ACPs should be filed in the person's medical records, but notes should be made on a handover sheet or be easily accessible in case of an emergency. A copy of the ACP should be provided on transfer to any other facility for treatment.

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