

Capacity to Communicate Project 2008
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Advocating for your family member



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Introduction

This publication is aimed at the family members of adult deafblind people. It is designed to provide you with ideas and skills for advocating for your family member. This guidance is set specifically in the context of the Mental Capacity Act, although it can be used in a wider context.

The main focus in this publication is on the process of advocacy: how to involve your family member in decisions, what questions to ask, how to evaluate options and present your thoughts coherently when representing your relative.

For a broader understanding of the Mental Capacity Act and your role as a family member you should also read *Making Decisions: A guide for family, friends and other unpaid carers* (booklet 2 in a series). This is available from the Office of the Public Guardian (see references) or by telephoning 0845 330 2900. The booklet is available in several languages and alternative formats.

This toolkit has come out of the Department of Health funded Capacity to Communicate Project run by Sense between 2006 – 2009. This project provided training and information, harnessing best practice around communication and advocacy issues for people who lack capacity for certain decisions and who have little or no formal communication, including deafblind people. It targeted advocates, advocacy organisations, local authorities, individuals and their families.

The three main outcomes of the three-year project were:

- Training for advocates and advocacy organisations on the process and practice of good communication with those who have little or no formal communication, including deafblind people; and an exploration of ethical dilemmas in providing an Independent Mental Capacity Advocate (IMCA) (see Glossary)
- Information for families on advocacy entitlements and its benefits – of which this publication forms the main part
- Information for local authorities outlining the value of advocacy for those lacking capacity, through a final summary publication.

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Overview of the Mental Capacity Act

As a parent or family member of a deafblind adult you may have been representing, or advocating for your relative for some time. Now there is a legal framework which outlines the process for making decisions for those unable to do so for themselves through The Mental Capacity Act (2005).

The Mental Capacity Act clarifies the process for caring for people who may lack capacity and how decisions should be made for your relative if they are unable to make decisions for themselves. It sets out when you should be consulted about decisions made on behalf of your relative and how they are protected or safeguarded in this process.

Lacking capacity

A person lacks capacity and is unable to make a decision if they cannot do any one of the following:

- Understand information given
- Retain information in order to make a decision
- Weigh up information
- Communicate the decision.

Key Principles

1. The Act presumes that all adults are legally able to make a decision themselves unless shown they are unable to.
2. Everyone should be given the help and support needed to make a decision and information should be provided in a way the person can understand.
3. People are allowed to make unwise or eccentric decisions and this is not an indicator of incapacity.
4. Any actions or decisions taken on someone's behalf must be done in their best interests and;
5. Any action should be the least restrictive of their freedom and rights.

If a person does not have capacity to make a decision for themselves then others will have to act in their best interests. A decision might be needed on a wide range of caring actions such as diagnostic tests and examinations, medical procedures and nursing care, and decisions about where someone should live and what services they need. Decisions may also include day to day assistance like washing, dressing, eating or mobility carried out by you or professionals.

Best Interests

When making decisions the carer or professional must have assessed that the person lacks capacity and that the action they take is in the person's best interests. To identify the person's best interests you must ask:

- Will the person regain capacity and could the decision be delayed?
- What can be done to involve the person in the decision-making process as much as possible?

- If the decision is about life-sustaining treatment it must not be motivated by desire to bring about the person's death
- What can be done to harness the past and present wishes and feelings of the person?
- What beliefs or values does the person have that might influence the decision?
- Any other factors that may be relevant.

Ensuring participation

Before deciding that someone lacks capacity to make a particular decision, it is important that all practical and appropriate steps are taken to enable them to make that decision themselves.

The decision maker must:

- **Provide all relevant information.** All practical and appropriate steps must be taken to help the person make a decision for themselves. Information must be tailored to an individual's needs and abilities. It must also be the easiest and most appropriate form of communication for the person concerned.
- **Communicate in an appropriate way.** To help someone make a decision for themselves, all possible and appropriate means of communication should be tried. The Mental Capacity Act Code of Practice gives guidance to decision makers on approaches to communication and seeking advice and support of interpreters and experts.
- **Make the person feel at ease.** To help put someone at ease and so improve their ability to make a decision, careful consideration should be given to both location and timing.
- **Support the person.** In some circumstances, individuals will be more comfortable making decisions when someone else is there to support them.



The starting assumption must be that the person has the capacity to make the specific decision. If, however, anyone thinks a person lacks capacity, it is important to then ask the following questions:

- Does the person have all the relevant information they need to make the decision?
- If they are making a decision that involves choosing between alternatives, do they have information on all the different options?
- Would the person have a better understanding if information was explained or presented in another way?
- Are there times of day when the person's understanding is better?
- Are there locations where they may feel more at ease?
- Can the decision be put off until the circumstances are different and the person concerned may be able to make the decision?
- Can anyone else help the person to make choices or express a view (for example, a family member or carer, an advocate or someone to help with communication)?

Anybody who claims that an individual lacks capacity should be able to provide proof. They need to be able to show, on the balance of probabilities, that the individual lacks capacity to make a particular decision, at the time it needs to be made.

Lasting power of Attorney (LPA)

If the person you are caring for has the capacity to understand what it means to appoint an attorney, they can choose one or more people to make decisions on their behalf in the future should they become unable to do this for themselves – this person is appointed by a formal document called a Lasting Power of Attorney (LPA).

There are two different types of LPA, which can be the same person or different people:

- A personal welfare LPA who takes decisions about health, personal welfare, day to day care and receiving medical treatment
- A property or affairs LPA who takes decisions about finances.

If the person you care for does not understand what it means to appoint an attorney then you might consider applying to the Court of Protection in order to be granted permission to make decisions on their behalf as a Deputy.



The role of the Deputy

Deputies deal with the property and affairs of someone who lacks capacity and the Court of Protection must grant the order to become a Deputy. The Deputy order you receive from the Court will set out the extent of your powers. It can apply to any area in which the person could have acted or made decisions for themselves if they had the capacity to do so.

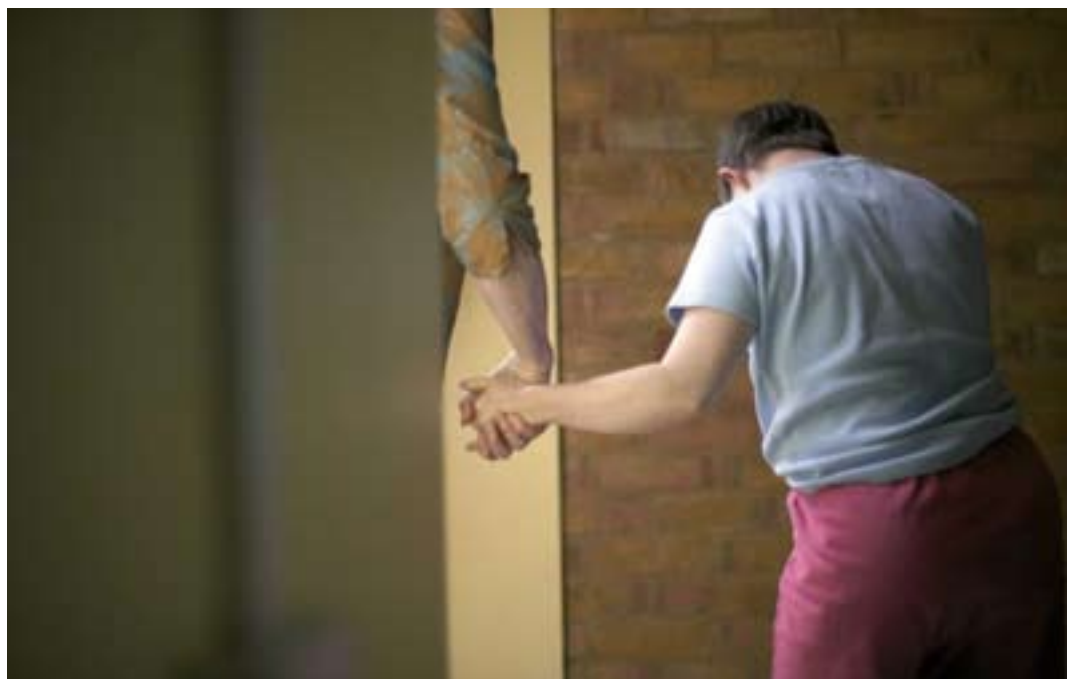
Your powers might relate to:

- finances;
- personal welfare, such as giving or withholding consent to medical treatment and/or social care interventions.

Powers given will depend on the needs of the person you have been appointed to assist and also the Court's decision. When acting as Deputy the decisions you make can have a major impact on the person who lacks capacity. In order to carry out your responsibilities sensitively, responsibly and rigorously you should always:

- only make those decisions you are authorised to make by the order of the Court;
- adhere to the Act's five statutory principles; (see page 4)
- make decisions in the person's best interests;
- fulfil your duty to apply certain standards of care and skill (a duty of care) when making decisions; and
- have regard to all relevant guidance in the Mental Capacity Act Code of Practice (see Glossary/References).

There is more information about this role available from the Court of Protection at the Office of the Public Guardian (See Sources of Support and Further Information at the end of this toolkit).



The Court of Protection

The Mental Capacity Act provides for a new Court of Protection to make decisions in relation to the property and affairs and healthcare and personal welfare of adults (and children in a few cases) who lack capacity. The Court also has the power to make declarations about whether someone has the capacity to make a particular decision.

The Court has the same powers, rights, privileges and authority in relation to mental capacity matters as the High Court. It is a superior court of record and is able to set precedents (examples to follow in future cases).

The Court of Protection has the powers to:

- decide whether a person has capacity to make a particular decision for themselves;
- make declarations, decisions or orders on financial or welfare matters affecting people who lack capacity to make such decisions;
- appoint deputies to make decisions for people lacking capacity to make those decisions;
- decide whether a Lasting Power of Attorney (LPA) or Enduring Power of Attorney (EPA) is valid; and
- remove deputies or attorneys who fail to carry out their duties, and
- hear cases concerning objections to register an LPA or EPA and make decisions about whether or not an LPA or EPA is valid.

Children and Young People

The Mental Capacity Act only applies where the person lacking capacity is 16 years old or older. Decisions for children younger than 16 who do not have capacity can be made with the consent of people with parental responsibility.

Most of the Act applies to young people aged 16–17 years, who may lack capacity to make specific decisions but there are three limitations:

- Only people aged 18 and over can make a Lasting Power of Attorney
- Only people aged 18 and over can make an advance decision to refuse medical treatment
- The Court of Protection may only make a statutory will for a person aged 18 and over.

People carrying out acts in connection with the care or treatment of a young person aged 16–17 who lacks capacity to consent will generally have protection from liability as long as the person carrying out the act:

- has taken reasonable steps to establish that the young person lacks capacity
- reasonably believes that the young person lacks capacity and that the act is in the young person's best interests, and
- follows the Act's principles.

Your role as a family member

The Mental Capacity Act provides clear responsibilities for you as a family member in day-to-day and major decisions.

You may need to assess the capacity of your relative because you need to do something in order to care for them. The Mental Capacity Act says you have to have reasonable belief that they lack mental capacity in order to do so. You need to consider whether they have a general understanding of the decision needing to be made and the consequences of the decision. You will need to consider whether they are able to weigh up information and use it to make a decision and if there is any way you can help them to do this as well as communicate their feelings and wishes.

This process applies to major as well as day-to-day decisions. And, if your relative has a condition which does not fluctuate, you may need to regularly make decisions on their behalf such as what they should wear. However, over time you should recognise that a person's capacity may change they may be able to learn new skills and gain new understanding which makes them able to make some decisions.

Supporting day to day decisions

Think about a day to day decision you ordinarily make for your relative. This could be about clothes/appearance (e.g. cutting/dying hair) food (e.g. diet) activities (e.g. horse riding) for example, which may not be as straightforward as first appears. These are the kinds of questions you may find useful to consider when you are acting in their best interests:

Assessing Capacity

- Do they have a general understanding of what decision needs to be made?
- Do they have a general understanding of the consequences of this decision?
- Can they weigh up this information and use it to make a decision?
- Is there any way you could help them to make the decision for themselves?
- Is there any way you can help them communicate their decision or their wishes and feelings?

Best Interests

- Will they regain or improve capacity and is it possible to delay the decision (perhaps it may be as simple as choosing the right time of day?)
- How can you encourage their participation in the decision?
- What are their past and present wishes and beliefs and values that might influence the decision (e.g. perhaps they have a particular dislike for a certain food)
- Is there anyone else you should involve in the decision?

Example

Mary cares for her son, Michael, who is 24, has a learning disability and is deafblind. Michael finds it very difficult to understand that he can make choices. As far as Mary can tell, he is not able to make decisions for himself. Michael attends a specialist day service five days per week and staff there are working to teach him about making choices. Mary knows that, given time, Michael will learn that he can make choices and that when he does, she will need to support him to make his own decisions. She regularly talks to the day service staff about this.

Being consulted in the decision making process

As a family member, a professional may also consult you about your relative's capacity concerning a particular decision about their health or accommodation needs.

The Mental Capacity Act requires a decision maker to consult family or friends when deciding on best interests. There may be times when it is not practical or appropriate to do so, for example in an emergency situation; and whether you are consulted or not depends on what sort of decision needs to be made and the circumstances. However, when it is practical and appropriate as a family member you will be consulted.

This does not mean you are making the decision and you should not be asked to give consent on behalf of your relative. You should be asked what you think would be in the person's best interests and whether you can give any information about the person's wishes, feelings, values or beliefs. You should not be asked what you would do in similar circumstances.

The decision maker must take account of what you have to say, but will balance this with other information to make their final decision.

The Act also creates the role of an Independent Mental Capacity Advocate to represent those who do not have family or friends. However, the Act also allows involvement of an IMCA where it was not practicable or appropriate to consult family or friends. There are four key situations this might occur:

- Where it is impractical because the family or friends live a great distance away
- Where family or friends have little knowledge of the person
- Where family or friends are unwilling to be consulted
- Where family or friends are too frail (mentally or physically).

In practice this range of reasons has expanded to include:

- Where there has been abuse by family or friends
- Where family members are in dispute
- Where family members and decision makers disagree
- Where there are potential conflict of interest (e.g. where a family member may gain from the decision).

However, even where an IMCA is involved they will often consult a family member as part of their advocacy involvement, so your views and input may still be required.

How to help the decision maker

You can help the decision maker – health or social care professional – to ensure:

- They take all reasonable practical steps to enable the person to participate in the decision as fully as possible
- All information relevant to the decision is given to the person in the easiest and most appropriate way for them. The Mental Capacity Act Code of Practice (see References) provides specific guidance around this including: taking time, providing information simply, describing foreseeable consequences and effects, explaining the choices
- They know about ways the person communicates – does your family member understand words, sentences, objects of reference, pictures?
- What concepts can they understand and how? Is the decision in question a concept they can weigh up and understand? (This might depend on presentation of information and communication)
- How do they receive communication and express themselves? Can they indicate yes/no, like or dislike?
- Your family member should feel at ease in this process. Select an environment for consultation and involvement that suits the person; making sure it is quiet and likely to be uninterrupted. Arranging to visit relevant locations e.g. if it's about a hospital or short-break stay, visiting the place with them.

You can help keep your family member at the centre of the decision making process and promote their involvement and communication. You can also safeguard their rights by asking questions and evaluating options. Let us look at this in more detail.



Supported decision making

The Mental Capacity Act is founded upon the process of supported decision making¹. This model starts from the following assumptions:

- All human beings communicate
- All human beings express choices and preferences about their lives
- These choices and preferences are the building blocks of decisions
- When people's choices and preferences lead directly to action this means someone is controlling their own life, even if they need substantial help to make choices happen.

However, there are factors that affect a person's ability to influence decisions, these include:

- How someone communicates
- The extent the person understands information and what is expected of them
- The extent to which people can retain and process information
- Different personal values and attitudes
- Lack of motivation and experience.

These factors relate to the test of capacity outlined in The Mental Capacity Act.

There are also a number of challenges and barriers which are imposed upon people and limit their control:

- How much time is available to make choices
- How the information is presented
- Power relationships with services and the person concerned
- Nature of relationships with supporters
- Limited opportunities to make choices
- Staff skills to enable choices to be made
- Undiagnosed (or unsupported) sight or hearing impairment
- People being labelled as challenging and having their views dismissed as a result
- Assumptions about the person's abilities
- Lack of awareness of cultural differences.



¹ Edge, J. (2001) Who's in control? Decision making by people with learning difficulties who have support needs. Values into Action

There are five key issues that you may need to consider as an advocate for your family member:

1. What **information** is relevant to the decision and how can it be relayed in the most appropriate way?
2. What is the person's **level of understanding** and what approaches can aid their understanding?
3. What **concepts** are involved in the decision and will the person understand them? Are there any related concepts which could provide a starting point? For example: if the issue is about a change of accommodation, might it be possible to ascertain how happy the person is with their present accommodation?
4. What **questions** do you need to ask and how might you go about this?
5. What is the best way to **interact with, observe, and record** responses?

The importance of communication

The Supported Decision-Making Model is predicated on the importance of communication. Communication is a process. It is the means by which people make contact with each other, share experiences, understand the world and find their place in it.

Communication helps us get hold of and use information to make choices, decisions and changes. Through communication we can understand and achieve our goals. We all communicate and we all need to communicate. People with sensory and multiple disabilities are often isolated from the world around them because their communication goes unrecognised.

Communication is also a shared responsibility, a two-way process: as much about our ability to understand and communicate as the other person's ability to do the same. We each have the responsibility to respond to the individual's communication and try to give meaning to it².

Communication is a process whereby people continuously respond and modify their behaviour. This approach suggests there is never one meaning to communication, rather different interpretations. For example, if I stood on your toe your reaction would be different depending on whether you thought I had done so purposefully or not – in other words what my intent was. It is vital to understand how people assign meaning to behaviour and the relationship between inference (the meaning we take from something) and communicative intent (the meaning intended)³.

Because the forms of communication are likely to be inadequate to realise only a limited set of meaning and functions in people with severe communication impairments the balance is weighted towards inference, and so the interpretation of communication becomes a vital and important issue, we need to check the accuracy of our interpretations and those of others.

² Swann, G. (2000) Communication and Advocacy Training Course. Sense

³ Grove, N. et al (2000) *See What I Mean: guidelines to aid understanding of communication by people with severe and profound learning disabilities*. BILD & Mencap

Communication is the key to enabling the person to participate as fully as possible in the decision making process.

Thinking in more detail about communication particularly in the context of participation and decision making we may ask the following questions⁴:

What is the person's level of understanding?

- Some difficulties with complex language
- Understands simple sentences
- Understands single words
- Understands tone of voice
- Understands simple signs
- Understands pictures/objects of reference
- Can they understand what or where questions?
- Can they understand who, why or when questions?
- Can they understand language or concepts relating to past, or future?
- What speed do they need their communication?

What is the person's level of intentional communication in everyday situations?

- Looks at something then at you
- Gestures, reaching, pointing
- Changes behaviour to make you understand what is wanted
- Purposeful movement to find or be near someone or something
- Persistent behaviour
- Other strategies

Identifying the person's means of expression

- Are words or vocalisations used?
- Are gestures signs or symbols used?
- Does the person repeat what others say?
- If single words or gestures are used give examples
- Does the person link two words or gestures together?
- Are signs clear?

Functional communication

- Can the person indicate yes or no? How do they do that?
- Can the person indicate positive or negative feelings? How do they do that?
- How do you know the person is happy, excited, at ease, unhappy, distressed or in pain?

⁴ Adapted from Silver, K (2005) *Assessing and Developing Communication and Thinking Skills in People with Autism and Communication Difficulties: A Toolkit for Parents and Professionals*. Jessica Kingsley Publishers and Grove, N. et al.(2000)

- What level of hearing does the person have?
- What level of vision does the person have?
- Does the person recognise: written words, spoken words, symbols, pictures, signs or objects of reference?
- How does the person feel about the meeting: unaware, confident, nervous, uninterested, and anxious?
- What strategies does the person need to interact: pausing, seating, physical support, pictures, objects?
- What motivates the person to communicate?
- Is the person able to direct others?
- Does the person initiate communication?
- Where and when is the person most communicative?
- With whom do they communicate most?
- Should closed (questions that would elicit a yes/no response) or open ended questions (for example: why, how and what questions) be asked?
- What resources will you need to communicate with the person?
- What key words (signs/symbols) will you need to use to convey the information?
- Does the person understand these concepts?
- How does the person attract attention or ask for something which is not there?
- How do they access their communication system?

Asking the right questions

As well as ensuring communication with the deafblind person is central to the process in a decision making situation, you will need to ask questions about the decision needing to be taken. There are key questions you may need to ask a health or social care decision maker as a family member or carer involved in the process:

- What is the decision that is needed to be made?
- What are the alternative courses of action?
- Who is making the decision?
- What is the timescale?
- What methods of participation has the decision maker tried?
- How can you help the decision maker?
- Who are the key people you need to talk to, their range of views and why?

Example

James is deafblind young man in his thirties and still lives at home and is cared for by his mother and father. It has become apparent that James is having a great deal of problems with his teeth and may need to have many of them removed in order to alleviate the pain. James' mother and father are consulted in the process. They ask about all the options, the pre-planning and after care that might be available. They discuss with the dentist the outcomes for James and how it would affect his quality of life, they ask for a second opinion. They explore what the least restrictive option would be.

Evaluating Options

The 'Watching Brief' Approach, developed by Asist Advocacy in Staffordshire, creates a way of asking relevant and pertinent questions and evaluating options in general terms. Questions are asked around key issues looking at specific criteria and effects on the person. You are essentially asking how the person's life can be enhanced (or made poorer) by a particular action. It is a means of evaluating an option and asking professionals supporting the person to carefully examine their reasoning.

Issue	How will the proposal...
Competence	<ul style="list-style-type: none"> • promote the person's independence? • support them to develop new skills and maintain existing ones? • manage risk?
Community Presence	<ul style="list-style-type: none"> • promote the person's presence in the local community? • affect existing opportunities? • provide new opportunities? • reduce social isolation?
Continuity	<ul style="list-style-type: none"> • help the person maintain links with their past? • address their hopes and ambitions for the future? • maintain continuity in their life?
Choice and Influence	<ul style="list-style-type: none"> • offer options? • involve the person in decision making? • take their wishes into account?
Individuality	<ul style="list-style-type: none"> • address the person's preferences? • promote individuality? • offer opportunities to express preferences?
Status and Respect	<ul style="list-style-type: none"> • promote self-respect and the respect of others? • reduce prejudice and social stigma? • value the person in a way consistent with their age, gender, cultural needs etc?
Partnerships and Relationships	<ul style="list-style-type: none"> • provide opportunities for interaction with others? • promote development and maintenance of positive relationships?
Well-being	<ul style="list-style-type: none"> • promote and maintain good health? • recognise and address health issues?

The Watching Brief approach is essentially about identifying what makes life worthwhile for the person.

Health Decisions

When faced with a potentially serious health decision it is important that you ask the right questions on behalf of your family member. Here are some questions which may help:

- What is the condition which needs to be treated?
- What is the decision which needs to be made?
- What are the options for treatment?
- What are the effects of treatment?
- How will this treatment affect the person's quality of life – physical, material, social, emotional, and spiritual abilities and interests – what is their lived experience?
- How does that person experience values and meaning in their own life – this might be radically different from our own e.g. wind on their face, gentle touch, food?
- Is a second medical opinion needed?

There are a number of key issues you may wish to consider around serious medical intervention⁵, which are generally reflected in the Mental Capacity Act. The Act is clear that no one can be labelled 'incapable' simply as a result of a particular medical condition or diagnosis and that 'Best interests' goes beyond the person's medical interests. Doctors must adhere to the principles of the Act and carry out their decision in the person's best interests as defined in the Act. The issues you may wish to consider are:

- Any intervention by doctors or the medical profession should be to restore health
- Considerations need to be given to quality of life, in particular where quality of life would be so poor following medical treatment that intervention cannot be justified
- There should be a holistic approach to quality of life – not purely clinical data
- Quality of life includes: physical, material, social, emotional, and spiritual abilities and interests
- Quality of life is related directly to what an individual believes about their direction and status – well being and satisfaction is derived from lived experience
- Any judgement on quality of life should compare the condition of the person before to what is expected after treatment, not a generic model of health to a non-disabled person
- A doctor's decision should be based purely on health, not their role to assess value or worth of treatment
- Casting doubt over whether someone's life is worth living can introduce questionable assumptions and may lead to discrimination
- Problems of identifying a threshold for quality of life ignores actual, lived experience which is highly individual

⁵ Mencap (2001) Considerations of 'Quality of Life' in cases of medical decision-making for people with severe learning difficulties

- The existence of a complex disability and lack of capacity does not justify different standards of medical treatment
- If there is uncertainty the patient's disability should not be grounds for withholding treatment.

Change of Accommodation decisions

If the decision concerns a change of accommodation you may need to ask and think about the following issues⁶:

What the person wants:

- Where do they live now?
- Who do they live with?
- What do they like about living there?
- What don't they like?
- What help do they get?
- Can they get extra help if needed?
- Have they ever expressed a desire to move?

Does the person want to move?

- To a better area?
- Better house?
- Do they need more space?
- Is there a medical reason?
- Do they need to be near friends or family?
- Do they want to be more independent?
- Can they not stay where they are?

Who does the person want to live with?

- Other people?
- Friends?
- Family?
- In a house with others they know?
- On their own?

Where do they want to be?

- Town or country?
- Busy or quiet?
- Near friends or family?
- Within easy reach of shops or other places?
- Near work or day service?

Who could help with ideas?

- Social worker or care manager?
- Housing adviser?
- Specialist adviser?
- Housing or care provider?



⁶ The Foundation for People with Learning Disabilities (2000) Everyday lives, everyday choices: for people with learning disabilities and high support needs.

Example

Jennifer is an older person who has acquired deafblindness. She has only one surviving sister and they are very close and live near each other. Jennifer has until now lived independently but she now requires increasing amounts of help in the home to support herself. Social services are concerned that she is at risk and say that her best option is to move into residential care. They have tried to talk to Jennifer but she is confused about discussions that have taken place. The social worker has conducted a test of capacity and determined that Jennifer lacks capacity to make this decision.

Jennifer's sister asks for a specific assessment of her deafblindness by a specifically trained person or team who can find out if all appropriate services are being provided. She talks to the social worker about Jennifer's past and her wishes to remain independent. She asks about the range of options available and discusses that if she were to move she would like to remain near her sister. The social worker evaluates all the information and makes a best interest decision.

Challenging decisions and bad practice

You may find a decision maker makes a decision you are not happy with. There are a number of channels for challenging the decision. For disagreements about **health care** or treatment:

- Involving the Patient Advice and Liaison service (PALS) or the Community Health Council (Wales)
- Using the NHS complaints procedure
- Referring the matter to the local continuing care review panel (Primary Care Trust).

The Department of Health has published a national framework for England of eligibility criteria for NHS continuing care. The framework, which came into force on 1 October 2007, sets out a range of factors PCTs should consider when deciding whether someone meets the criteria for NHS continuing care. These include behaviour, psychological and emotional needs, and mobility.

For disagreements about **social care**:

- The care home's own complaint procedure
- Using the local authority's complaints procedure.

If there is substantial concern you may also refer the case to the Court of Protection.

Conclusion

This publication has provided ideas and skills for advocating for your family member specifically in the context of the Mental Capacity Act.

The Mental Capacity Act clarifies the process for caring for people who may lack capacity and how decisions should be made for your relative if they are unable to make decisions for themselves. The Mental Capacity Act provides a functional test of capacity, has governing principles and says that all decisions made on behalf of the person must be in their best interests. One of the principles is ensuring the person participates as fully as possible in the decision making process.

As a family member you may need to assess the capacity of your relative because you need to do something in order to care for them. This process applies to major as well as day-to-day decisions.

As a family member, a professional may also consult you about your relative's capacity concerning a particular decision about their health or accommodation needs. You can help the decision maker – health or social care professional – to ensure they take all reasonable practical steps to enable the person to participate in the decision as fully as possible, all information relevant to the decision is given to the person in the easiest and most appropriate way for them and they understand how the person communicates and what concepts they understand.

As well as ensuring communication with the deafblind person is central to the process in a decision making situation you will need to ask questions about the decision needing to be taken and be prepared to scrutinise and analyse options available. You may also wish to challenge a decision which you think has not been made in the person's best interests.



Glossary

Mental Capacity Act 2005 for England and Wales provides a framework to empower and protect people who may lack capacity to make some decisions for themselves. It clarifies who can take decisions in which situations, and how they should go about this. It also allows people to plan ahead for a time when they may lack capacity. It covers major decisions about someone's property and affairs, healthcare treatment and where the person lives, as well as everyday decisions about personal care (such as what the person eats), where the person lacks capacity to make those decisions themselves.

Mental Capacity Act Code of Practice (the 'Code') provides information and guidance for everyone affected by the Act, and explains how the Act works in practice. It describes the responsibilities of those who work with and care for adults who lack capacity, including family members, professionals and carers.

Independent Mental Capacity Advocate (IMCA) The Mental Capacity Act created a new service, the Independent Mental Capacity Advocate (IMCA) service. Its purpose is to help vulnerable people who lack capacity who are facing important decisions made by the NHS and Local Authorities about serious medical treatment and changes of residence – for example, moving to a hospital or care. Local authorities and NHS Trusts will be required, when making important decisions about serious medical treatment or change of accommodation for people who lack capacity, to appoint an IMCA to represent the individual if there is no-one else to support them. Regulations passed in the autumn 2006 extended the powers of local authorities and the NHS to instruct IMCAs in certain cases involving care reviews and adult protection cases. The IMCA's advice must be taken into account in the decision.



The Court of Protection was created under the Mental Capacity Act 2005. It has jurisdiction over the property, financial affairs, healthcare and personal welfare of people who lack mental capacity to make decisions for themselves. The Court also has the power to make declarations about whether someone has the capacity to make a particular decision. The Court has the same powers, rights, privileges and authority in relation to mental capacity matters as the High Court. It is a superior court of record and is able to set precedents (set examples to follow in future cases). The Court of Protection has the powers to:

- decide whether a person has capacity to make a particular decision for themselves;
- make declarations, decisions or orders on financial or welfare matters affecting people who lack capacity to make such decisions;
- appoint deputies to make decisions for people lacking capacity to make those decisions;
- decide whether a Lasting Power of Attorney (LPA) or Enduring Power of Attorney (EPA) is valid; and
- remove deputies or attorneys who fail to carry out their duties, and
- hear cases concerning objections to register an LPA or EPA and make decisions about whether or not an LPA or EPA is valid.

Lasting Power of Attorney (LPA)

An LPA is a legal document that someone (the Donor) makes using a special form. It allows that person to choose someone now (the Attorney) that they trust to make decisions on their behalf at a time in the future when they either lack the mental capacity or no longer wish to make those decisions themselves. The decisions could be about the Donor's property and affairs or about their personal welfare. Making an LPA is the only way to make plans for a time in the future when you may lack the capacity to make decisions for yourself. An LPA can only be used after it is registered with the OPG.

There are two types of LPA: A Property and Affairs LPA allows the Donor to appoint an Attorney to manage their finances and property whilst they still have capacity to make decisions for themselves. A Personal Welfare LPA allows the Donor to appoint an Attorney to make decisions on their behalf about their personal welfare. A Personal Welfare LPA can only be used when the Donor lacks the capacity to make these decisions for themselves. An Attorney will not be able to make decisions about a Donor's property and affairs unless they have also been appointed as a Property and Affairs Attorney using a separate LPA. An LPA is different to a Power of Attorney and an Enduring Power of Attorney (EPA). For more information about this role visit the website of the Office of the Public Guardian.

Enduring Power of Attorney

The Mental Capacity Act replaced Enduring Powers of Attorney (EPA) with a new and different type of power of attorney called a Lasting Power of Attorney (LPA). This means that you cannot make any changes to an existing EPA or make a new one. However if a person has an unregistered EPA, it can still be used and their Attorney will still need to register it with the Office of the Public Guardian if they have reason to believe the person is, or are becoming, mentally incapable in the future. An LPA can be made to run alongside an EPA if you wish. For example you may have an existing EPA that makes provision for decisions about your property and affairs, and decide to make a Personal Welfare LPA to run alongside that, to provide for decisions concerning your healthcare and welfare. An unregistered EPA can be replaced with a Property and Affairs LPA or revoked at any time if the person has mental capacity to do so. However, if the EPA has been registered, it cannot be revoked except by permission of the Court of Protection.

Deputy

Deputies deal with the property and affairs of someone who lacks capacity and the Court of Protection must grant the order to become a Deputy. The Deputy order you receive from the Court will set out the extent of your powers. It can apply to any area in which the person could have acted or made decisions for themselves if they had the capacity to do so. Your powers might relate to:

- finances;
- personal welfare, such as giving or withholding consent to medical treatment and/or social care interventions.

Powers given will depend on the needs of the person you have been appointed to assist and also the Court's decision.






Sources of Support and Further Information

Sense

101 Pentonville Road, London N1 9LG

-  Tel: 0845 127 0060
-  Textphone: 0845 127 0062
-  Fax: 0845 127 0061
-  E-mail: info@sense.org.uk
-  www.sense.org.uk

**Office of the Public Guardian will be moving offices as of Spring 2009.
Please contact them on the details below for their new address.**

-  Phone: 0845 330 2900 – Phone lines are open from 9am – 5pm
-  Email: customerservices@publicguardian.gsi.gov.uk
-  www.publicguardian.gov.uk

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