














Capacity, care planning and advance care planning in life limiting illness

***A Guide for Health
and Social Care Staff***

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Foreword

There have been a number of policy initiatives which emphasise the intention of government to offer a person more choice about their care, promote models of partnership working in health and social care decision-making and increase the quality and range of information available to individuals [1-3]. In particular, the National Institute for Health and Clinical Excellence (NICE) *Guidance: Improving supportive and palliative care for adults with cancer* [4] published in 2004 - recommended that assessment and discussion about a person's physical, psychological, social, spiritual, and financial support needs should be undertaken at key points (such as at diagnosis; at the start, during, and at the end of treatment; at relapse; and when death is approaching).


This was followed by the implementation in 2007 of the *Mental Capacity Act* of 2005 (MCA), supported by a Code of Practice [5]. The Act seeks to empower people to make decisions for themselves wherever possible, and protect people who lack capacity by providing a flexible framework that ensures individuals' best interests must be the basis for the decision making process. The Act offers guidance on giving appropriate help and support to people making their own decisions, determining if people have mental capacity to make their own decisions and acting in someone's best interests when they lack capacity. Chapter 9 of the Act has specific information on the legislative framework for when someone chooses to make an advance decision to refuse treatment prior to loss of capacity.

In 2008 the Department of Health published the *End of Life Care Strategy*  [6], which drew attention to the central importance of this area of practice for everyone affected by life limiting or life threatening illness.

The same year, the NHS Next Stage Review [7], led by Lord Darzi, laid great emphasis on giving people more control and influence over their health and healthcare, pledging that, by 2010, everyone with a long-term condition will have a personalised care plan. Care plans should be agreed by the person (or their representatives if the person lacks capacity) and a named professional carer and provide a basis for the NHS and its partners to organise services around the needs of individuals. However, the National Audit Office [8] has pointed out that the wishes of people approaching the end of their life are not always made clear to those who need to know.



The Department of Health through the National End of Life Care Programme  aims to support the development of protocols to help capture, document, and share accurate information on the person's preferences. This information should be regularly updated and shared with all providers across the health, social care, independent, and voluntary sectors who influence decisions about where and how people receive care.

This document seeks to provide guidance about this area of practice for all

health and social care staff who are responsible for the care of people affected by life limiting or life threatening illness. It has been written to complement the guidance aimed at doctors, which was published in 2010 by the GMC '*Treatment and care towards the end of life: good practice in decision making*'  [9].

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 hand¹ 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

¹The 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 overburdening 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

1. Aims

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 multi-disciplinary teams working across local health, social care and voluntary sector services[9] and an on-going 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 (see below).

Care planning and 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 hand² 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 what is in their best interests. If any advance statements exist which the person made before losing capacity, these should be taken into account in the process of determining best interests. If a person who has lost capacity has a valid and

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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.

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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.



2. 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 a 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.

3. Capacity

The term '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*.

3.1 Assessing capacity to make decisions

An individual's capacity must be assessed on a decision specific basis by the health and social care staff member responsible for the aspect of the person's care and treatment which is relevant. An individual may retain the ability to make a simple decision but not more complex decisions (Chapter 4, Mental Capacity Act 2005 Code of Practice). Their capacity may fluctuate over time in relation to those decisions.

- The staff member does not need to be an expert in assessing capacity, but they must take reasonable steps to come to a judgement about the person's capacity, depending on their role, skills and knowledge.
- If they decide that the person lacks capacity to make a specific decision, the staff member must hold a reasonable³ belief that the action proposed is in the person's best interests (Mental Capacity Act 2005 Code of Practice, para 6.22). This is not simply what the staff member believes to be in the person's best interests, but a process required by the Mental Capacity Act (2005). The only exceptions are emergencies and urgent psychiatric treatment under the Mental Health Act (2007)⁴.

Two key statutory principles of the Mental Capacity Act (2005) are:

- A person must be assumed to have capacity unless it is established that they lack capacity;
- A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.

3.1.1 The two stage test for capacity

The test for capacity is the same test regardless of the nature of the decision which has to be made.

It is a two-stage test.

- 1st stage: does the person have an impairment or disturbance of the mind or brain? If 'yes', then proceed to 2nd stage of the test. If 'no', then it must be concluded that the person has capacity.
- 2nd stage: does the impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

³The definition of 'reasonable' is set out in the Mental Capacity Act 2005 Code of Practice, paragraphs 6.29 - 6.34 and 4.44 - 4.45

⁴<http://www.legislation.gov.uk/ukpga/2007/12/contents>

In order to be able to make the decision the person must be able to:

- a) Understand the information. The carer must make every effort to make this information clear and accessible,
 - b) Retain the information. This only needs to be long enough to use and weigh up the information,
 - c) Use and weigh up the information relevant to this decision,
 - d) Communicate their decision in some way. The carer must try every method possible to enable this.
- If the person is unable to do any one of these then the person lacks capacity for that particular decision.
 - As set out above, a person is not to be treated as unable to make a decision unless all practical and appropriate steps to enable them to make that decision have been taken without success. Such steps may include, for example, returning to the person later in the day to talk to them about the decision that needs to be made or using simple language; it will also include providing appropriate support or equipment for people with complex communication needs.

An example

Caroline has dementia and lives at home with the support of carers from a domiciliary care agency. Over the last two days, she has become confused and seems to be unable to make decisions about the care she receives. The care worker has suggested that the GP be called because of concerns that Caroline is ill. Caroline is adamant that she does not require the GP. It is clear that Caroline is unwell and the care worker, having consulted the family, assesses that Caroline lacks the capacity to make the decision about whether or not to call the doctor. So the care worker calls the doctor and records her actions in the care plan.

The GP visits Caroline and diagnoses a urinary tract infection. He requests a urine sample for analysis and commences treatment with antibiotics. Within three days, Caroline regains capacity to make a decision like calling the GP.

Key points

In this scenario the care worker is the decision maker and has responsibility for making an assessment of Caroline's capacity to make a decision about calling out the GP.

The care worker does not have to be an expert in assessing capacity, but has to take due care and to carefully record his/her actions.

People who lack capacity to make a particular decision can often regain capacity to make that decision, at a later time.



3.2 Maximising capacity


A person must be given all help that is practicable to maximise their capacity. This means providing information tailored to their abilities and communicating with them in a way they find easiest.

- Section 1 of the Mental Capacity Act 2005 Code of Practice (Chapter 3, para 3.8) states: “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success”.
- Sometimes people will be more comfortable about making decisions when someone who knows them can support them (MCA 2005, Code of Practice, para 3.15). It will thus usually be appropriate, if the person wishes, to involve their close relatives and partners or other carers, in discussion of the issues and to help the person to make choices or to communicate their wishes.
- In some cases, relatives, partners or other carers may have been granted legal power, by the person or by the courts, to make healthcare decisions when the individual lacks capacity to make their own choices (Mental Capacity Act 2005, Code of Practice, chapters 7 and 8).


4. Care planning

4.1 What is 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. The person receiving care may wish to involve others in the care planning process (for example, their husband, wife or partner).

- Before care planning is undertaken, an assessment of the person's capacity to participate in care planning and make the relevant decision(s) must be carried out and the necessary steps taken to maximise capacity (see section 3).
- If a person lacks capacity to decide, care planning should involve their relatives, partner, close companions and any other care staff who know them or are responsible for their care. Where a person lacks capacity to make specific decisions, care planning must focus on determining their best interests using the process required by the Mental Capacity Act.
- If any advance statements exist which the person made before losing capacity, these should be taken into account in the process of determining best interests. If there exists a valid and applicable advance decision to refuse treatment (ADRT)  or Lasting Powers of Attorney (LPA) made when the patient had capacity, then these are binding. 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.

4.2 What are care plans?

A care plan (sometimes known as a 'support plan')  documents the care and treatment actions necessary to meet a person's needs, preferences and goals of care. These must have been agreed with the person receiving care or by those acting in the person's best interests. Where care plans are made for someone who lacks capacity to participate in care planning, they may include reference to an advance statement, ADRT or Lasting Power of Attorney that the person made before losing capacity, or to any other available information about what their



views might have been.


Care plans may include any aspect of health and social care. These might include any of following aspects, but are not restricted to them:

- The goals that the person wishes to work towards and the actions they wish to take to achieve these (achieving a greater degree of comfort by adjusting the times that they take analgesia, so that they can go out more frequently; or making plans to enable part time working now that they are unable to work full time, are simple examples).
- The actions agreed that are necessary to meet personal care needs and care goals (for example, how help will be provided with washing and dressing, what services are to be provided to help the person at home or to provide them with social support).
- Any contingency plans that need to be made to address any foreseeable health care problems associated with the person's illness (for example, what will be done if the person suffers severe pain or breathlessness).

Information in a care plan provided by a person with capacity to decide can be used at a later date to inform any best interests decisions (see section 4.3) that need to be made once they have lost capacity to decide, although careful judgement is required to assess the degree to which the information is up to date, applicable and valid to the circumstances at hand.

4.3 Care planning and decision making on the basis of the best interests of a person who lacks capacity to decide or consent

A person may lack capacity to make some or all decisions or to consent to actions connected with health and social care provision. These individuals will be reliant on staff to follow a careful process of care planning and decision making which maximises their ability to participate in care planning and make associated decisions (even if this is partial) and protects their 'best interests'.

- Best Interests should be determined by following the process defined in the MCA 2005 Code of Practice (chapter 4) which requires that all relevant circumstances are taken into account.
- Best interests assessment will often involve consulting relevant members of the multi-disciplinary team as well as people close to the person. This may involve, for example, convening a case conference. Sometimes it will also involve appointment and consultation with an IMCA  (see 4.1. and 4.3.7).
- If the person appointed Lasting Powers of Attorney before loss of capacity, then any decisions made under the direction of the attorney must be in the person's best interests.

4.3.1 Defining best interests

There is no definition of 'best interests' in the Mental Capacity Act, because

so many types of decisions and actions may be necessary and people and circumstances differ greatly (Mental Capacity Act 2005, Code of Practice, para 5.5).

4.3.2 What must be taken into account when determining someone's best interests?

The Mental Capacity Act 2005 Code of Practice (para 5.13) has a non-exhaustive checklist which must be considered when trying to work out someone's best interests:

- Determining what is in someone's best interests cannot be based merely on their age, appearance, condition or an aspect of their behaviour which may lead others to make unjustified assumptions about what is in their best interests.
- All relevant circumstances should be considered when determining someone's best interests. Every effort should be made to encourage and enable the person who lacks capacity to take part in the decision making process.
- If there is a chance that the person will regain capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent.
- Special considerations apply about life sustaining treatment.
- The person's past and present wishes and feelings, beliefs and values should be taken into account, where appropriate and applicable information about these is available. These may be in an advance statement made by the person when they had capacity for those decisions or could be in information recorded as part of the general care planning process.
- The views of other people who are close to the person who lacks capacity should be considered, as well as the views of any deputy or attorney.

4.3.3 Talking to relatives, partners or others close to the individual when the person lacks capacity

If a person lacks capacity, then their relatives or partners must be consulted as part of the process of determining best interests and in order to enable them to understand the care and treatment decision making process.

- Staff need to be clear about the limits of the decision making powers that relatives and partners have.
- Relatives and partners can inform best interests but have no legal authority or right to make decisions for a person who lacks capacity unless they have been granted such powers (by appointment as an LPA) by the person who now lacks capacity or by the courts (Mental Capacity Act 2005, Code of Practice, chapters 7 and 8).



4.3.4 Studying care records to inform best interests

Assessment of best interests should also involve careful study (as far as is practicable) of any care records, such as clinical notes, to see if any advance statements of wishes and preferences or valid and applicable advance decisions to refuse treatment exist, or if any other appropriate and applicable information exists about what the person's views might have been.

- These steps may not always be possible, e.g. if an individual is admitted to hospital as an emergency, is unconscious and requires rapid treatment.
- Health and social care staff who are trying to determine a person's best interests must follow their professional guidance, as well as other relevant guidance, about confidentiality (Mental Capacity Act 2005, Code of Practice, para 5.57).

4.3.5 Dealing with disagreements about best interests

Disagreements may arise between the health or social care worker who has responsibility for the best interests decision and those close to the person who lacks capacity, or between them and members of the health or social care teams, or within the health or social care teams or those close to the person who lacks capacity.

- Depending on the seriousness of any disagreement, it should usually be possible to resolve it; for example, seeking advice from a more experienced colleague, obtaining a second opinion, holding a case conference, by involving an independent advocate (where that is appropriate), or using local mediation services[9].
- Some decisions about types of treatment are so serious⁵ that they must involve the Court of Protection (see also 4.3.8 below), unless the person has previously made a Lasting Power of Attorney for health and welfare, appointing a person or persons to make such health care decisions or has a valid advance decision to refuse the treatment.

4.3.6 Responsibilities of the decision maker when the person lacks capacity

During the care and treatment delivery process, many different people may be required to make decisions or act on behalf of a person who lacks capacity to make decisions for themselves.

- The 'decision-maker' is usually the person responsible for the person's care at that time. This can be a relative or partner, but is often a health or social care professional responsible for the individual's care at the time (Mental Capacity Act 2005, Code of Practice, chapter 5).
- It is the responsibility of the decision-maker to work out what would be in the best interests of the person who lacks capacity and to record how this assessment was carried out.

- Staff must make sure that they understand the scope and responsibilities of their own role, the roles and specialist skills of other health and social care team members, and the lines of accountability for the person's care[9]

4.3.7 The role of Independent Mental Capacity Advocates (IMCA) when the person lacks capacity

If the person has no-one to support or represent them (sometimes referred to as being 'unbefriended') and the decision involves a serious issue such as life prolonging treatment, staff must consult their employing organisation about the appointment of an Independent Mental Capacity Advocate (IMCA), as required by the Mental Capacity Act 2005.

- The IMCA will have authority to make enquiries about the person who lacks capacity to decide and contribute to the decision by representing the person's interests, but cannot make a decision on behalf of the person[9].
- IMCAs must also be involved in decisions such as placement in a care home for longer than 8 weeks or for a period of longer than 28 days in hospital. They may also be appointed or consulted in adult protection cases.

4.3.8 The role of The Court of Protection when the person lacks capacity

As noted above, some treatment decisions are so serious that they have to be referred to the Court of Protection, unless the person has previously made a Lasting Power of Attorney appointing a person or persons to make such decisions for them, or they have made a valid and applicable advance decision to refuse the proposed treatment.

4.4 Different responsibilities and competences

Staff have different responsibilities and competences relating to particular types of decisions that need to be made during general care planning.

- Sometimes it will be necessary to consult with colleagues or other involved parties such as: families, carers or advocates.
- This is to ensure that a person with capacity is provided with accurate information and appropriate support to maximise their ability to take part in the planning process, to weigh up any risks and benefits and to make decisions.

4.4.1 Working as part of a team

Staff must be clear about the scope and responsibilities of their own role and the lines of accountability for the person's care[9]. They should recognise when to call for support or assistance from other team members and should consider consulting colleagues from health, social care, or voluntary sector services

⁵Examples of serious medical treatment are provided in the Mental Capacity Code of Practice, para 10.45. What constitutes 'serious' will need determining by consultation with colleagues since it will vary contextually and on a case to case basis.



who may have information or knowledge about the person which can help in the delivery of safe, effective and timely care[9].

- They should always consult the person concerned, as well as that person's usual carers and people who are close to the person, where the person agrees that this may be done or the staff member judges that the person has lost capacity to make a specific decision and it is necessary to do so in order to establish that person's best interests.

4.4.2 Recognising the need to refer for specialist expertise

Sometimes care decisions which become necessary during care delivery will involve complex issues or have major consequences, or be associated with disagreements about the person's capacity to decide. In these circumstances, staff must call on colleagues with appropriate specialist expertise.

- It is therefore necessary that staff develop a good knowledge of access and referral processes within their locality and area of work.
- The person's usual carers and people close to the person may have knowledge or insight to contribute.
- These issues about recognising different responsibilities and competences are also of relevance in considering advance care planning.

5. Advance Care Planning (ACP)

5.1 What does advance care planning mean?

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.

The legal context of advance care planning varies across the world.

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.

These are only relevant to the care and treatment to a person once they have lost capacity to make decision(s) about the issues they cover.

5.2 What issues might advance care planning include?

An ACP discussion might include the individual's preferences, wishes, beliefs, values and feelings about:

- personal goals or aspirations for care
- their illness and prognosis
- the types of care or treatment that are available and their benefits, harms and risks
- the types of decisions that may need to be made about their care and treatment in the future

5.3 Who takes part in advance care planning?

Advance care planning centres on discussions with a person who has capacity to make decisions about their care and treatment. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement that discussions are documented, regularly reviewed, and communicated to key persons involved in their care.



5.4 How does advance care planning fit with care planning?

The difference between advance care planning and care planning is that the process of ACP can only involve someone with capacity to decide and usually 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. Although advance care planning is often focused on informing decisions once a person has lost capacity, the process can help a person with life limiting illness to consider clinical or personal arrangements for the future progression of their illness which are not specific to anticipation of loss of capacity. To this extent, advance care planning is 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.

Example

A patient with a chronic respiratory condition had previously had several crises caused by respiratory infection. On each occasion the breathlessness and anxiety had prompted the patient to ask for admission to hospital. Since the last admission she has been encouraged to write an advance statement. She decided that she wished to state that she would want to remain at home in the future. In addition, she had appointed her daughter as her Lasting Power of Attorney (LPA) for her property and affairs.

Her GP was called because of another respiratory crisis. Once again, her breathlessness and anxiety prompted the patient to request to be admitted to hospital. There was nothing to lead the GP to suspect she may have lost capacity. At this point the daughter took the GP to one side to point out that she was her mother's appointed LPA and did not wish her mother to be admitted to hospital. She also showed the GP her mother's advance statement stating her wish to remain at home.

The GP took advice and acknowledged that the patient's decision took precedence. She recovered fully in hospital and returned home. The daughter only had LPA authority for property and affairs, not for health and welfare (including healthcare and consent to medical treatment). In any event, the daughter's role as an attorney does not become active until her mother has lost capacity to decide.

Key points:

- *in the absence of any suspicions of an impairment or disturbance of mind or brain it must be assumed a patient has capacity;*
- *the decisions of a patient with capacity override all other documented choices or arrangements they may have recorded in the past;*
- *LPAs only have a role when the person appointing them has lost capacity to decide. The scope of LPA must be checked.*

5.5 Potential benefits and risks of advance care planning

Although the evidence remains limited in scope, advance care planning discussions have been found to have a number of benefits in research studies, with evidence that some people have experienced an increased sense of control, of hope and/or perceive that their relationships with others are stronger as a result [10, 11]. Advance care planning discussions can help people to anticipate the sorts of decisions that may need to be made in the future as their illness progresses. This anticipation may allow them to both prepare for making those decisions in the event that they retain capacity (as many people are likely to do even when severely ill) and/or allow them to make an advance statement or advance refusal of treatment to reflect some specific choices that they wish to be considered in the event that they lose capacity [12]. In addition, there is some limited evidence that advance care planning can aid transitions to timely palliative care and improve the sense of satisfaction with end of life care reported by bereaved carers [13]. An evidence based review [14] of advance care planning practice found that ACP discussions on admission to a care home may cause distress, but can be successful once a person has had time to adjust and if staff are appropriately trained. The review also found that whilst ACP discussions are widely recommended at the time of diagnosis of a life threatening illness, some individuals who are ill or who require hospital admission may not feel able to engage.

Not every person will wish to engage in advance care planning.

Some people may experience negative outcomes from the process since it may challenge their coping style or bring to mind issues about their illness and their future which they are not ready to think about. Others are comfortable with such discussions but, should they lose capacity in the future, prefer to leave such decisions to their carers. Individuals who record choices about their future care and treatment should understand that these WILL be taken into account if they lose capacity. In addition, they need to understand that any valid and applicable ADRT will replace any best interests decision making process about the specific treatment to which the ADRT relates.

5.6 Avoiding a prescriptive style of initiating and conducting ACP

A rigid, prescriptive or routinised approach to initiating and conducting advance care planning must be avoided if harm is to be prevented to the person concerned. This can be achieved by using an open question style of dialogue and ensuring appropriate expertise through training. It is important to think about appropriate timing and an appropriate environment in which to initiate advance care planning.



5.7 Considering the use of ACP: timing and context

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. cancer, motor neurone disease or dementia
- When there is a significant shift in treatment focus e.g. chronic renal failure where options for treatment require review
- At the time of an assessment of the individual's needs
- Following multiple hospital admissions

The following are examples of situations in which ACP may be appropriate:

- 1) Mrs Adams - A 54 year old woman with cancer of the colon with liver metastases. She develops jaundice which cannot be treated and is feeling increasingly weak and tired. This lady is now recognising she has a progressive disease and may wish to discuss her future care.
- 2) Mr Brown – A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home, has had two hospital admissions in the last year and is worried about the prospect of any more emergencies and coping with the future.
- 3) Mrs Carter – An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She has recently fallen, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'.

5.8 The outcomes of advance care planning discussions

Some people may wish to document the outcome of their advance care planning discussion(s), but this is not mandatory. Under the Mental Capacity Act 2005, there are three types of documented outcomes in advance care planning:

- 1) advance statements
- 2) advance decisions to refuse treatment
- 3) appointment of Lasting Powers of Attorney.


In addition, the person may wish to name someone whom they wish to be consulted in the event that they lose capacity.

5.8.1 Advance statements

These are written statements (either written down by the person themselves or written down for them with their agreement) the person might make before losing capacity about their wishes and feelings (Mental Capacity Act Code of Practice, 2007, P291) regarding issues they wish to be considered in the case of future loss of capacity due to illness, such as the type of medical treatment they would

want or not want, where they would prefer to live or how they wish to be cared for. They are not the same as advance decisions to refuse treatment and are not binding.

5.8.2 Professional responsibilities in relation to advance statements

Although advance statements are not legally binding, carers are required under the Mental Capacity Act to take them into account when considering the individual's best interests. There is no set format for advance statements, although some local and national examples exist such as Preferred Priorities for Care .

5.8.3 Advance decisions to refuse treatment (ADRT)

During the course of discussions about advance care planning it may become apparent that the person wishes to make a legally-binding advance decision to refuse treatment.

An advance decision to refuse treatment (ADRT) is a decision to refuse a specific treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.

An advance decision to refuse treatment

- Can be made only by someone over the age of 18 who has mental capacity
- Is a decision relating to refusal of specific treatment and may also include specific circumstances
- Can be verbal, but if an advance decision includes refusal of life sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'
- Will only come into effect if the individual loses capacity
- Only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision
- Is legally binding if valid and applicable to the circumstances.
- Can be overridden by the Mental Health Act, but only for psychiatric treatment.

Example

A young man, whose friend died after prolonged hospital treatment, made a signed and witnessed treatment specific advance decision and statement refusing any treatment to keep him alive by artificial means if he was injured

⁶<http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>



in this way. A few years later, he is seriously injured in a road traffic accident and is paralysed from the neck down and is only able to breathe with artificial ventilation.

Initially he remains conscious and is able to consent to treatment on being taken to hospital. He participates actively in a rehabilitation programme. Some months later, he loses consciousness. It is at this point that his written advance decision is located, though he has not mentioned it during his treatment.

His previous consent to treatment and involvement in rehabilitation is clearly inconsistent with his actions prior to his lack of capacity. Anyone assessing the advance decision would need to make careful consideration of the considerable doubt this inconsistency puts on its validity.

Key points

The validity and applicability of any advance decision to refuse treatment must be carefully considered.

If the person has done anything which clearly goes against the advance decision, this will suggest that they have changed their mind.

5.8.4 Professional responsibilities in relation to advance decisions to refuse treatment

The making of an advance decision should be under the guidance of someone who understands the complexities of the process as well as the clinical implications of the decision.

The professional involved in the discussion should be willing and able to discuss what is involved in the making of an advance decision or be able to give direction as to the appropriate action to be taken. Chapter 9 of the Mental Capacity Act Code of Practice provides detailed advice about professional responsibilities and issues to consider in relation to advance decisions to refuse treatment, including how to check that one exists and guidance on making, updating and cancelling them.

A health care professional who has to make a decision about a person's medical treatment when the person lacks capacity is legally obliged to establish the validity and applicability of any ADRT.

Where people are detained under the Mental Health Act 1983 (and can therefore be treated for their disorder without their consent under Part 4), they can be treated even though they have made an advance decision refusing the treatment in question.

5.8.5 Lasting power of attorney (LPA)

Lasting Power of Attorney refers to the appointment of a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. This is

known as ‘Lasting Powers of Attorney’ (LPA) under the provisions of the Mental Capacity Act. LPA can apply to health and welfare or property⁷ and affairs. Only health and welfare attorneys can make healthcare decisions, and they can only make decisions about life-sustaining treatment if this has been specifically allowed in the LPA document. LPAs come into effect only when the person in question loses capacity to make the decision(s) to which the powers of attorney relate. An LPA must be in a prescribed form and be registered with the Office of the Public Guardian.

5.8.6 Giving lasting power of attorney for health and welfare: an example

It is important to ascertain the validity of any LPA and its scope. The Court of Protection can provide information about validity and provide directions about use of the LPA and, if required, removal of LPA powers if the attorney does not act in a person’s best interests. Comprehensive information about this issue is available in the Mental Capacity Act Code of Practice, chapters 7 and 8. An explanation about the Court of Protection and its powers is in paragraph 8.1 of the Code of Practice.

Mrs Jones has never trusted doctors and prefers to rely on alternative therapies and remedies. Having seen her father suffer for many years after invasive treatment for cancer, she is clear that she would wish to refuse such treatment for herself, even with the knowledge that she would die without it. When she is diagnosed with bowel cancer, Mrs Jones discusses this issue with her husband.

Mrs Jones trusts her husband more than anyone else and knows he will respect her wishes about the forms of treatment she would or would not accept. She therefore asks him to act as her attorney to make health and welfare and healthcare decisions on her behalf, should she lack the capacity to make her own decisions at any time in the future.

Mrs Jones makes a health and welfare LPA appointing her husband to make all decisions relating to her health care and welfare. She includes a specific statement authorising him to refuse life-sustaining treatment on her behalf. This is to ensure that Mr Jones has the authority to make best interests decisions about her treatment.

Key points

A health and welfare LPA allows a person to choose one or more people who can make decisions for things such as medical treatment, in the event of the person’s loss of capacity.

If the person wishes the attorney(s) to be able to make decisions about life sustaining treatment, this must be specified.

Any care or treatment decisions made under the authority of an LPA must be done in the person’s best interests and only when they have lost capacity to make the decisions in question.

⁷Note that pet care is included within the local authority duty to protect property



5.8.7 The role of the office of the public guardian

An LPA must be in a prescribed form and be registered with the Office of the Public Guardian⁸.

The Office of Public Guardian website provides information on:

- making personal arrangements
- what to do if there are concerns about someone else making decisions
- information for those allowed to make decisions for others under lasting powers of attorney.

⁸<http://www.publicguardian.gov.uk/>



6. Core competences

As a result of studying this guide, health and social care staff should now be able to:

- Distinguish between: 'care planning' and 'advance care planning', and appreciate areas of overlap.
- Be able to define advance care planning and identify the outcomes possible under the terms of the Mental Capacity Act, 2005
- Appreciate the need to assess and review a person's capacity to participate in care planning and to make any associated decisions, and know how to assess capacity
- Appreciate the need to protect and advocate for a person's best interests if they lack the capacity to participate in care planning and /or to make a particular decision, by following the 'best interests' process required by the MCA.
- Understand that discussions about care and treatment should be person centred and, as far as possible, take the form of a dialogue over time.
- Understand the importance of involving, where appropriate, those close to a person (for example relatives and partners) but have knowledge of the limits of the decision-making powers that relatives and partners have.
- Understand key principles of good practice in record keeping.
- Appreciate the importance of recognising when they have reached the limits of their knowledge and competence and know when and from whom to seek advice.
- Appreciate the importance of being able to give a realistic account of the support, services and choices available in the particular circumstances. This should entail referral to an appropriate colleague or agency when necessary.
- Understand the importance of having adequate knowledge of the benefits, harms and risks associated with treatment or care options to enable a person to make an informed decision or to assist in the assessment of best interests, if the person lacks capacity to make an informed decision.
- Understand that confidentiality should be respected in line with current good practice and professional guidance.

6.1 End of life care – common core competences

In January 2010, Skills for Health (SfH) and Skills for Care (SfC) set out a framework [15] of competences and National Occupational Standards (NOS) relating to end of life care which include advance care planning.

These can be found on the websites: **www.skillsforhealth.org.uk** and **www.skillsforcare.org.uk**. The framework is currently being reviewed to include additional areas in end of life care such as spirituality and bereavement



as well as new sessions aimed at social care staff. The framework is being used to inform health and social care qualifications within the new Qualifications and Credit Framework (QCF) which has replaced National Vocational Qualifications (NVQs). Like NVQs, QCF qualifications are derived from NOS however they differ from NVQ units because they contain learning outcomes instead of knowledge and performance criteria statements. Further information can be found on the Skills for Health and Skills for Care websites.

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8. Glossary (alphabetically listed)

Advance Care Planning (ACP)

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 or decisions relating to their care and treatment so that these can then be referred to by their carers (whether professional or family carers) in the event that they lose capacity to decide once their illness progresses. The legal context of advance care planning varies across the world.

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.

Advance decision to refuse treatment (ADRT)

This is a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment. An advance decision to refuse treatment:

- Can be made by someone over the age of 18 who has mental capacity
- Is a decision relating to refusal of specific treatment and may also include specific circumstances
- Can be verbal, but if an advance decision includes refusal of life-sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'
- Will only come into effect if the individual loses capacity
- Only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision
- Is legally binding if valid and applicable to the circumstances.

Advance statements

These are written statements (either written down by the person themselves or written down for them with their agreement) the person might make before

losing capacity about their wishes and feelings (Mental Capacity Act Code of Practice 2007, P291) regarding issues they wish to be considered in the case of future loss of capacity due to illness, such as the type of medical treatment they would want or not want, where they would prefer to live or how they wish to be cared for. Advance statements should be used to help find out what somebody's wishes and feelings might be, as part of working out their best interests when they have lost capacity to decide. They are not the same as advance decisions to refuse treatment and are not binding.

Best interests

Under the Mental Capacity Act, any decision made or any action done for a person who lacks capacity to make specific decisions must be in accordance with their best interests. There are minimum standard steps to work out someone's best interests, and this document includes the non exhaustive checklist set out in section 5.13 of the Mental Capacity Act Code of Practice.

Capacity

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.

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 hand⁹ 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 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, has not recorded any choices about their care and treatment or made an advance decision to

⁹The 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



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.

Care plans

A care plan (sometimes known as a 'support plan') documents the care and treatment actions necessary to meet a person's needs, preferences and goals of care. These must have been agreed with the person receiving care or by those acting in the person's best interests. Where care plans are made for someone who lacks capacity to participate in care planning, they may include reference to an advance statement, ADRT or Lasting Powers of Attorney that the person made before losing capacity, or to any other available information about what their views might have been.

Lasting powers of attorney (LPA)

An LPA is a statutory form of power of attorney created by the Mental Capacity Act. Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. The LPA replaces the Enduring Power of Attorney (EPA) the Enduring Powers of Attorney Act 1985. Unlike the EPA, this can extend to include health and welfare as well as property and affairs (see: www.dca.gov.uk/menincap/faq.htm).

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