Executive summary

Many people, by the time they reach the end of their lives, have multiple conditions and complex needs that require a proactive, coordinated response [6]. Making appropriate plans to meet a person's changing needs and aid timely transitions to end of life care are critical components of the quality improvement process in health and social care. The process of planning often involves multidisciplinary teams working across local health, social care and voluntary sector services[9] and an ongoing dialogue with a person and those close to them about how to meet their current needs and those that can be anticipated in the future. This guide has been developed to help health and social care staff who are involved in care planning and decision making for people with life limiting illness. It addresses:

1) The importance of assessing a person's capacity to make particular decisions about their care and treatment and of acting in the best interests of those who are assessed as lacking capacity to make these decisions.
2) The differences and relationship between care planning and advance care planning.

Capacity, care planning and advance care planning

Capacity refers to the ability to make a decision about a particular issue at the time the decision needs to be made or to give consent to a particular act. Assessing capacity and maximising capacity are essential aspects of the care planning process. It is important to appreciate that only people who have capacity can participate in advance care planning.

Care planning embraces the care of people *with and without capacity* to make their own decisions. It involves a process of assessment and person centred dialogue to establish the person's needs, preferences and goals of care, and making decisions about how to meet these in the context of available resources. It can be oriented towards meeting immediate needs, as well as predicting future needs and making appropriate arrangements or contingency plans to address these.

Where a person lacks capacity to decide, care planning must focus on determining their *best interests* (through consultation with the person's companions and key professional carers) and making decisions to protect these. Any information about what the person's views might have been about the issue at hand[1] and any relevant advance statement (see below) that they made prior to their loss of capacity, should be taken into account when trying to work out

[1] *The Mental Capacity Act 2005 Code of Practice (Chapter 5, p 65) uses the term 'views' to refer to:*
- *the person's past and present wishes and feelings - these may have been expressed verbally, in writing, or through behaviour or habits*
- *any beliefs and values (e.g. religious, cultural, moral or political) that would be likely to influence the decision in question*
- *any other factors the person themselves would be likely to consider if they were making the decision or acting for themselves*

what is in their best interests. If a person who has lost capacity has a valid and applicable advance decision to refuse treatment (ADRT) and/or has registered Lasting Powers of Attorney (LPA), these must be respected. Anything done under the authority of the LPA must be in the person's best interests.

If a person who lacks capacity has no close family or friends and has not recorded any choices about their care and treatment or made an advance decision to refuse treatment in advance of losing capacity, then an *Independent Mental Capacity Advocate* (IMCA) should be instructed and consulted regarding decision making about serious medical treatment or about 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.

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, set on record: choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses.

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

i) **advance statements** to inform subsequent best interests decisions;
ii) **advance decisions to refuse treatment** which are legally binding if valid and applicable to the circumstances at hand;
iii) **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.

For those people who have capacity and who wish to participate, advance care planning can be an integral part of the wider care planning process.

For individuals with capacity it is their current wishes and decisions about their care and treatment which need to be considered and respected during care planning and decision making.

Key principles

1. Effective communication, carried out with compassion and sensitivity, is fundamental to the process of providing good quality person centred care towards the end of life.
2. Care planning is the first step in making care and treatment decisions for a person with life limiting illness, irrespective of their capacity to participate or to decide.

3. A person's participation in care planning (including advance care planning) is voluntary.
4. If a person with capacity chooses not to participate in care planning, their adequately informed consent must be gained in relation to any decisions about their care or treatment that result from care planning. Only a person with capacity who chooses to do so can take part in advance care planning.
5. There is a balance between the duty of providing the information a person wants or needs to ensure their adequately informed consent and over burdening a person with too much information.
6. The care provider may respond to 'cues' which indicate a person's desire to make specific wishes or concerns known, e.g. worries about who will care for them.
7. Care and treatment decision-making by a person with life limiting illness requires that the individual has the capacity to understand, discuss options available and make decisions.
8. Where a person lacks capacity to decide, care planning must focus on determining their best interests and making decisions to protect these.
9. Any information given by an individual during any care planning discussion should be recorded and used correctly, with due reference to the Mental Capacity Act (2005).
10. Advance care planning is an aspect of care planning which can only be undertaken by a person who has capacity to decide. No pressure should be brought to bear by a health or social care worker, family or any organisation on the individual concerned to take part in advance care planning.
11. Should an individual with capacity wish to record choices about their care and treatment, or an advance decision to refuse treatment, in advance of losing capacity, they should be guided by a professional with appropriate knowledge and this should be documented according to the requirements of the Mental Capacity Act 2005.
12. Any choices or advance decisions to refuse treatment recorded in advance of loss of capacity only become relevant when a person loses the capacity to decide about those issues.
13. Where an individual has capacity to decide, then they must check and agree the content of any care planning record.
14. Staff should make or share records of any discussion only with the person's permission or if, in the case of someone who lacks capacity, this is judged to be in their best interests.
15. There should be locally agreed policies about where care planning documentation (including any formalised outcomes of advance care planning) is kept and systems in place to enable sharing between the health and social

care professionals involved in the care of the individual, including out of hours providers and ambulance services.

16. The person concerned should be encouraged to regularly review any care planning documentation, to update this as appropriate, and to ensure that revisions are shared with those they wish to involve in their care.

ACP Outcomes

- Advance statement
- Advance decision to refuse treatment
- Lasting Power of Attorney (for property and affairs, and/or health and welfare)
- Nomination of someone to be consulted