



Decision-making and mental capacity

NICE guideline

Published: 3 October 2018 nice.org.uk/guidance/ng108

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should <u>assess and reduce the environmental impact of implementing NICE recommendations</u> wherever possible.

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Overview

This guideline covers decision-making in people 16 years and over who may lack capacity now or in the future. 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.

This guideline should be read in conjunction with the Mental Capacity Act 2005. It is not a substitute for the law or relevant Codes of Practice.

It does not cover Deprivation of Liberty Safeguards processes.

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.

Context

The Care Quality Commission (CQC) estimates that around 2 million people in England and Wales may lack the capacity to make certain decisions for themselves at some point because of illness, injury or disability. The Mental Capacity Act 2005 was designed to empower and protect individuals in these circumstances. However, the CQC identified serious issues with the practical implementation of the Act. This subject was subsequently reported on by a House of Lords Select Committee in 2014, adding further momentum towards the need for improvement in practice.

It is in this context that the Department of Health commissioned this guideline, which makes recommendations for best practice in assessing and supporting people 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 the mental capacity to make specific decisions, they remain at the centre of the decision-making process. The guideline supports the empowering ethos and principles introduced by the Mental Capacity Act 2005 and explained in the Code of Practice. These are:

- 1. A person must be assumed to have capacity unless it is established that he lacks capacity.
- 2. 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.
- 3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- 4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- 5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The guideline helps health and social care practitioners to implement these principles and improve the quality of the decision-making support they provide. It applies to a range of decisions, including care, support and treatment, financial matters and day-to-day living, and aims to be proportionate, recognising that practitioners may need to provide rapid assistance in emergencies.

The guideline is based on the best available evidence from research, expert testimony, expert

consensus and developments in law. It also identifies where evidence is lacking and makes recommendations for future research. The recommendations for research address the following: training and support for practitioners, interventions to support and improve decision-making capacity for treatment, advocacy and support for decision-making, mental capacity assessment tools, and the components of a mental capacity assessment.

The guideline applies to, and reinforces, the assessment, support and exercise of capacity whenever this is required by legislation, including but not confined to the Mental Capacity Act 2005, Mental Health Act 1983 and Care Act 2014. Practitioners should use the guideline to enhance the specific requirements of such legislation, codes of practice and other guidance relevant to their work. The guideline does not seek to repeat these, or be a step-by-step guide to their implementation.

Decision-making and mental capacity can be a particularly complex area for young people aged 16–18 years. A detailed overview of the legal provisions relating to the care and treatment of young people falls outside the scope of this guideline. However, the <u>Children Act 1989</u> and <u>Children and Families Act 2014</u> interface with the other Acts referred to above and in some circumstances provide an additional framework for the way in which young people should be involved in decision-making about their lives.

Where a young person over 16 is found to lack capacity to make a particular decision, it is important that the best interests process under the Mental Capacity Act 2005 is followed and that young people are as involved as possible in decisions made on their behalf.

In some cases, it will be possible for someone with parental responsibility to make a decision on behalf of the young person who lacks capacity. However, this will not always be appropriate. In these circumstances, the Mental Capacity Act Code of Practice should be followed to determine who should lead the best interests process.

Effective safeguarding identification and processes must always be followed, with acute awareness necessary among practitioners about the more subtle forms of abuse such as coercion. Practitioners must always refer to local safeguarding procedures.

The guideline focuses on the following key areas:

- advance care planning
- supporting decision-making
- assessment of mental capacity to make specific decisions at a particular time

• best interests decision-making for individuals who are assessed as lacking capacity to make a particular decision at a particular time.

The structure of the guideline is as follows:

- <u>Section 1.1</u> overarching principles
- <u>Section 1.2</u> supporting decision-making
- <u>Section 1.3</u> advance care planning
- Section 1.4 assessment of mental capacity
- <u>Section 1.5</u> best interests decision-making.

Sections 1.2, 1.4 and 1.5 each begin by citing the relevant principle from the Mental Capacity Act 2005 along with an explanatory note about the practical application of the principle. This helps to ensure that the recommendations are interpreted within the framework of the Mental Capacity Act and Code of Practice.

The guideline does not cover:

- decision-making activities and support for children under 16 years
- the issue of deprivation of liberty and the 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 <u>your care</u>.

<u>Making decisions using NICE guidelines</u> 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

Recommendations for service providers and commissioners

- 1.1.1 Service providers and commissioners should ensure that practitioners undergo training to help them to apply the Mental Capacity Act 2005 and its Code of Practice. Training should be tailored to the role and responsibilities of the practitioner and cover 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 <u>consent</u>, and how to proceed if a person might lack capacity to give or refuse their consent to any proposed intervention
 - how and when to have potentially difficult conversations about loss of autonomy, advance care planning or death
 - required communication skills for building trust and working with people who may lack capacity
 - clarity on roles and responsibilities
 - the advantages, challenges and ethics of advance care planning, and how to discuss these with the person and their carers, family and friends
 - the processes and law surrounding <u>advance decisions to refuse treatment</u> and <u>lasting</u> <u>powers of attorney/court appointed deputies</u>
 - condition-specific knowledge related to advance care planning, where appropriate
 - the conduct of decision- and time-specific capacity assessments

- the process of best interests decision-making in the context of <u>section 4</u> of the Mental Capacity Act 2005 and associated guidance
- the role of Independent Mental Capacity Advocates in best interests decision-making
- 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 assess where appropriate and necessary the mental capacity of the people they are working with and audit the tools against adherence to the Mental Capacity Act Code of Practice
 - train relevant practitioners in the use of these tools.
- 1.1.3 Co-develop policies and Mental Capacity Act 2005 training programmes with people who have experience of supported decision-making and of having their mental capacity assessed, and their carers, family and friends.

Recommendations for individual practitioners

- 1.1.4 Practitioners involved in making decisions regarding individuals who lack capacity or supporting decision-making in individuals who have capacity must follow the 5 key principles set out in section 1 of the Mental Capacity Act 2005. As a starting point they must assume capacity unless there is evidence to suggest an assessment is required.
- 1.1.5 When giving information about a decision to the person:
 - it must be accessible, relevant and tailored to their specific needs
 - 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 past and present wishes, beliefs and preferences in a way that practitioners from multiple areas (for example care and support staff, paramedics) can access and update. This information should be used to inform advance planning, supported decision-making and best interests decision-making.

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

- 1.1.7 Practitioners should tell people about advocacy services as a potential source of support for decision-making, including:
 - enabling them to make their own key decisions, for example, about their personal welfare, medical treatment, property or affairs
 - facilitating their involvement in decisions that may be made, or are being made under the Mental Capacity Act 2005.
- 1.1.8 As a minimum, <u>independent advocacy</u> must be offered by local authorities as described in the <u>Care Act 2014</u>, <u>Mental Capacity Act 2005</u> and <u>Mental Health</u> Act 2007.
 - [This recommendation is adapted from the NICE guideline on <u>learning</u> <u>disabilities and behaviour that challenges: service design and delivery</u>]
- 1.1.9 Consider expanding the commissioning of statutory Independent Mental Capacity Advocates.
- 1.1.10 Commissioners, public bodies and providers of statutory advocacy services should work closely to ensure that:
 - statutory duties on public bodies to refer to and involve advocacy are consistently adhered to and monitored and
 - failures in the duty to refer to statutory advocacy are addressed.
- 1.1.11 Relevant commissioners and providers should work with public bodies and providers to increase investment in training for statutory independent mental capacity and other statutory advocates in key areas, in order to ensure they are able to support:

- people who have communication difficulties and
- Independent Mental Capacity Advocates to have expertise in specific areas that
 require additional skills and knowledge for example working with people with
 impaired executive function arising from acquired brain injury, mental illness, dementia
 or other illness.

1.2 Supporting decision-making

'A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.' (Principle 2, section 1(3), Mental Capacity Act 2005)

Principle 2 of the Mental Capacity Act 2005 requires practitioners to help a person make their own decision, before deciding that they are unable to make a decision. Supporting decision-making capacity effectively requires a collaborative and trusting relationship between the practitioner and the person. It does not involve trying to persuade or coerce a person into making a particular decision, and must be conducted in a non-discriminatory way. It requires practitioners to understand what is involved in a particular decision, and to understand what aspects of decision-making a person may need support with, and why.

This may mean helping a person with their memory or communication, helping them understand and weigh up the information relevant to a decision, or helping to reduce their distress. Various ways to support decision-making capacity are described in Chapter 3 of the Mental Capacity Act 2005 <u>Code of Practice</u>.

- 1.2.1 Find out from the person how they want to be supported in decision-making in accordance with principle 2 of the Mental Capacity Act 2005. If they would like someone to support them, find out from the person who needs support who this should be. Be aware of the possibility that the nominated person may be exercising undue influence, duress or coercion regarding the decision, and take advice from a safeguarding lead if there is a concern.
- 1.2.2 At times, the person being supported may wish to make a decision that appears unwise. As confirmed by the third key principle of the Mental Capacity Act 2005, a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision.
- 1.2.3 Practitioners supporting a person's decision-making should build and maintain a trusting relationship with the person they are supporting.

- 1.2.4 Practitioners should take a personalised approach, accounting for any reasonable adjustments and 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 health condition
 - the person's communication needs
 - the person's previous experience (or lack of experience) in making decisions
 - the involvement of others and being aware of the possibility that the person may be subject to undue influence, duress or coercion regarding the decision
 - situational, social and relational factors
 - cultural, ethnic and religious factors
 - cognitive (including the person's awareness of their ability to make decisions), emotional and behavioural factors, or those related to symptoms
 - the effects of prescribed drugs or other substances.

They should use this knowledge to develop a shared and personalised understanding of the factors that may help or hinder a person's decision-making, which can be used to identify ways in which the person's decision-making can be supported.

Providing information to support decision-making

- 1.2.5 At the start of the decision-making process, practitioners should clearly determine what information they need to cover the <u>salient</u> details of the decision they are supporting the person to make. This will depend on the nature and complexity of the decision itself.
- 1.2.6 Offer tailored, accessible information to the person being supported. This should be about the process and principles of supported decision-making as well as about the specific decision.
- 1.2.7 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 that options are presented in a balanced and non-leading way.
- 1.2.8 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.
- 1.2.9 Consider tailored training programmes for the person, to provide information for specific decisions for example sexual education programmes and medication management.

Supporting decision-making

- 1.2.10 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 paragraphs 3.10 and 3.11 of the Mental Capacity Act Code of Practice.
- 1.2.11 Involve significant and trusted people in supporting decision-making, in line with the person's preferences and:
 - have due regard for the principle of confidentiality set out in paragraph 3.15 of the Mental Capacity Act Code of Practice
 - ensure that this support is free from coercion or undue influence, for example that it does not undermine the person's ability to understand, retain, use and weigh information and express a choice.
 - If there are no significant trusted people, or no-one willing to take on this role, think about involving an advocate.
- 1.2.12 Practitioners should be aware of the pros and cons of supporting decision-making and be prepared to discuss these with the person concerned. The benefits could include increased autonomy, being better informed and sharing decisions with people interested in their welfare. However, practitioners should also be aware that talking about potentially upsetting issues including declining health or end of life can be potentially distressing, and a person may feel overwhelmed with having to make a difficult decision at a difficult time and having to deal with possibly 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 Practitioners should increase the person's involvement in decision-making discussions by using a range of interventions focused on improving supported decision-making.
- 1.2.15 Where possible and relevant, 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, clinical psychology and liaison psychiatry) that could enable the person to make their decision when their level of need requires specialist input. This is especially important:
 - when the person's needs in relation to decision-making are complex
 - if the consequences of the decision would be significant (for example a decision about a highly complex treatment that carries significant risk).
- 1.2.17 Practitioners should make a written record of the decision-making process, which is proportionate to the decision being made. Share the record with the person and, with their <u>consent</u>, other appropriate people. Include:
 - what the person is being asked to decide
 - how the person wishes to be supported to make the decision
 - steps taken to help the person make the decision
 - other people involved in supporting the decision
 - information given to the person
 - whether on the balance of probabilities a person lacks capacity to make a decision
 - key considerations for the person in making the decision
 - the person's expressed preference and the decision reached

- needs identified as a result of the decision
- any further actions arising from the decision
- any actions not applied and the reasons why not.
- 1.2.18 Organisations should ensure they can demonstrate compliance with principle 2, section 1(3) of the Mental Capacity Act 2005 by monitoring and auditing:
 - person-reported outcomes, including the extent to which the person experiences collaboration and empowerment when making important decisions and the extent to which they experience support for their decision-making
 - practitioner-reported outcomes, including the frequency and quality of steps they have taken to support decision-making
 - process outcomes, including the frequency and quality of formal recording of steps taken to support decision-making and the use of overt and covert coercion during decision-making.

1.3 Advance care planning

Advance care planning involves helping people to plan for their future care and support needs, including medical treatment, and therefore to exercise their personal autonomy as far as possible. This should be offered to everyone who is at risk of losing capacity (for example through progressive illness), as well as those who have fluctuating capacity (for example through mental illness).

Some approaches involve the production of legally binding <u>advance decisions</u>, which only cover decisions to refuse medical treatment, or the appointment of an <u>attorney</u>. Others, such as <u>joint crisis planning</u> and advance statements, which can include any information a person considers important to their health and care, do not have legal force, but practitioners must consider them carefully when future decisions are being made, and need to be able to justify not adhering to them.

People can initiate advance care planning (such as advance statements) independently, without the input of practitioners. However, in some circumstances, professional input from a clinician with the appropriate expertise may assist a person to consider the matters they wish to address either by way of an advance care plan, an advance refusal of treatment and/or creation of a formal proxy decision-making mechanism such as a Lasting Power of Attorney. Skilled practitioners need to be able to have sensitive conversations with people in the context of a trusting and collaborative

relationship, and provide the person with clear and accessible information to help them make these important decisions.

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
 - ensure that protocols and plans reflect the optional nature of advance care planning
 - commission training on advance care planning, including advance decisions to refuse treatment and a Lasting Power of Attorney
 - 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 accessible 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
 - the impact that a subsequent loss of capacity may have on decisions made
 - 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 the person wishes to engage in advance care planning, enable them to do so.

- 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, 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 challenges of this type of planning
 - consider the use of checklists to support discussions.
- 1.3.8 If the person has given <u>consent</u> for carers, family and friends or advocates 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 circumstances, 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 the future.
- 1.3.11 Practitioners must ensure that all notes made on advance care planning are contemporaneous. In addition:
 - notes should be agreed with the person at the time and
 - consent should be sought from the person to share the information with other people as appropriate.
- 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 any advance care plans 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 Practitioners and individuals may wish to consider the use of advance care planning in the context of joint crisis planning.
- 1.3.18 Offer joint crisis planning to anyone who has been diagnosed with a mental disorder and has an assessed risk of relapse or deterioration, and anyone 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

'A person must be assumed to have capacity unless it is established that he lacks capacity.' (Principle 1, section 1(2), Mental Capacity Act 2005)

Mental capacity within the meaning of the Mental Capacity Act 2005 involves being able to make a particular decision at the time it needs to be made (<u>section 2</u> of the Mental Capacity Act 2005, and Chapter 4 of the <u>Code of Practice</u>).

Under the Mental Capacity Act 2005, capacity is decision-specific, and an individual is assumed to have capacity unless, on the balance of probabilities, proven otherwise. The concept of capacity under the Mental Capacity Act 2005 is relevant to many decisions including care, support and treatment, financial matters and day-to-day living. However, the Mental Capacity Act 2005 does not cover all decisions, and there are some decisions that are subject to a separate capacity test.

To lack capacity within the meaning of the Mental Capacity Act 2005, a person must be unable to make a decision because of an impairment or disturbance in the functioning of the mind or brain. That is, the impairment or disturbance must be the reason why the person is unable to make the decision, for the person to lack capacity within the meaning of the Mental Capacity Act 2005. The inability to make a decision must not be due to other factors, for example because of undue influence, coercion or pressure, or feeling overwhelmed by the suddenness and seriousness of a decision.

A lack of capacity cannot be established based merely by reference to the person's condition or behaviour. It can only be established if their condition also prevents them from understanding or retaining information about the decision, using or weighing it, or communicating their decision. It cannot be established unless everything practicable has been done to support the person to have capacity, and it should never be based on the perceived wisdom of the decision the person wishes

to make.

Effective assessments are thorough, proportionate to the complexity, importance and urgency of the decision, and performed in the context of a trusting and collaborative relationship.

- 1.4.1 Health and social care organisations should monitor and audit the quality of mental capacity assessments, taking into account the degree to which they are collaborative, person centred, thorough and aligned with the Mental Capacity Act 2005 and Code of Practice.
- 1.4.2 Include people's views and experiences in data collected for monitoring an organisation's mental capacity assessment activity.
- 1.4.3 Organisations should ensure that assessors can seek advice from people with specialist condition-specific knowledge to help them assess whether, on the balance of probabilities, there is evidence that the person lacks capacity for example clinical psychologists and speech and language therapists.
- 1.4.4 Organisations with responsibility for care and support plans should record whether a person has capacity to <u>consent</u> to any aspect of the care and support plan.
- 1.4.5 Organisations should have clear policies or guidance on how to resolve disputes about the outcome of the capacity assessment, including how to inform the person and others affected by the outcome of the assessment.

Conducting an assessment of mental capacity

- 1.4.6 Assess mental capacity in line with the process set out in <u>section 2</u> and <u>section 3</u> of the Mental Capacity Act 2005.
- 1.4.7 While the process applies to all decisions that fall within the scope of the Mental Capacity Act 2005, both large and small, the nature of the assessment and the recording of it should be proportionate to the complexity and significance of that decision.
- 1.4.8 Assessors should have sufficient knowledge of the person being assessed (except in emergencies or where services have had no previous contact with the

person) to be able to:

- recognise the best time to make the decision
- 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.
- 1.4.9 Practitioners should be aware that people can be distressed by having their capacity questioned, particularly if they strongly disagree that there is a reason to doubt their capacity.
- 1.4.10 In preparing for an assessment, the assessor should be clear about:
 - the decision to be made
 - if any inability to make a decision is caused by any impairment of or disturbance in the functioning of the mind or brain in that person
 - the options available to the person in relation to the decision
 - what information (the <u>salient factors</u>) the person needs in order to be able to explore their options and make a decision
 - what the person needs in order to understand, retain, weigh up and use relevant information 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 introduce the assessment and conduct it in a way that is respectful,
 collaborative, non-judgmental 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 and more able to make the decision
 - 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

- how to identify the steps a person is unable to carry out even with all practicable support
- whether involving people with whom the person has a trusted relationship would help the assessment.
- 1.4.11 The assessor should take into account the person's decision-making history when preparing for an assessment, including the extent to which the person felt involved and listened to, the possible outcomes of that assessment, and the nature and outcome of the decisions they reached.
- 1.4.12 Practitioners must take all reasonable steps to minimise distress and encourage participation.
- 1.4.13 Where consent has been provided, health and social care practitioners should identify people who could be spoken with in order to inform the capacity assessment. For example, this may include the individual's family or friends.
- 1.4.14 Practitioners should use accessible language or information in an accessible format to explain to the person:
 - that their capacity to make a particular decision is being assessed
 - why their capacity is being assessed
 - the outcome of that assessment
 - what they can do if they are unhappy with the outcome.
- 1.4.15 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. If the assessment concludes that a person would, with appropriate support, have capacity to make their own decisions, the assessment should establish which elements of the decision-making process the person requires assistance with, in order to identify how decision-making can be supported.
- 1.4.16 Use of single tools (such as the Mini-Mental State Examination) that are not designed to assess capacity may yield information that is relevant to the assessment, but practitioners should be aware that these should not be used as

the basis for assessing capacity.

- 1.4.17 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.
- 1.4.18 Where the person has identified communication needs, the assessor should also think about using communication tools to help with the assessment.
- 1.4.19 Practitioners should be aware that it may be more difficult to assess capacity in people with <u>executive dysfunction</u> for example people with traumatic brain injury. Structured assessments of capacity for individuals in this group (for example, by way of interview) may therefore need to be supplemented by real-world observation of the person's functioning and decision-making ability in order to provide the assessor with a complete picture of an individual's decision-making ability. In all cases, it is necessary for the legal test for capacity as set out in <u>section 2</u> and <u>section 3</u> of the Mental Capacity Act 2005 to be applied.
- 1.4.20 If a person refuses to engage in some or all aspects of a capacity assessment, the assessor should try to establish the reasons for this and identify what can be done to help them participate fully. This may involve consulting with others involved in their care and support, reviewing records or giving the person a choice about who else can be involved.
- 1.4.21 Information gathered from support workers, carers, family and friends and advocates should be used to help create a complete picture of the person's capacity to make a specific decision and act on it.
- 1.4.22 When assessing capacity, practitioners must take account of the principle enshrined in section 1(4) of the Mental Capacity Act 2005 and not assume that the person lacks capacity because they have made a decision that the practitioner perceives as risky or unwise.

- 1.4.23 Practitioners should understand that the person has to retain information only for the purposes of making the specific decision in question, and for the period of time necessary to make the decision.
- 1.4.24 Practitioners should be aware that a person may have decision-making capacity even if they are described as lacking 'insight' into their condition. Capacity and insight are 2 distinct concepts. If a practitioner believes a person's insight/lack of insight is relevant to their assessment of the person's capacity, they must clearly record what they mean by insight/lack of insight in this context and how they believe it affects/does not affect the person's capacity.

Recording the outcome of the assessment

- 1.4.25 The assessor should record any differing views on the person's capacity and how the outcome of the assessment addresses or answers those differing views.
- 1.4.26 If, following the assessment of capacity, the practitioner finds no evidence to displace the assumption of capacity, this should be documented.
- 1.4.27 If the outcome of the assessment is that the person lacks capacity, the practitioner should clearly document the reasons for this. The documentation should also make clear what impairment/disturbance of the mind or brain has been identified, the reasons why the person is unable to make a decision (with reference to section 3 of the Mental Capacity Act 2005) and the fact that the person's inability to make a decision is a direct consequence of the impairment or disturbance identified.
- 1.4.28 The person assessing mental capacity should record:
 - the <u>practicable steps</u> they have taken to help the person make the relevant decision for themselves and any steps taken by other parties involved
 - whether the person has capacity to make the decision
 - if the person is assessed as lacking capacity, why the practitioner considers this to be an <u>incapacitous</u> decision as opposed to an unwise decision.
- 1.4.29 All assessments of mental capacity must be recorded at an appropriate level to the complexity of the specific decision being made at a particular time. This may

be as a stand-alone assessment document, contained within the individual's health or social care record or in care and support plans, following local policy. The timescale for review of the assessment should be specified and recorded.

After the assessment

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

1.5 Best interests decision-making

'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.' (Principle 4, section 1(5) Mental Capacity Act 2005)

When a person does not have capacity to make a decision, all actions and decisions taken by practitioners or their <u>attorney</u> or <u>Court Appointed Deputy</u> must be done or made in the person's best interests. Any advance statements expressing the individual's views about the decision in question should be taken into account and given appropriate weight.

When making a decision under the Mental Capacity Act 2005, a decision maker must be identified. This could be an attorney appointed by the individual or a Court Appointed Deputy with relevant decision-making powers, or the practitioner or team who is responsible for providing a health or social care intervention.

The decision maker is responsible for determining the person's best interests. They must be able to demonstrate they have adhered to all the requirements of section 4 of the Mental Capacity Act 2005 and Chapter 5 of the Code of Practice. Wherever possible, this means helping the person who lacks capacity to be involved in the decision-making process, consulting with their family, carers and Independent Mental Capacity Advocates, and seeking or establishing the person's known wishes, preferences and values, placing these at the heart of the decision-making process where possible.

Depending on the complexity, urgency and importance of the decision, and the extent to which there is agreement or disagreement between an attorney or Court Appointed Deputy and/or other people involved in the person's care, it would be advisable to convene a meeting at which a decision regarding appropriate next steps can be made. This may include considering possible ways of resolving any disputes.

The Mental Capacity Act 2005 excludes some decisions from its remit, for example, those relating to voting and family relationships. It is therefore not possible for best interests decisions to be made in respect of the excluded issues.

Helping practitioners to deliver best interests decision-making

- 1.5.1 In line with the Mental Capacity Act 2005, practitioners must conduct a capacity assessment, and a decision must be made and recorded that a person lacks capacity to make the decision in question, before a best interests decision can be made. Except in emergency situations, this assessment must be recorded before the best interests decision is made.
- 1.5.2 Ensure that everyone involved in the best interests decision-making process knows and agrees who the decision maker is.
- 1.5.3 As part of the best interests decision-making process, practitioners must take all reasonable steps to help the person to provide their own views on the decision.
- 1.5.4 Health and social care services must ensure that best interests decisions are being made in line with the Mental Capacity Act 2005.
- 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.

Involving family members or other people involved in a person's care in best interests

decision-making

- 1.5.7 Unless it would be contrary to the person's best interests to do so, health and social care practitioners should work with carers, family and friends, advocates, attorneys and deputies, to find out the person's values, feelings, beliefs, wishes and preferences in relation to the specific decision and to understand the person's decision-making history.
- 1.5.8 In some cases, the views of the interested parties may differ from those of the person or the decision maker. However, this does not necessarily mean it would be contrary to the person's best interests to consult them.
- 1.5.9 If a decision maker considers it helpful or necessary to convene a meeting with the relevant consultees to assist with the decision-making process, they should:
 - Involve the person themselves, unless a decision is made that it would be contrary to their best interests for them to attend the meeting. Where this is the case, this decision and the reasons for it should be recorded.
 - Consult carers, family, friends, advocates and any attorney or deputy 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 assist the decision maker in making a decision in the person's best interests.
 - Clarify the role of each person attending the meeting, especially the identities of the decision maker and the meeting chair, as these may be different people.
 - 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 consulted as part of the best interests decision have their views encouraged, respected and heard. This does not mean that the views of consultees should necessarily be followed; the decision maker is ultimately responsible for deciding what course of action would be in the person's best interests.

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 the person's best interests are served. This might include:
 - a less formalised approach for day-to-day decisions that is, recurring decisions being recorded in support or care plans
 - a decision-making approach appropriate to the circumstances and personalised to the individual, making all reasonable adjustments
 - formal best interests meetings for significant decisions:
 - if this is the most appropriate way to undertake the required consultation or
 - if the outcome of the decision is likely to have a serious impact on the person's health or wellbeing or
 - if there are likely to be conflicting opinions about the person's best interests.
- 1.5.13 Carers and practitioners must, wherever possible, find out the person's wishes and feelings in order to ensure any best interests decision made reflects those wishes and feelings unless it is not possible/appropriate to do so. Where the best interests decision ultimately made does not accord with the person's wishes and feelings, the reasons for this should be clearly documented and an explanation given. The documentation of the assessment should also make clear what steps have been taken to ascertain the person's wishes and feelings and where it has not been possible to do this, the reasons for this should be explained.
- 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:
 - how to identify any decision-making instruments that would have an impact on best interests decision-making occurring (for example a Lasting Power of Attorney, <u>advance decisions to refuse treatment</u>, court orders)
 - when to instruct an Independent Mental Capacity Advocate
 - a prompt to consult interested parties (for example families, friends, advocates and

- relevant professionals) and a record of who they are
- guidance about recording the best interests process and decision. This may include, for example, a balance sheet, which may assist in documenting the risks and benefits of a particular decision
- instructions on what information to record, ensuring this covers:
 - a clear explanation of the decision to be made
 - the 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, evidencing each element of the assessment
 - a clear record of the person's wishes, feelings, cultural preferences, values and beliefs, including any advance statements
 - the concrete choices that have been put to the person
 - the salient details the person needs to understand
 - the best interests decision made, with reasons.
- 1.5.15 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 past and present 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 (including possible human rights infringements)
 - 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).
- 1.5.16 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.

- 1.5.17 As people's circumstances change, review the decisions regularly to ensure that they remain in a person's best interests.
- 1.5.18 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.
- 1.5.19 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 a dispute cannot be resolved locally, it may be necessary for the matter to be referred to the Court of Protection for a determination of the person's best interests.
- 1.5.20 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 with people who may lack mental capacity in the future is a voluntary process of discussion about future care between the person and their care providers. If the person wishes, their family and friends may be included in the discussion. With the person's agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.

Advance decisions to refuse treatment

An advance decision to refuse treatment (sometimes referred to as a living will and sometimes abbreviated to ADRT) is a decision an individual can make when they have capacity to refuse a specific type of treatment, to apply at some time in the future when they have lost capacity. It means that families and health professionals will know the person's decisions about refusing treatment if they are unable to make or communicate the decisions themselves.

An advance decision must be valid and applicable before it can be legally binding. For example, one of the conditions is that the individual is aged 18 or over at the time the decision is made. To establish whether an advance decision to refuse treatment is valid and applicable, practitioners must have regard to sections 24–26 of the Mental Capacity Act 2005. If the advance decision purports to refuse life-sustaining treatment, additional requirements apply. (See Chapter 9 of the Code of Practice.)

Capacitous

Where used in this guideline, the term 'capacitous' is used to reflect the status of someone who has capacity to make decisions regarding their care and treatment – that is, those matters to which the Mental Capacity Act 2005 applies. This could be someone for whom there is no evidence to suggest the presumption of capacity should be displaced, or someone whose capacity to make decisions regarding their care and treatment has been formally assessed and who has been found to have capacity to make those decisions.

Contemporaneous

This is being used to describe how, during advance care planning, the practitioner should take notes of the discussions and decisions reached at the same time as those discussions are taking place.

Consent

The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they cooperate with the treatment or actively seek it.

Court Appointed Deputy

A person appointed by the Court of Protection who is authorised to make decisions (relating to the person's health, welfare, property or financial affairs) on behalf of someone who lacks mental capacity and who cannot make a decision for themselves at the time it needs to be made.

Executive dysfunction

The completion of tasks that involve several steps or decisions normally involves the operation of mental processes known as 'executive functions'. If these executive functions do not develop normally, or are damaged by brain injury or illness, this can cause something called 'executive dysfunction'. This involves a range of difficulties in everyday planning and decision-making, which can be sometimes hard to detect using standard clinical tests and assessments.

Independent advocacy

Independent advocates can have a role in promoting social inclusion, equality and social justice and can provide a safeguard against the abuse of vulnerable people. Independent advocates take action to act to help people say what they want, secure their rights, represent their interests and obtain the services they need. Together with their provider organisations they work in partnership with the people they support and speak out on their behalf.

Joint crisis planning

A joint crisis plan enables the person 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. When the person lacks capacity to make decisions regarding their care and treatment and is unlikely to gain or regain capacity, a joint crisis plan about what to do in the event of a future crisis may be developed through a best interests decision-making process. A joint crisis plan does not have the same legal status as an advance decision to refuse treatment.

Lasting Power of Attorney

A legal instrument that allows a person (the 'donor') to appoint one or more people (known as 'attorneys') to make decisions on their behalf. There are 2 types: health and welfare, and property and financial affairs, and either one or both of these can be made. To have legal force, lasting powers of attorney must be created in accordance with section 9 and section 10 of the Mental

Capacity Act 2005. The attorney must have regard to <u>section 4</u> of the Mental Capacity Act 2005, the Mental Capacity Act <u>Code of Practice</u>, and must make decisions in the best interests of the person.

Mental Capacity Act 2005

The Mental Capacity Act 2005 is designed to protect and empower people who may lack capacity to make their own decisions about their care and treatment. It is a law that applies to people aged 16 and over in England and Wales and provides a framework for decision-making for people unable to make some or all decisions for themselves.

Mental Health Act 1983

The Mental Health Act 1983 provides for the detention of persons in hospital for assessment and/ or treatment of mental disorder and for treatment in the community in some circumstances. The Act provides for the process of assessing individuals and bringing them within the scope of the Act, for treatment of individuals subject to the Act's provisions and sets out the rights and safeguards afforded to individuals who are subject to the Act's powers.

Practicable steps

'Practicable steps' links to principle 2 of the <u>Mental Capacity Act</u> (and Chapter 3 of the <u>Code of Practice</u>), which states that 'all practicable steps' should be taken to help a person make a decision before being treated as though they are unable to make the decision. There are obvious steps a person might take, proportionate to the urgency, type and importance of the decision 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 or clinical psychologist.

Practicable steps could also involve ensuring the best environment in which people are expected to make often life-changing decisions – for example giving them privacy and peace and quiet, or ensuring they have a family member or other trusted person to provide support during decisionmaking, if this is their wish.

Salient factors

<u>Section 3(1)</u> of the Mental Capacity Act 2005 makes clear that a person will be unable to make a decision for themselves if they are unable to understand the information relevant to the decision. Case law has confirmed that the information to be provided to the person regarding the decision does not have to include every single detail relating to the decision, but must include the 'salient factors'. The salient factors are those which are most important to the decision to be made. This

would include information that is subjectively important to the person being assessed (for example information relating to the likely level of disability a person would have if they did/did not undergo the treatment in question) and also key pieces of objective/factual information relevant to the decision to be made (for example the side effects of a particular treatment, or the known complications or survival rates of a particular surgical procedure). The seriousness of the decision, and the timeframe within which it must be made, will impact on the nature and amount of information that will need to be provided to the person.

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

Putting this guideline into practice

NICE has produced tools and resources 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 <u>principles 1 and 2</u> of the Mental Capacity Act 2005, supported decision-making is fundamental to:
 - effective implementation of the legislation
 - empowering people who have difficulties making their own decisions independently.

Alongside local policies and training, organisations need to ensure that their procedures and forms for capacity and best interests assessments 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 Act. Practitioners need to understand the status of the person's decision-making capacity at that specific point in time and how their particular impairment of the mind or brain affects their current ability to make decisions. Training should be delivered with input from people who use services. It should start with basic training and continue throughout an individual's employment, particularly whenever legislation is updated.
- Access to independent advocacy. This is affected by a range of factors, including:
 - a shortage of well-trained advocates
 - practitioner knowledge of the different types of advocacy
 - practitioners being unaware of the duty to refer for advocacy
 - advocacy services being under-resourced and in high demand.

Additionally, there is consistent evidence of a lack of understanding among commissioners, public bodies, practitioners and people who use services of the critical role that independent advocacy can play in upholding rights and providing an ultimate safeguard from abuse. Consequently, ensuring the recommendations relating to independent advocacy are acted on 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 <u>into practice</u> pages for more information.

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

More information

You can also see this guideline in the NICE pathway on <u>decision-making and mental capacity</u>.

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

See also the guideline committee's discussion and the evidence reviews (in the <u>full guideline</u>), and information about <u>how the guideline was developed</u>, 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 <u>full guideline</u>.

1 Training and support for practitioners

What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act 2005 at improving practice 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 2005 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, an acquired brain injury or a mental illness. Interventions should be designed to address the needs of those cohorts, should take into account the natural course of capacity (whether stable or fluctuating) and should be 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 (including participant experience of the 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

What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people to make decisions?

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 to make decisions. However, the guideline committee thought that this was an area in which emerging practice shows promise. Expert witness testimony highlighting the Swedish 'Personal Ombudsman' 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 need support to make a decision. The effectiveness component will ideally include 3 arms: usual care, usual care plus advocacy, and usual care plus support with enhanced advocacy. Studies should also 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 2005. 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 Act. The controlled effectiveness component will ideally include 3 arms: usual care, usual care plus mental capacity assessment tools, and usual care plus support with enhanced assessment tools. Studies should also 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

Although the Mental Capacity Act Code of Practice provides some fundamental guidance on conducting and recording capacity assessments, there is a lack of clarity about the way in which practitioners actually 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.

Update information

October 2018: A small change was made to the introductory text in sections 1.2 Supporting decision-making, and 1.4 Assessment of mental capacity. The wording in recommendation 1.4.23 was amended to clarify how long someone needs to retain information related to decision-making.

ISBN: 978-1-4731-2959-7

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