Advance care planning discussions and guidance notes

Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, to record choices about their future care and treatment and / or an advance decision to refuse a treatment in specific circumstances. These can subsequently be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity. They can be used to influence best interest decisions and decide once their illness progresses future care and treatments. It is not a “one-off” plan making session and requires ongoing review and discussion. It is an inclusive, personalised, proactive and transparent process that cuts across health, social and community care settings. It focuses on what matters most to the patient, so that they are involved in decisions and more in control of living their life with their condition in an individualised and person centred way. Advance care planning assists to help care with an advanced progressive incurable illness so they can live as well as possible until they die. It should enable both patients and their families to identify with all holistic needs important to them.

This is particularly important for people with Dementia or those whose condition means they may no longer have the ability to communicate their needs or wishes.

Under the terms of the Mental Capacity Act 2005 formalised outcomes of advance care planning might include one or more of the following:

- **Advance Statements** to inform subsequent best interest decisions.
- **Advance Decisions to Refuse Treatment** which are legally binding if valid and applicable to the circumstances at hand.
- **Appointment of Lasting Powers of Attorney** ('health and welfare' and/or 'property and affairs').

Not everyone will wish to make such records. Less formally, the person may wish to name someone whom they wish to be consulted if they lose capacity. However, the discussions and information should be provided to all patients to provide the opportunity to forward plan and discuss their future in line with the National End of Life Care Strategy (2008), Ambitions for Palliative and end of life Care (2015), NICE guidance and Essex Partnership Foundation NHS Partnership Trust End of Life Care Framework and clinical guidance 2018.

**Preferred Priorities for Care (PPC)** is a document which provides an example of an advance care plan which is used for people to record in writing their priorities and preferences for their future care and their preferred place of
death (PPD). The document is patient held, so they can take it with them if they receive care in different care settings and share with all services they access. The approaches to these discussions must aim to help people to have an informed choice to prepare for the future by encouraging and helping them to think and talk about an area of care that is important to them.

Should the person lose capacity to make a decision about issues discussed, a previously completed PPC acts as an advance statement. This means that the information included within the PPC can be used as part of an assessment of a person’s best interests when making decisions about their care.

Advance Care Planning may be instigated by either the individual or a care provider at any time, not necessarily in the context of illness progression but may be at one of the following key points in the individual’s life:

- Following a new diagnosis of a life limiting condition e.g. dementia, frail elderly, neurological illness, heart failure and Chronic Obstructive airways disease.
- When there is a significant shift in treatment or where options for treatment require review.
- At the time of an assessment of the individual’s needs.
- Following multiple hospital admissions and when prognostic indicators are present in line with Gold Standard Framework, proactive identification guide (2016).
- Following discussions and individuals identifying concerns for future care needs.

Independent Mental Capacity Advocate - IMCA:

An IMCA is a person who is employed by local authority to support people who have no relatives and lack capacity. They act for a person who lacks capacity and has no close family or friends and have not recorded any choices about their care or treatment, or lack an advance decision to refuse treatment; in such cases an IMCA should be instructed and consulted regarding making decisions. This could include placement in hospital for longer than 28 days or a care home for longer than 8 weeks. IMCAs may also have a role in case reviews or adult protection cases, where no one else is available to be consulted.

It is essential to achieve open discussion and questioning styles and dialogue to ensure individualised approaches are established.
Opening the Conversation:

Advance care planning may be instigated by a patient, their family 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

What options might be available to the patient?

A patient 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 and best suited for them. Unrealistic requests should be dealt with sensitively, and possible acceptable alternatives discussed. For instance, a patient may request to die in a hospice but if they have limited beds this may not be possible, so they should be aware of all the options.

What sort of things might be identified?

A patient’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.
- They may discuss their family and needs of dependants and pets.
- Deactivation of implantable cardioverter-defibrillators.
- Organ and tissue donation.

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. It is important that the patient understands wishes need to be shared and recorded.
- 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. It is important the patient realises the importance of data sharing and provides consent. Without consent it makes it much more complicated to ensure wishes are carried out.

References:


End of Life Care Strategy, Department of Health 2008

Gold Standards Framework:
http://www.goldstandardsframework.org.uk/advance-care-planning


NICE Guidance, Quality Standards Programme. (Dementia)


NHS National End of Life Programme - Care towards the end of life for people with dementia (2010)

NHS England – My future wishes – Advanced Care Planning (ACP) for people with dementia in all care settings (2018)