Liverpool Heart and Chest Hospital NHS
NHS Foundation Trust

Introduction to Principles of Advance Care Planning

e-LfH e-Learning for Healthcare

NHS Health Education England

Inspected and rated Outstanding ☆ Care Quality Commission

Learning Objectives

- By the end of this session you will be able to:Define advance care planning
- Describe the process of advance care planning
- Discuss the reasons why advance care planning has been introduced
- Identify principles of good practice within the process of advance care planning
- Examine frequently asked questions patients may pose concerning advance care planning
- Identify where you can find out more about advance care planning

Introduction

- "Advance Care Planning (ACP) is a voluntary process of discussion between an individual and their care providers. It is to make clear a person's wishes in anticipation of a deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others."

(National End of Life Care Programme, *Advance Care Planning: a guide for health and social care staff*. February 2007)

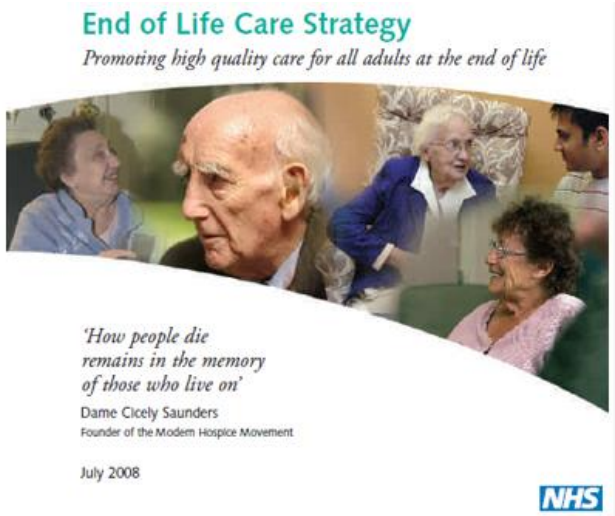
- "All people approaching the end of life need to have their needs assessed and their wishes and preferences discussed."

(Department of Health. *End of Life Care Strategy: promoting high quality care for all adults at the end of life*, July 2008)

National end of life care programme

What is Advance Care Planning? Background

- The Department of Health End of Life Care Strategy was published in July 2008 and provides a comprehensive framework aimed at promoting high quality care for all adults approaching the end of life in all care settings in England.
- One of the key aims of the strategy is to ensure, as far as possible, that people approaching the end of life have their needs and preferences for future care met. Every individual may have a different idea about what a 'good death' might be, but for many, the common factors are:
- 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 friends and family



What is Advance Care Planning? Definition

- At some time in a person's life, they may want to think about the consequences of becoming seriously ill or disabled. They may wish to discuss their feelings, and consider recording their wishes and preferences.
- Advance care planning is a voluntary process of discussion about future care between an individual and those who provide care for them, for example a nurse, doctor, care home manager or a family member.
- **Question:** What is the difference between ACP and planning in general?
- **Answer:** The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes. It takes place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or the ability to communicate wishes to others.

What is Advance Care Planning?
Components of ACP

The process of advance care planning can be broken down into four broad components.

- Opening the conversation
- Exploring the options
- Identifying wishes and preferences
- Recording/Communicating wishes and preferences

Opening the conversation

Advance care planning may be instigated by either an individual or a care provider at any time, but may be due to a trigger event. This trigger could be:

- The death of a spouse or close friend
- A new diagnosis of a life limiting disease
- A change in progress of an existing illness
- New treatment options to consider
- A need to consider a different care setting
- A change in personal circumstances, for example retirement
- Changes within the family dynamics

Exploring the options

- What options might be available to the patient?

An individual may have strong views about things they would or would not like to happen. These decisions may range from place of care to the appointment of a Lasting Power of Attorney or making Advance Decisions to Refuse Treatment. It may be necessary to seek further advice and support about what is available. Unrealistic requests should be dealt with sensitively, and possible acceptable alternatives discussed.

Identifying wishes and preferences

What sort of things might be identified?

- An individual's wishes and preferences will be very personal to them:
- They may reflect religious and spiritual beliefs
- They may reflect names of people they wish to represent them
- They may also reflect a chosen place of care, thoughts on treatment options, or basic concerns on practical issues

What methods of recording or communicating wishes are available?

- A statement of wishes and preferences is a summary term embracing the method by which people may want to make their wishes known. Methods of communicating this could be written, recorded conversations, pro forma or medical notes.
- The content of the statement can be both medical and non medical. For example, preferred place of care, beliefs and values, religious requirements, organ donation and treatment options.
- Permission to share these plans with anybody else, including the patient's family and health or social care professionals, must be sought before these plans are disclosed.

The statement is not legally binding but should be used when determining a person's best interests in the event they lose capacity to make those decisions.

Advance care planning has a number of benefits. It:

- Provides information about a person's priorities which can be considered at a future time when acting in a person's best interests
- Reflects a person's aspirations
- Identifies issues which may need to be dealt with sooner rather than later
- Can make professionals aware of a person's wishes and the need for review as circumstances change
- Can promote, where appropriate, important discussions between family members
- Can provide an opportunity to discuss appointing Lasting Power of Attorney or making an advance decision to refuse treatment

Principles of Good Practice Overview

The process of advance care planning is a voluntary one, with no pressure on an individual from professionals, family members or organisations.

ACP is a patient-centred dialogue carried out and reviewed over a period of time. The content of any discussion should be determined by the individual concerned, although they may wish to include a carer, relative or significant other in the discussion.

ACP can be introduced by the individual, or by a professional if they judge it is likely to benefit the care of the individual. Discussion should be introduced sensitively, and confidentiality should be respected in line with professional guidance.

There are a number of additional principles that you need to be aware of.

Setting

The time and setting for the discussion should be appropriately chosen. This should be in private, with adequate time, and the patient should have decided whether or not to have anybody else present.

Being open to discussion

Members of staff should be open to any discussion which may be instigated by an individual.

Being fully informed

The member of staff facilitating the ACP discussion needs to be able to fully provide the patient with relevant information. For example, if treatment decisions are involved, the patient needs to know the potential benefits, harms and risks of that treatment. They also need to know something about their prognosis - with and without that treatment - in order to make their decisions.

Having adequate knowledge

Members of staff should have adequate knowledge of the benefits, harms and risks associated with the patient's treatment.

Awareness of limitations

Members of staff should recognise when they have reached the limitations of their own knowledge.

Assess capacity

Members of staff should assess whether the patient has the capacity to understand, discuss and agree the options available to them. ACP requires patients to have mental capacity at the time, in anticipation of a future loss of capacity.

Review

Wishes can be discussed, reviewed and updated at any time. Patients should be advised to think about reviewing their ACP if their current wishes change, and advised that they can instigate this themselves at any time.

Issues Associated with ACP
Advance Decisions to Refuse Treatment

Question: Can a person make an advance decision to refuse treatment?

Answer: During the process of advance care planning, an individual may choose to make an advance decision to refuse treatment. An advance decision enables someone aged 18 or over, while still capable, to refuse specified medical treatment for a time in the future when they lack the mental capacity to consent to or refuse treatment.

An advance decision to refuse treatment must be valid and applicable to current circumstances.

Question: How can you act in someone's best interests in the absence of any documentation about wishes and preferences?

Answer: When an individual lacks capacity, a person acting in their best interests should:

Do whatever is possible to permit and encourage the individual to take part in decision making

Try, where possible, to identify all the things that they would take into account if they were making the decision for themselves

Make a best interest judgement, weighing up the likely benefits, risks and harms of what is proposed, for that person

Patients will invariably have many questions regarding their advance care planning.

Can we do this later?

Remember, the process is a voluntary one with no pressure on an individual from professionals, family members or organisations.

Do I have to be ill before discussing advance care planning?

Advance care planning may be instigated by either an individual or a care provider at any time, but may be due to a trigger event.

Examples of a trigger could be:

- The death of a spouse or close friend
- A new diagnosis of a life limiting disease
- A change in progress of an existing illness
- New treatment options to consider
- A need to consider a different care setting
- A change in personal circumstances, e.g. retirement
- Changes within the family dynamics

Can my daughter do this for me?

No. The content of any discussion should be determined by the individual concerned, although they may wish to include a carer, relative or significant other in the discussion.

Do I have to tell my family?

The patient does not need to tell his or her family. The process is a voluntary one, with no pressure on an individual from professionals, family members or organisations.

How do I find out what my options are?

Members of staff should be open to any discussion which may be instigated by an individual. They should be fully informed of a patient's illness, treatment options, prognosis and social situation.

Can I change my mind?

Wishes can be discussed, reviewed and updated at any time. The ACP is only used when a person loses capacity. Whilst the person has capacity, he or she is free to make his or her own decisions.

Will the doctor do what I ask?

The statement is not legally binding but should be used when determining a person's best interests in the event they lose capacity to make those decisions.

If I become very ill, can my family change my wishes?

No. The family cannot change your wishes.

Issues Associated with ACP Checklist

There are a number of questions you should ask yourself before embarking upon a patient's advance care planning.

Question: What questions should you be asking?

Answer: Questions to ask yourself include:

- Are you the right person to do advance care planning?
- Do you have time to do this?
- Do you understand the basic principles of advance care planning?
- Do you have a good understanding of the individual's condition, treatment options and prognosis?
- Do you have knowledge of local resources?
- Are you currently influenced by any other factor such as professional, organisational or family pressure?

Issues Associated with ACP Checklist

Question: What other things should you consider?

Answer: You should also ask yourself:

- Do you understand the legal status and implication of advance care planning?
- Can you determine if an individual has the mental capacity to make decisions?
- Do you possess adequate communication skills?
- Are you aware of the relevant guidance on advance decisions to refuse treatment?
- Do you have a colleague who would be more appropriate to have this discussion?

Think again about what advance care planning is? Have your ideas now changed?

Feedback

ACP can best be defined as discussing and identifying an individual's own preferences and wishes about future care in anticipation of future loss of capacity.

It is a voluntary process which can be reviewed and amended at any time.

It only comes into use if the patient has lost capacity to make his or her own decisions.

Session Key Points

- Advance care planning is a voluntary process during which an individual expresses their wishes and preferences about future care
- It is to make clear a person's wishes in anticipation of a deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others
- The resulting outcome is not legally binding but should be taken into account when making best interest decisions about an individual's future care
- Advance care planning can be made up of several elements which do not have to be completed all at once
- Wishes and preferences should be reviewed and, if necessary, updated on a regular basis