Decision-making and mental capacity

NICE guideline: short version

Draft for consultation, December 2017

This guideline covers decision-making in people over 16. it aims to help health and social care practitioners support people to make their own decisions where they have the capacity to do so. It also helps practitioners to keep people who lack capacity at the centre of the decision-making process.

Who is it for?

- Health and social care practitioners working with people who may (now or in the future) lack mental capacity to make specific decisions
- Independent advocates, with statutory and non-statutory roles
- Practitioners working in services (including housing, education, employment, police and criminal justice) who may come into contact with people who lack mental capacity
- People using health and social care services who may (now or in the future) lack mental capacity to make specific decisions, as well as their families, friends, carers and other interested parties.

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the guideline's page on the NICE website. This includes the guideline committee's discussion and the evidence reviews (in the full guideline), the scope, and details of the committee and any declarations of interest.

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Context

This guideline aims to help health and social care practitioners in settings where they are supporting adults, aged 16 years and older, with decision-making activities. It helps to ensure that people are supported to make decisions for themselves when they have the mental capacity to do so, and where they lack mental capacity to make specific decisions they remain at the centre of the decision-making process.

This NICE guideline has been commissioned by the Department of Health as a result of historic concerns raised by the Care Quality Commission. The Care Quality Commission identified serious issues with the practical implementation of the Mental Capacity Act. This subject was subsequently reported on by a House of Lords Select Committee in 2014, adding further momentum towards improvement.

The recommendations are relevant when supporting adults who may in the future lose, or have already lost, mental capacity to make specific decisions about health care, including consenting to medical treatment; social care; or financial matters.

In doing so practitioners must comply with the statutory functions of the agencies they work for under the Mental Capacity Act 2005, Mental Health Act 2007, and Care Act 2014. They must also comply with all legislation, codes of practice and guidance relevant to their work. This guideline seeks to complement and build on these existing requirements, to support their implementation and drive improvements in the quality of support. Although it is particularly aligned with the Mental Capacity Act 2005, the guideline is not intended as a step by step guide to the implementation of the legislation. Guidance for decisions made under the Mental Capacity Act 2005 is published in the Mental Capacity Act Code of Practice.

The guideline focuses on the key areas of:

- Advance care planning – supporting people to make arrangements for a time when they may lack mental capacity to make decisions for themselves, so that their wishes, values and beliefs can guide and inform those decisions
- Supported decision-making – ensuring that people who have the mental capacity to make specific decisions for themselves are given the help and support they need to do so

- Assessment of mental capacity to make specific decisions at a particular time
- Best interests decision-making – using the provisions of the Mental Capacity Act to make decisions for a person who has been assessed as lacking mental capacity to make that specific decision for themselves; maximising the participation of that person in the decision-making; considering their wishes, values and beliefs; and ensuring appropriate access to independent advocacy services.

The guideline does not cover:

- decision-making activities and support for children under the age of 16
- Deprivation of Liberty Safeguards processes.

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Overarching principles

1.1.1 Service providers and responsible bodies should ensure that all practitioners undergo training to help them to apply the Mental Capacity Act 2005 and its Code of Practice. This includes role appropriate training for new staff, pre-registration, and continuing development and practice supervision for existing staff. Where appropriate, training should be interdisciplinary, involve experts by experience and include:

- the statutory principles of the Mental Capacity Act 2005
- the importance of seeking consent for the process of advance care planning
- how and when to have potentially difficult conversations about loss of autonomy, advance care planning or death
- required communication skills for building trust to supported decision-making
- clarity on roles and responsibilities
- the advantages, disadvantages and ethics of advance care planning, and how to discuss these with the person and their carers, family and friends
- condition-specific knowledge related to advance care planning, where appropriate
- the conduct of decision-specific capacity assessments
- the process of best interests decision-making in the context of section 4 of the Mental Capacity Act and associated guidance

- how to direct people to sources of advice and information.

1.1.2 All health and social care organisations should:

- develop local policy and guidance about which interventions, tools and approaches will be used to support decision-making
- identify or devise specific tools to help health and social care practitioners to assess the mental capacity of the people they are working with.

1.1.3 Co-develop policies and Mental Capacity Act training programmes with people who have experience of supported decision-making and of having their mental capacity assessed, and their carers, family and friends.

1.1.4 Practitioners should think about decision-making capacity every time a person is asked for consent, or to make a decision, during care and support planning (that is, not only as disagreement resolution).

1.1.5 When giving information about a decision to the person:

- it must be accessible, relevant, and tailored to the specific needs of the individual
- it should be sufficient to allow the person to make an informed choice about the specific decision in question
- it should be supported by tools such as visual materials, visual aids, communication aids and hearing aids, as appropriate.

1.1.6 Record and update information about people’s wishes, beliefs and preferences in a way that practitioners from multiple areas (for example care staff, paramedics) can access and update. This information should be used to inform advance planning, supported decision-making and best interests decision-making.

Using independent advocacy to support decision-making and assessment under the Mental Capacity Act

1.1.7 Commissioners should ensure that arrangements for the provision of independent advocacy include support for people to:

- enable them to make their own key decisions, for example, about their personal welfare, medical treatment, property or affairs
- facilitate their involvement in decisions that may be made, or are being made under the Mental Capacity Act.

This could be achieved through expansion of existing statutory independent advocacy roles and/or commissioning and provision of non-statutory independent advocacy.

1.1.8 Practitioners should tell people about advocacy services as a potential source of support for decision-making, and for those who lack capacity, a referral should be made to an independent mental capacity advocacy. Where statutory criteria are met, practitioners must refer to the relevant advocacy service. Otherwise, think about referral to non-statutory advocacy services which will be dependent on local commissioning arrangements.

1.1.9 Consider providing independent advocacy when there is a safeguarding concern.

1.1.10 Commissioners, public bodies and providers of independent advocacy services should work closely to ensure that:

- statutory duties on public bodies to refer to and involve independent advocacy are consistently adhered to and monitored **and**
- failures in the duty to refer to statutory independent advocacy are addressed.

1.1.11 Commissioners, using their powers, including under the Mental Capacity Act 2005, should work with public bodies and providers to increase investment in training for statutory independent mental capacity and other statutory advocates in key areas. This includes training:

- in communication with people who have minimal or no verbal communication **and**

- for Independent Mental Capacity Advocates to have expertise in specific areas that require additional skills and knowledge – for example working with people with acquired brain injury.

1.2 Supported decision-making

1.2.1 Ask the person how they want to be supported and who they would like to have involved in decision-making in accordance with Mental Capacity Act Code of Practice, principle 2.

1.2.2 Practitioners supporting a person's decision-making should build and maintain a trusting relationship with them.

1.2.3 Practitioners should take into account the wide range of factors that can have an impact on a person's ability to make a decision. These should include:

- the person's physical and mental condition
- the person's communication needs
- the person's previous experience (or lack of experience) in making decisions
- the involvement of others
- situational, social and relational factors
- cultural, ethnic and religious factors
- cognitive and emotional factors, or those related to symptoms.

They should use this knowledge to support the person's decision-making.

Providing information to support decision-making

1.2.4 Practitioners should clearly determine, at the start, what information they need to cover the salient details of the decision they are supporting the person to make. This will depend on the nature and complexity of the decision itself.

1.2.5 Offer accessible information to everyone involved in supporting decision-making. This should be about the process and principles of supported decision-making as well as about the specific decision.

1.2.6 When providing the person with information to support a particular decision:

- do so in line with the NHS Accessible Information Standard
- support them to identify, express and document their own communication needs
- ensure options are presented in a balanced and non-leading way.

1.2.7 Record the information that is given to the person during decision-making. Give the person an opportunity to review and comment on what is recorded and write down their views.

1.2.8 Consider tailored training programmes for the person, to provide information for specific decisions – for example sexual education programmes and medication management.

Supporting decision-making

1.2.9 Support people to communicate so that they can take part in decision-making. Use strategies to support the person's understanding and ability to express themselves in accordance with sections 3.10 and 3.11 of the Mental Capacity Act Code of Practice.

1.2.10 Support the person with decision-making even if they wish to make an unwise decision.

1.2.11 Involve significant and trusted people in supporting decision-making, in line with the person's preferences. Have due regard for the principle of confidentiality set out in section 3.15 of the Mental Capacity Act Code of Practice. Ensure that this support is based on the person’s wishes and preferences and is free from coercion or undue influence. If there are no significant trusted people, think about involving an advocate, particularly if the advocate has worked with the person before.

1.2.12 Practitioners should talk to the person and their carer, family and friends, as appropriate, about the potential consequences of supported decision-making. These could include increased autonomy, being better informed, sharing decisions with people interested in their welfare, talking about potentially upsetting issues including declining health or end of life, feeling overwhelmed with having to make a difficult decision at a difficult time and dealing with conflicting opinions.

1.2.13 Give people time during the decision-making process to communicate their needs and feel listened to. Be aware that this may mean meeting with the person for more than 1 session.

1.2.14 Health and social care practitioners should increase the involvement of people and their carers, family and friends in decision-making discussions by using a range of interventions focused on improving shared decision-making and supported decision-making.

1.2.15 Where possible, ensure that the same practitioner provides continuous support to the person as they make different decisions at different points in time.

1.2.16 Health and social care practitioners should refer to other services (for example speech and language therapy and clinical psychology) that could help support decision-making when the person's level of need requires specialist input. This is especially important:

- when the obstacles to decision-making are complex **or**
- if there is a dispute between those making and supporting decisions **or**
- if the consequences of the decision would be significant (for example a decision about a highly complex treatment which carries significant risk).

1.2.17 Practitioners should make a written record of the decision-making process including:

- steps taken to help the person make the decision
- individuals involved in supporting the decision
- information given to the person
- key considerations for the person in making the decision

- the decision reached
- needs identified as a result of the decision
- any further actions arising from the decision.

1.2.18 Organisations should ensure they can demonstrate that they monitor compliance with principle 2, section 1 (3) of the Mental Capacity Act.

1.3 Advance care planning

Advance care planning is one way of discussing and setting out a person's wishes in relation to future care and treatment decisions. Other ways of doing this include appointing a Lasting Power of Attorney or making an advance decision to refuse treatment.

Helping practitioners to undertake advance care planning

1.3.1 Healthcare commissioners and providers should:

- develop standard protocols and plans for joint working and sharing of information on advance care plans between practitioners, people and families
- commission training on advance care planning
- demonstrate that protocols are in place and training is available by including advance care planning in audits.

Providing information about advance care planning

1.3.2 Offer people verbal and written information about advance care planning, including how it relates to their own circumstances and conditions. All information sharing must fulfil the requirements of the NHS Accessible Information Standard.

1.3.3 If a person has recently been diagnosed with a long-term or life-limiting condition, give them information on:

- their condition
- the process of advance care planning
- how they can change their minds or amend the decisions they make while they retain capacity to make them

- services that will help in advance care planning.

Developing advance care plans collaboratively

1.3.4 All health and social care practitioners who come into contact with the person after diagnosis should help them to make an informed choice about participating in advance care planning. If they wish to do so, practitioners should facilitate this.

1.3.5 Offer the person a discussion about advance care planning:

- at the most suitable time once they receive a diagnosis likely to make advance care planning useful **and**
- at other times, allowing people to think through and address different issues in their own time.

1.3.6 Practitioners involved in advance care planning should ensure that they have access to information about the person's medical condition that helps them to support the advance care planning process. It is the practitioner's responsibility to identify what information they need.

1.3.7 When approaching discussions about advance care planning, health and social care practitioners should:

- be sensitive, recognising that some people may prefer not to talk about this, or prefer not to have an advance care plan
- be prepared to postpone discussions until a later date, if the person wishes
- recognise that people have different needs for knowledge, autonomy and control
- talk about the purpose, advantages and disadvantages of this type of planning
- consider the use of checklists to support discussions.

1.3.8 If the person has given consent for carers, family and friends to be involved in discussions about advance care planning, practitioners should take reasonable steps to include them.

1.3.9 Health and social care practitioners should help everyone to take part in advance care planning and co-produce their advance care plan if they choose to have one (including people with fluctuating or progressive conditions). They should:

- work with the person to identify any barriers to their involvement, and investigate how to overcome these
- help them to communicate by providing communication support appropriate to their needs (for example, communication aids, advocacy support, interpreters, specialist speech and language therapy support, involvement of family members or friends).

1.3.10 During advance care planning discussions, practitioners should:

- take into account the person's history, social circumstance, wishes and feelings, values and beliefs (including religious, cultural and ethnic factors), aspirations and any other factors they may consider important to them
- help the person to anticipate how their needs may change in future.

1.3.11 In line with the Mental Capacity Act Code of Practice practitioners should ensure that:

- all notes made on advance care planning are contemporaneous **and**
- the notes are agreed with the person using services at the time **and**
- permission is sought to share the information with other people.

1.3.12 Provide the person with an accessible document that records their wishes, beliefs and preferences in relation to advance care planning and which they may take with them to show different services. It may include who the person wants to have involved in decision-making or their preferences for issues such as treatment, support or accommodation.

1.3.13 Practitioners should share the advance care plan in a clear and simple format with everyone involved in the person's care, if the person has given consent.

1.3.14 Practitioners should ensure that information about a person’s advance care plan is, with their consent, transferred between services when their care provider changes.

1.3.15 Review advance care plans at reviews of treatment or support, while the person has capacity, and amend as necessary, if the person wishes.

1.3.16 When people are reaching the end of life, give them the opportunity to review or develop an advance care plan if they haven't already done so.

Joint crisis planning

1.3.17 Offer joint crisis planning to anyone who has a mental disorder with an assessed risk of relapse or deterioration and who is in contact with specialist mental health services. The offer should be documented and, if the person accepts it, the plan should be recorded.

1.4 Assessment of mental capacity

1.4.1 Health and social care organisations should monitor and audit the quality of mental capacity assessments.

1.4.2 Consider including people’s views and experiences in data collected for monitoring an organisation’s capacity assessment activity.

1.4.3 Organisations should ensure that assessors should be able to seek advice from people with specialist condition-specific knowledge to assist them to assess capacity – for example clinical psychology and speech and language therapists.

1.4.4 Organisations with responsibility for accessible care plans should ensure that they record that the person consents to the care plan and identifies if they are unable to consent.

1.4.5 Organisations should have clear policies or guidance on how to resolve disputes about the outcome of the capacity assessment.

Assessing capacity to make decisions

1.4.6 Assess mental capacity in line with the process set out in section 3 of the Mental Capacity Act. Be aware that the process applies to all decisions, large and small, though the measures adopted and recording will be proportionate to the complexity and significance of that decision.

1.4.7 Assessors should have sufficient knowledge of the person being assessed to be able to:

- provide tailored information, including information about the consequences of making the decision or of not making the decision
- know whether the person would be likely to attach particular importance to any key considerations relating to the decision.

1.4.8 Practitioners should be aware that people may find capacity assessments distressing, particularly if they strongly disagree that they lack capacity.

1.4.9 In preparing for an assessment, the assessor should be clear about:

- the person's options
- what information, knowledge and experience the person needs about their options
- what the person needs to understand, retain, weigh up, use and communicate in relation to this decision, including the use of communication aids
- how to allow enough time for the assessment, giving people with communication needs more time if needed
- how to assess capacity in a way that is respectful and preserves the person's dignity
- how to make reasonable adjustments including, for example, delaying the assessment until a time when the person feels less anxious or distressed
- how to ensure that the assessment takes place at a location and in an environment and through a means of communication with which the person is comfortable

- whether involving people with whom the person has a trusted relationship would help the assessment decision.

1.4.10 The assessor should take into account the person’s decision-making history when preparing for an assessment.

1.4.11 Practitioners must take all reasonable steps to ensure that the process of capacity assessment does not cause a person distress or harm.

1.4.12 Health and social care practitioners should take a structured, person-centred, empowering and proportionate approach to assessing a person's capacity to make decisions, including everyday decisions. The assessment should show where a person has capacity and where they do not. However, they should be aware that for certain areas, such as voting, there is no legal requirement to establish capacity.

1.4.13 As stated in principle 2 of the Mental Capacity Act, health and social care practitioners must take a collaborative approach to assessing capacity, where possible, working with the person to produce a shared understanding of what may help or hinder their communication and decision-making. This may include involving an interpreter, speech and language therapist, someone with sensory or specialist communication skills, clinical psychologists or other professionals to support communication during an assessment of capacity.

1.4.14 Where the individual has identified communication needs the assessor should also think about using communication tools to help with the assessment. Where tools are used, their use should be recorded as recommended by their employer or organisation.

1.4.15 Health and social care practitioners should work with the person where possible and where consent has been provided to identify people they should liaise with about how to carry out the capacity assessment. This could include support workers, carers, family and friends and advocates. They should use the information gathered to help create a complete picture of the person’s functional capacity to make a specific decision and act on it.

1.4.16 The assessor should record any differing views on capacity that they are aware of and how the outcome of their assessment addresses or answers those concerns.

1.4.17 Health and social care practitioners should conduct an assessment at a level proportionate to the decision being made.

1.4.18 If a person refuses to engage in a capacity assessment, the assessor should give them a choice about who else could be involved or any other changes that can be made to help them.

1.4.19 Practitioners should use accessible language or an accessible format to tell the person:

- that their capacity is being assessed **and**
- the outcome of that assessment.

1.4.20 Practitioners should be aware that people with executive dysfunction – for example, people with traumatic brain injury – may be at risk of having their decision-making capacity overestimated. Structured assessments of capacity should be supplemented by real-world observation of the person’s functioning and ability.

1.4.21 When assessing capacity, practitioners should take account of principle 3 of the Mental Capacity Act and not assume that the person lacks capacity because they have made a decision that the practitioner perceives as risky or unwise.

1.4.22 Practitioners should understand that the person has to retain the most important points from a discussion only for the purposes of making the specific decision in question, and for the period of time necessary to make the decision.

1.4.23 Practitioners should be aware that if a person is judged to lack insight into their condition, this does not necessarily reflect lack of capacity to make a decision, depending on the nature of the decision being made.

1.4.24 If a practitioner assesses a person as lacking capacity, they must document this, together with the evidence that led to this conclusion.

1.4.25 The person assessing mental capacity should record:

- the practicable steps they have taken to help the person make the relevant decision for themselves and any steps taken by other parties involved
- if the person has capacity but makes an unwise decision
- if the person has capacity and gives valid consent.

1.4.26 All assessments of mental capacity must be recorded at an appropriate level to the complexity of the decision being made, as a stand-alone assessment, in patient notes or in care plans following local policy.

1.4.27 Provide the person with emotional support and information after the assessment, being aware that the assessment process could cause distress, disempowerment and alienation.

1.5 Best interests decision-making

There are some decisions that cannot be made under the provisions of best interests decision-making in the Mental Capacity Act. For example, a person's capacity to vote does not need to be established and best interests decisions cannot be made on the issue. Other examples of excluded decisions include sexual activity and divorce or in circumstances where an advance decision to refuse treatment has been made.

Helping practitioners to deliver best interests decision-making

1.5.1 In line with the Mental Capacity Act 2005, practitioners must not hold a best interests discussion until a capacity assessment has been conducted, and a decision made and recorded that a person lacks capacity to make the decision in question (except in emergency situations).

1.5.2 Ensure that everyone involved in the best interests decision-making process knows who the decision maker is.

1.5.3 Regardless of whether a person has capacity to make a specific decision, practitioners must take all reasonable steps to help them be involved in making decisions.

1.5.4 Health and social care services should ensure that best interests decisions are being made in line with the Mental Capacity Act.

1.5.5 Health and social care services should:

- implement a service-wide process for recording best interests decisions and ensure that staff are aware of this **and**
- have clear systems in place to support practitioners to identify and locate any relevant written statement made by the person when they had capacity, at the earliest possible time.

1.5.6 Health and social care services should have clear systems in place to obtain and record the person's wishes and feelings in relation to a relevant decision, as well as their values and beliefs, or any other factor that would be likely to influence such a decision. Services should:

- have mechanisms in place to make these available in a timely way
- ensure that the person's personal history and personality is represented in the above.

1.5.7 Ensure that knowledge of the Independent Mental Capacity Advocate role in best interests decision-making is embedded in all Mental Capacity Act training, including introductions to health and social care and in preregistration training.

Helping and supporting family members in respect of best interests decision-making

1.5.8 Health and social care practitioners should work with carers, family and friends to find out the wishes and preferences of the person in relation to the specific decision and to understand the person's decision-making history.

1.5.9 If a decision maker is calling a best interests meeting, they should:

- involve the person themselves, unless a decision is made that it would be harmful for them to attend the meeting
- consult carers, family and friends about the meeting in advance, giving them time to ask questions and give their opinions, for example about how to include the person in decision-making
- make it clear that the purpose of the meeting is to make a decision
- provide all information in an accessible format.

1.5.10 Practitioners should access information about the person informally if needed, as well as through any formal meetings.

1.5.11 The decision maker should ensure that all people concerned with the best interests decision are able to be fully involved. This means making sure they have their views encouraged, respected and heard.

Undertaking best interests decision-making

1.5.12 When making a decision on behalf of the person who lacks capacity, practitioners should use a range of approaches, as needed, to ensure that people's best interests are met, if they lack capacity. This might include:

- a less formalised approach for day-to-day decisions – that is, recurring decisions being recorded in support or care plans
- formal best interests meetings for significant decisions
- a decision-making approach appropriate to the circumstances and personalised to the individual, making all reasonable adjustments.

1.5.13 Carers and practitioners must wherever possible find out the views and beliefs of the person in the first instance and should be able to demonstrate that they have done so. For example:

- recording in care records what steps have been taken, including reasons why this has not been done
- identifying which steps have been taken to find out the person’s wishes.

1.5.14 Health and social care organisations should provide toolkits to support staff to carry out and record best interests decisions. These toolkits should include:

- a clear definition of the decision to be made
- steps that have been taken to help the person make the decision themselves
- a current assessment concluding that the person lacks the capacity to make this decision
- any other decision-making instruments that would prevent best interests decision-making occurring (for example a Lasting Power of Attorney, advance decisions, court orders)
- a clear record of the person's wishes, feelings, cultural preferences, values and beliefs, including advanced statements
- a prompt to consult interested parties (for example families, friends and Independent Mental Capacity Advocate and relevant professionals) and a record of who they are
- advice about the degree of formality needed for the decision being made, for example a best interests meeting
- guidance about recording best interests process and decision including a balance sheet of risks and benefits.

1.5.15 Anyone responsible for leading best interests decision-making must consider how best to involve the person in the process and document the steps taken.

1.5.16 Practitioners must think about whether a decision can be delayed until the person has capacity to make a decision and allow all practicable steps to be taken in the interim to help them gain capacity.

1.5.17 When making best interests decisions, explore whether there are less restrictive options that will meet the person's needs. Take into account:

- what the person would prefer, including their wishes and feelings, based on past conversations, actions, choices, values or known beliefs
- what decision the person who lacks capacity would have made if they were able to do so
- all the different options
- the restrictions and freedoms associated with each option
- the likely risks associated with each option (including the potential negative effects on the person who lacks capacity to make a decision – for example trauma or disempowerment).

1.5.18 When determining best interests the decision maker must establish whether the decision will deprive the person of their liberty and, if so, ensure that the appropriate legal authority is obtained in a timely manner.

1.5.19 When an Independent Mental Capacity Advocate has been instructed they should be involved in the process until a decision has been made and implemented fully.

1.5.20 Record best interests decisions in a way that is proportionate to its complexity, for example in a best interests toolkit or individual care record. As people’s circumstances change, review the decisions regularly to ensure that they remain in a person’s best interests.

1.5.21 After the outcome has been decided, the decision maker should ensure that it is recorded and communicated to everyone involved and that there is opportunity for all participants to offer feedback or raise objections.

1.5.22 If there is a dispute about a person’s best interests, resolve this, where possible, before the decision is implemented – for example through further meetings or mediation. If this cannot be resolved locally, refer to the Court of Protection to determine the person’s best interests.

1.5.23 Decision makers should specify a timely review of the implementation of the actions resulting from the best interests decision. If the review establishes that the best interests decision was not successfully actioned, the decision maker should take suitable steps such as:

- convening a multi-agency meeting to resolve issues leading to the best interests decision not being successfully implemented, **or**
- reassessing and making a new best interests decision that is more achievable, **or**
- taking steps to refer the decision to the Court of Protection, **or**
- re-considering whether any further action is appropriate.

Terms used in this guideline

Advance care planning

Advance care planning (ACP) with people who may lack mental capacity now or in the future, is a voluntary process of discussion about future care between the individual and their care providers. If the individual wishes, their family and friends may be included in the discussion. With the individual’s agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care.

Advance decisions to refuse treatment (living wills)

An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT or a living will) is a decision people can make now to refuse a specific type of treatment at some time in the future. It is legally binding and considered valid if the person is aged 18 or over and had the capacity to make, understand and communicate the decision when it was made.

Advance directive

An advance directive is a way of making a person's views known if he or she should become mentally incapacitous of giving consent to treatment, or making informed choices about treatment, at some future time.

Consent

When a person who may lack mental capacity now or in future gives permission to someone to do something for them.

Duty of care

Duty of Care is defined simply as a legal obligation to: always act in the best interests of people who may lack capacity, not act or fail to act in a way that results in harm and act within your competence and not take on anything you do not believe you can safely do.

Joint crisis planning

A Joint Crisis Plan enables the individual and services to learn from experience and make plans about what to do in the event of another crisis. It is developed by seeking agreement between the person who may lack mental capacity now or in future and their mental health team about what to do if they become unwell in the future.

Lasting Power of Attorney

A Lasting Power of Attorney (LPA) allows the person to give someone they trust the legal power to make decisions on their behalf in case they become unable to make decisions for themselves. The person who makes the LPA is known as the 'donor' and the person given the power to make decisions is known as the 'attorney'.

Mental Capacity Act 2005

The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over and covers people in England and Wales who can't make some or all decisions for themselves.

Mental Health Act 1983

The Mental Health Act (MHA) 1983 is a piece of legislation (in England and Wales) which tells people with mental health problems what their rights are regarding: assessment and treatment in hospital, treatment in the community and pathways into hospital, which can be civil or criminal.

Participation

When a person takes part in decisions about things that affect them and other people. This may be about day to day life activities of people who may lack mental capacity such as what to eat or how to spend time.

Practicable steps

‘Practicable steps’ links to principle 2 of the Mental Capacity Act, which states that ‘all practicable steps’ should be taken to help a person make a decision before being treated as though they are unfit to make the decision. There are obvious steps one might take, including the use of specific types of communication equipment or types of languages such as Makaton or the use of specialist services, such as a speech and language therapist. Practicable steps could also involve ensuring the best environment in which people are expected to make often significant decisions – for example giving them privacy and peace and quiet or ensuring they have a family member to provide support during decision making, if this is their wish.

Proxy

When authority is given to a person to act for someone else, such as a person authorized to act on behalf of someone who lacks mental capacity to make decisions.

Psychiatric advance directive

Psychiatric advance directives (PAD) are legal instruments that allow competent individuals to appoint proxies and specify how treatment decisions should be made in the event they become incompetent. A PAD describes treatment preferences, or names a person to make treatment decisions, should the person with a mental health condition be unable to make decisions.

Substitute decision-making

Decisions are made on behalf of someone lacking capacity by a person permitted to do so under the law. This 'Substitute Decision Maker' must be willing, available and capable of taking on this responsibility.

Supporter

Supporters are people who support someone who lacks decision making mental capacity in this specific context.

For other social care terms see the Think Local, Act Personal Care and Support Jargon Buster.

Putting this guideline into practice

[This section will be finalised after consultation]

NICE has produced tools and resources [link to tools and resources tab] to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Ensuring a greater focus on supported decision making. Underpinned by Principles 1 and 2 of the MCA, supported decision making is fundamental to effective implementation of the legislation and to empowering individuals who have difficulties making their own decisions independently. Organisations need local policies and local training, and to ensure that their policies, procedures and forms for capacity assessment and best interests are congruent with an emphasis on supported decision making.
- Ensuring a workforce that is well-trained and well-developed in supporting decision making and in implementing the MCA, with an awareness of the nature and functional impact of the impairments that give cause to question whether the MCA applies and how it should be assessed. Practitioners need to understand the nature of the person’s condition; how that impairment/condition affects decision making; how their decision making can be supported; and what help to seek and from where. Training must be delivered with input from people who use services. It should start at pre-registration level and continue throughout an individual’s employment, particularly whenever legislation is updated. Ensuring training is delivered to all health and social care practitioners to a minimum standard will be difficult.

- Access to independent advocacy. There is consistent evidence of a lack of understanding amongst commissioners, public bodies, practitioners and people who use services of the critical role independent advocacy can play in upholding rights and providing an ultimate safeguard from abuse. Consequently, ensuring the recommendations relating to independent advocacy are acted upon will be a challenge of communication and persuasion beyond statutory requirements, and they will require a concerted effort to implement effectively.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations

and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

More information

The following sentence is for post-consultation versions only – editor to update hyperlink with guideline number]You can also see this guideline in the NICE pathway on [pathway title]. [Note: this should link to the specific topic pathway, not to the overarching one.]

To find out what NICE has said on topics related to this guideline, see our web page on adult social care.

[The following sentence is for post-consultation versions only – editor to update hyperlink with guideline number]See also the guideline committee's discussion and the evidence reviews (in the full guideline), and information about how the guideline was developed, including details of the committee.

Recommendations for research

The guideline committee has made the following recommendations for research. The committee's full set of research recommendations is detailed in the full guideline.

1 Training and support for practitioners

What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions?

Why this is important

The guideline committee agreed that effective training and support on the Mental Capacity Act and how to apply its principles in practice is essential for practitioners working with people who may lack capacity to make a decision. The evidence the committee reviewed often referred to training and support, but very few studies looked at this area specifically. Some of the evidence suggested that practitioners did not always understand the requirements of the Act and that their practice did not always comply with these. Much of the evidence was of low to moderate quality and there was no good quality evidence evaluating the effectiveness of training and support in relation to the Act.

A better understanding of what training and support increases compliance with the Act could improve outcomes for people who may lack capacity to make a decision. Qualitative studies exploring the current barriers to delivering effective training and support and the challenges that practitioners face in using this learning in practice would help to inform measures for improvement.

Comparative studies are needed to determine the effectiveness and cost effectiveness of different approaches for delivering training and support to practitioners. Evaluating whether these increase compliance with the requirements of the Act would be especially informative.

2 Targeted interventions to support and improve decision-making capacity for treatment

What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups?

Why this is important

Evidence suggests that tailored approaches such as speech and language therapy and psychological and psychosocial interventions can lead to improvements in a person’s capacity to make a decision. However, the studies were limited in number and generally of low quality. The guideline committee agreed that further research in this area would be valuable, particularly in relation to the decision-making capacity for treatment of people with dementia, a learning disability, a head injury or a mental illness. Interventions should be designed to address the needs of these cohorts and underpinned by a comprehensive understanding of the needs associated with each condition.

High-quality comparative studies evaluating the effectiveness of these different types of interventions are needed to help ensure that practitioners refer people to the most appropriate programmes. This would empower people to make their own decisions about their treatment wherever possible.

3 Advocacy and support for decision-making on the presumption of capacity

What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?

Why this is important

The evidence reviewed did not include any studies that evaluated the effectiveness or acceptability of advocacy as a means of supporting people who may lack capacity to make a decision. However, the guideline committee thought that this was an area in which emerging practice shows promise. Expert witness testimony highlighting the Swedish ‘personal Ombuds’ peer support scheme also suggested that further research into the use of advocacy as a means of supporting decision-making might be useful. Although provision for advocacy already exists for people assessed as lacking capacity to make a decision (through an Independent Mental Capacity Advocate), this type of support could also benefit people who, although retaining capacity, may need support to make a decision.

High-quality mixed methods studies with a controlled effectiveness component (preferably randomised) are needed to evaluate the effectiveness and cost effectiveness of advocacy as a tool to support the decision-making of people who may lack capacity to make a decision (on the presumption of capacity). These should include a qualitative component that explores whether advocacy as a means of support to make decisions is acceptable to people using services and valued by practitioners.

4 Using mental capacity assessment tools to assess capacity

What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005?

Why this is important

There is a lack of evidence from the UK on the effectiveness and acceptability of approaches to capacity assessment that are in line with the meaning of mental capacity as outlined in the Mental Capacity Act. Although the guideline committee reviewed some evidence evaluating the accuracy of specific tools, these are not necessarily compatible with the definition of mental capacity.

There is a need for high-quality mixed methods studies that evaluate the accuracy or effectiveness of mental capacity assessment tools that are compliant with the Mental Capacity Act. These should include a qualitative component that explores whether such tools and approaches are acceptable to people using services and valued by practitioners.

5 Components of a mental capacity assessment

What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?

Why this is important

There is a lack of clarity about the way in which practitioners conduct assessments of capacity to make a decision and how the process and outcomes of these assessments are being recorded. The guideline committee reviewed the small amount of available evidence suggesting that practice may be improved through the use of standardised forms. However, these studies tended to be poorly designed – for example, relying on audit data.

There is a need for high-quality research that explores in detail how to conduct an effective capacity assessment. This could include studies comparing one-off capacity assessments with multiple assessments, and comparative studies evaluating whether certain approaches or tools are appropriate.

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