Website Summary: Community & District Nurses

Unit 1: Introduction to advance care planning

Advance Care Planning is relevant to all adults over 18, especially those with a progressive life limiting condition. Conversations should take place early.

Key principles of advance care planning

- It is a **voluntary process**.
- It is an **individualised approach**. The individuals wishes are central to the process.
- It is important to ensure the **rights of the individual** are always upheld. Where possible they must be involved in conversations.
- Remember to **manage expectations**. Advance care planning should discuss **realistic** treatment options with individuals and their loved ones.
- Advance care planning is an **ongoing process**, decisions are not set in stone. Preferences can evolve and **should be revisited** especially if circumstances change.

Unit 2: Benefits & Challenges of advance care planning

Benefits of advance care planning (for care recipients)

- The individual's preferences are known which increases likelihood that they are carried out.
- It provides comfort that individuals important will not have to make decisions on their behalf.
- It gives the individual a voice if they lose capacity in the future.
- It promotes shared decision making and a sense of control over future care.
- It provides the opportunity for realistic conversations about future care.
- It can reduce the risk of family disagreements and misunderstanding.

Benefits of advance care planning (for Community and District Nurses)

- ACP provides reassurance and creates a less stressful/more positive work environment as staff know they are following an individual's wishes.
- ACP improves communication and reduces misunderstandings, conflict or disagreements about the individual's future care.

Challenges faced during advance care planning discussions (examples)

The individual may be reluctant to discuss advance care planning.
ACP is voluntary – note this on their record and look for cues to sensitively approach this topic again in the future. The person may change their mind.

There may be disagreements between family members about an individual's decisions.
The process should centre around the individual making the plan. Be sensitive, empathetic, use active listening skills and let everyone voice their concerns. Aim to help everyone understand the individual's wishes.

Expectations may be different from reality
A person's wishes and preferences may not always be achievable. If this happens, be open, honest and have realistic discussions about future care, what treatment options are available, including discussion on risks and benefits.

Unit 3: Key components of an advance care planning discussion

Mental capacity

This provides a legal framework for supporting people to make decisions about care and treatment. It can fluctuate with time. Always assume an individual has capacity to make a decision, unless it is established following the appropriate assessment that they lack capacity. Individuals should be supported to make their own decisions, where possible.

Statement of wishes and preferences for future care

This is a record of what is important to an individual and how best to meet their care needs on a day-to-day basis and what matters to the person, considering their feelings, beliefs, and values. It should also consider psychological, social and spiritual support. This aspect of advance care planning is not legally binding.

Emergency care planning

This includes clinical recommendations on the care that an individual would or would not like to receive in an emergency situation. Health care providers may need to take different actions to the wishes that have been expressed if there are medical indications that an intervention is no longer clinically appropriate. This includes: preferred place of care, anticipatory medication, comorbidity management and Cardiopulmonary Resuscitation (CPR and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR).

Best interests decision making

This is when a choice about care is made on behalf of an individual who is assessed as lacking mental capacity. This decision must be taken with their best interests in mind and be based on the decision that the individual would have made if they had capacity.

Unit 4: Advance care planning discussions

These discussions can happen informally and provide insight into an individual's wishes, and can be the trigger for more detailed conversations. Below is advice for carrying out structured advance care planning conversations.

1. **Preparation**

- Before the meeting check whether the individual already has an advance care plan in place and/or has discussed this with those important to them.
- If so, this should form the basis of your discussion.
- Encourage the individual involved to have an advance care planning discussion with those important to them before the meeting. You could signpost to the section for individuals receiving care and those important to them.

2. Introducing the discussion

The purpose of the meeting

Outline and confirm the purpose of the meeting, which is to support the individual and those important to them to discuss wishes and preferences for care to enable a personalised future care plan to be completed

The discussion

Check whether everyone involved in the discussion knows what an advance care plan is, and why it is important.

Establish and agree upon ground rules for the meeting, emphasising that all comments and viewpoints will be acknowledged and respected.

Indicate the length of the meeting – up to 60 minutes is usually sufficient.

Offer the opportunity for any questions or points of clarity

Identify any concerns or questions that the individual or family / carers may have – prioritise these and confirm which can be dealt with at the meeting.

If possible, the plan should be written-up following conversation rather than during so you can focus on facilitating the discussion

Clarify if any specific decisions need to be made

3. Determine what is already known

Has the individual previously considered their own preferences and wishes and have these been shared with anyone?

- If an advance care plan is already in place, ensure this forms the basis of the conversation and consider if this needs to be reviewed.
- If necessary, provide further information on the individual's current plan of care.

4. Advance Care planning

- Talk through each component outlined in Unit 3 of this resource as necessary and provide information and support to allow the individual to make informed decisions about each area at a pace tailored to their needs.
- **Remember** – advance care planning can involve a series of discussions.
- During the discussion, check in with the individual and those important to them to see whether the discussion is valuable and is meeting their needs.

5. Concluding the discussion

Summarise

Summarise the discussion and check understanding.

Questions/clarifications

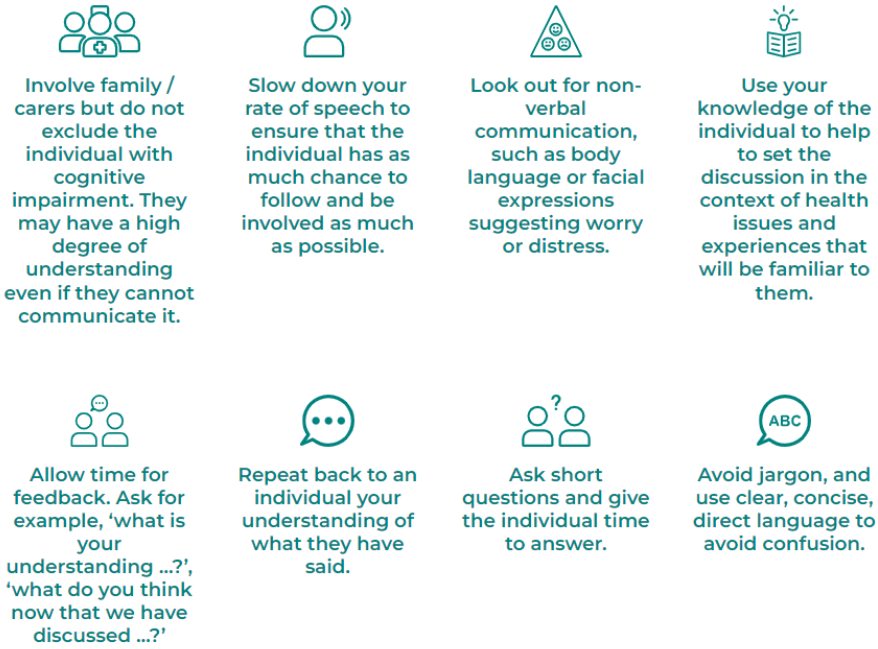
Offer another opportunity for questions, comments, and concerns – signpost to other resources they can look at for further information.

Consent

Check consent to share information to identify from the individual who information can be shared with and ensure this is recorded.

Record the advance care plan and share decisions

Advance care planning with individuals with cognitive impairment



Diversity, sensitivity, and inclusion in advance care planning communication

An individual's personal, cultural, and religious background may impact their decision making.

Preferences for treatments: For example, an individual's spiritual beliefs may have an impact on their views towards use of life-sustaining treatments or the use of sedation towards the end of life.

Inclusion of family: There may be cultural variations on the importance of family centred decision-making versus individual decision-making.

Language and expectations: Cultural or language differences can lead to misunderstandings about the purpose of advance care planning. Therefore, you may need to make sure that someone is able to act as an interpreter.

Avoiding assumptions about approaches towards advance care planning based on an individual's cultural/spiritual background, sexual orientation/identity.

Family unit: Family structures are diverse, do not make assumptions about the nature of a relationship.
Sight, speech or hearing impairment: ensure the needs of everyone are taken into account during conversations.

The importance of reflective practice and debriefing

After facilitating an advance care planning discussion, it can be helpful to reflect on the process and debrief with a colleague where possible.

Gibbs reflective cycle:

1. Description –
    - Write a description of the experience. What happened? Where and when did it happen? What was the outcome? What did you want to happen?
2. Feelings –
    - What were you thinking and feeling during the situation? What were you thinking and feeling after the situation? What do you think other people were feeling?
3. Evaluation
    - What was good and bad about the experience? What went well? What didn't go as well as you might have hoped?
4. Analysis
    - Why did it go well? Why didn't it do well? What sense can you make of the situation?
5. Conclusion –
    - What did you learn from this situation? What could you have done differently and how might this have led to a different outcome?

6. Action plan –
    - How will you deal with similar situations in the future? What would you do differently? How will you develop the skills that you need?

Unit 5: Recording and sharing advance care plans

Record any decisions, wishes or preferences the individual and those important to them make regarding future care**.** Record any worries or concerns the individual or those important to them have**.**

➢ How to record

Be thorough, detailed and ensure that the information is clear and unambiguous.
Some decisions may need to be legally recorded through an Advance Decision to Refuse Treatment (ADRT), an advance directive (Scotland) and/or Power of Attorney.

➢ Where to record?

It is important to note that there is currently **no standardised process** for recording or sharing Advance Care Plans across the UK. The recording and storing of an advance care plan will be different in different settings dependent on an organisation's care record system. If you are unsure of the process for recording and sharing advance care plans, we recommend that you speak to a colleague with experience in the advance care planning process.

➢ Sharing advance care plans

An advance care plan should follow an individual throughout their care journey. With consent it should be shared with necessary health and social care professionals. This increases the likelihood of the individual's preferences and wishes being known and carried out.

➢ Updating an advance care plan

Advance care plans may need to be updated if the preferences, health or cognitive capacity of an individual changes or if they are clearly entering the end-of-life stage.

➢ Implementing and recording changes

If changes are made to an advance care plan, it is important that they are updated across electronic care records and paper systems.

Unit 6: Timing and communication during advance care planning conversations

Timing
Introducing the topic of advance care planning early can help prepare for more in-depth conversations as an individual's condition progresses.

Choice of words and avoiding jargon
Be supportive and empathetic and use positive, clear language. Use language that the individual will understand. Where possible, avoid medical or technical terms.

Finding your own words & approach to advance care planning
Engage in active listening to notice cues to start a conversation. Be warm, sensitive, and empathetic. Think about how you would like you or your family member to be spoken to. Ensure that people feel listened to and able to share. Reflect back to demonstrate that you are listening.

Non-verbal cues
If you notice any non-verbal cues, open-ended question such as 'what are you thinking?' to help the individual express how they feel and if they want to continue the discussion.

10 Tips for having advance care planning discussions

1. **Be prepared**
   Understand the advance care planning process and what is expected of you as the community or district nurse providing care. Always be ready to have an advance care planning conversation.

2. **Ensure the individual is ready**
   Ensure the individual is ready to have this conversation. This may depend on their frame of mind and how they are feeling on the day. When deciding to have a conversation consider how they are feeling and what is going on in their lives at the at the present time. Encourage the person to involve those who are important to them.

3. **Early planning**
   Offer to discuss advance care planning as early as possible and at a convenient time for the individual and those who are important to them or help them identify someone they trust.

4. **Look for cues**
   Look out for cues that someone is ready to engage in these conversations (for example, if an individual mentions dying, is admitted to hospital or discusses disease progression).

5. **Be sensitive**
   Think about how you would like to be spoken to. Be sensitive when introducing advance care planning and do not be afraid to be kind. If you are kind in your approach, then you are less likely to upset someone.
6. **Listen**
   Use active listening throughout the process to ensure the individual's wishes and preferences are being appropriately heard and recorded.
7. **Be natural**
   Be natural, use your own words and use a gentle and caring tone throughout the conversation.
8. **Respect**
   Respect the opinions of everyone in the process particularly the individual in receipt of care.
9. **It is a process**
   Advance care planning is a process and should be carried out over time - it is not a single conversation.
10. **Be realistic**
    Avoid language that will make people feel confused or cause unrealistic expectations of options available in future.

Unit 7: Caring for yourself

Your support network

You might find it useful to talk things through with: **work colleagues, senior colleagues or line managers, family and friends or seek professional guidance**.

Resilience

Resilience refers to 'your ability to positively manage significant challenges or adverse events...we build resilience in the face of adversity.'

Tips for building resilience

- Make time for yourself.
- Practice self-compassion.
- Keep things in perspective.
- Seek support.
- Engage in reflective practice.

Take care of yourself so you can take care of others

Self-care can be defined as: **"Taking proactive steps to preserve or improve your physical and mental health, wellbeing, happiness and quality of life."**

More information can be found within the resources section of the website:
https://www.acpcommunity.co.uk/test/community-nurses/resources/