

Guidance

for Primary Care Health Professionals
on the Mental Capacity Act 2005



**Collingham
Healthcare
Education Centre**

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This *Guidance* provides introductory information to primary health professionals on the Mental Capacity Act 2005 (MCA 2005), the associated Code of Practice (Code) and how the statutory framework may affect the work that you do. It is not intended to replace the MCA 2005 and the associated Code. You should continue to consult the MCA 2005 and the Code for guidance on how the law may apply in specific situations. The checklists and case studies used in this *guidance* are for illustrative purposes only and should not be interpreted as providing situation-specific advice.

Preface

One of the enduring fascinations of general practice is the unexpected complexity of decisions presented in a routine day. Some are clinical, some relate to our relationships with our patients and others to ethics. One complex area that encompassed all three is that of the capacity of an individual patient to make a decision.

Most people can decide for themselves and come to a consultation as a partner in their care. However in primary care we encounter many people with minor or major, short term or long term difficulties in making decisions for themselves. In the past we have used our “common sense”, talking to relatives and carers and then hoping that what we did would turn out to be okay.

This situation placed us clinicians at some risk, and created considerable uncertainty in the consultation. Now help is at hand.

As I see it, the Mental Capacity Act 2005 – which only came into effect in 2007 – is a framework that allows us to be guided in handling these complex cases. Although this Guidance is intended to complement, and not replace, the use of the MCA 2005 and the Code, and does not provide situation-specific advice, it serves to clarify the Act. If we follow the principles in the Act, the guidance of the Code that accompanies the Act and the good advice set out in this document, we, as primary care clinicians, will be protected. That is, of course, if we also keep good records!

More importantly perhaps, our patients will be protected too. This framework should help to ensure that their rights are given proper weight and considered fairly when clinical decisions are being made.

Many health professionals will fear that this is totally new territory. However, we have become attuned to the requirements of *Gillick* competence and the Mental Capacity Act 2005 can be seen as a logical next step. Others will be rightly concerned about the time this will add to a busy working day. Although this guidance appears complex at first, it describes what good doctors and nurses already do.

This booklet is an excellent distillation of the Mental Capacity Act 2005 for those working in primary care. It demystifies the Act and offers clear checklists to make our working lives easier. I commend it to you.

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Introduction

Who is this *Guidance* for?

This *Guidance* is for primary care staff working with the Mental Capacity Act 2005 (“MCA 2005”) in England and Wales. This *Guidance* seeks to introduce you to some of the most important aspects of the MCA 2005 and the Code of Practice (“Code”) in the context of primary care. It is vital that you follow the requirements of the MCA 2005 and the Code when treating or caring for people who may lack or have reduced capacity to make a specific decision.

This *Guidance* is not intended to replace the Code. The Code should always be your principal source of reference for any questions that arise about the steps you should take when you think a person you are treating or caring for may lack or have reduced capacity to make a specific decision. Rather, this *Guidance* should be used by primary care staff to consult when necessary and as part of the member of primary care staff’s reflective learning.

This *Guidance* also uses checklists to illustrate how primary care staff may approach specific issues in practice in the context of the MCA 2005. The approaches used in the checklists are designed to encourage you to approach issues around capacity in practice in a way envisaged by the MCA 2005 and the Code. There has to be flexibility. The checklists are not intended to cover all issues around capacity that may arise. Precisely how you approach these issues may differ from case to case.

There is a glossary of relevant terms used in this *Guidance*, at the end.

Your obligations under the MCA 2005 and the Code

The MCA 2005 applies to people who make decisions for those who may lack or have reduced capacity to make a specific decision. As a doctor or nurse working in primary care, you are under a duty to have regard to the Code when making any decision or taking any action for a person who lacks the capacity to make a decision or to consent to an act themselves.

It is vital to try to involve a person who you think may lack or have reduced capacity to make a specific decision, in the decision-making process. We have tried to emphasise the importance of this in the *Guidance*.

In section 4, we introduce you to the 2 stage statutory test for assessing a person’s capacity. In order to put this in proper context, in section 2 we explain the five principles (which should inform everything you do when working with people whom you believe may lack capacity) and the importance of taking all practicable steps to help and support a person to make their own decision, without success (section 3).

For ease of expression, this book uses “he” to mean “he or she” (unless otherwise apparent or appropriate).

Section 1: Fundamentals

What kinds of decision require a formal, recorded assessment of capacity?

There is currently no Department of Health guidance which explains exactly what level of assessment should be undertaken by primary care staff in particular situations and what should be recorded. This is because the MCA 2005 encourages all practitioners (not just primary care staff) to carry out situation specific assessments of mental capacity and local procedures vary for different kinds of staff (for example, nurses, occupational therapists, social workers, care workers in homes and care workers in domestic situations).

The kinds of decision covered by the MCA 2005 range from the minor to the serious. However, as a general approach, the more serious a decision (in relation to which the assessment of a person's capacity relates), the more formal should be the assessment. More serious decisions have greater consequences for the person who is thought to lack capacity and justify a more formal assessment of capacity.

What is lack of capacity under the MCA 2005?

Lack of capacity means the inability to make a particular decision or consent to a particular act at the time the decision has to be made.

Must lack of capacity be permanent?

No. Lack of capacity may be temporary or permanent. It is very important to remember that a person's ability or otherwise to make a particular decision or consent to a particular act is time-specific. If a person lacks capacity temporarily (perhaps because of the effects of medication or alcohol), depending upon the circumstances it may be appropriate to wait until the person regains capacity to make the particular decision or consent to a particular act. All assessments of capacity should be decision and time-specific.

Who may lack capacity?

If a person lacks capacity, this may be due to a range of causes commonly encountered in primary care. These include dementia, significant learning disabilities, brain injury, concussion following a head injury, the effects of a stroke, brain tumours, physical and medical conditions that cause confusion, drowsiness or loss of consciousness, neurological disorder, conditions associated with some forms of mental illness, delirium and the effects of drug or alcohol use. Lack of capacity may be temporary or permanent.

What kinds of decision are not covered by the MCA 2005?

Decisions about marriage or civil partnership, divorce, sexual relationships, adoption and voting cannot be made by another person on behalf of a person who lacks capacity.

What is the Code of Practice?

The Code of Practice (Code) tells you how the MCA 2005 applies in a range of practical situations, and explains the law in more detail. As someone who works in primary care with people who may lack capacity from time to time, you are under a legal duty to have regard to the Code. Put simply, this means that you have to be familiar with the guidance in the Code, follow it and, if you do not follow it, be able to show good reasons why you did not.

Section 2: Five principles

The MCA 2005 is designed to empower and protect people who lack capacity. The five principles work towards this, for example by enhancing the ability of people who lack capacity to participate in decision-making as much as possible.

You need to remember the five principles whenever you propose to make any decision or take any act for a person who you consider may lack capacity. These principles should inform everything that you do when working with people whom you believe may lack capacity.

You should assume that every person over the age of 16 years has the capacity to make their own decisions, unless it can be shown that the person lacks capacity.

This principle supports the idea that every adult has a right to make their own decisions, providing they have the capacity to do so. Even if a person needs help to make a decision, this may not mean they lack the capacity to make it.

You should not treat someone as being unable to make a decision until all practicable steps to help and support them to make a decision have been taken, without success.

This principle supports the idea that every adult should be offered appropriate help and support to make their own decision (see section 3).

You should not treat a person as lacking the capacity to make a decision, simply because his decision is unwise.

This principle supports the idea that people have a right to make unwise decisions and this should not lead you to conclude that this must indicate a lack of capacity to make a decision. There may be cause for concern if somebody repeatedly makes unwise decisions that put them at significant risk of harm or exploitation, or makes an unwise decision that is obviously irrational or out of character.

Any act done or decision made on behalf of a person who lacks capacity must be done or made in their best interests.

This principle is straight forward. There is no definition of best interests, but there is now a clearer route to establishing it (see section 5).

Any act done or decision made on behalf of a person who lacks capacity must be the least restrictive of that person's basic rights and freedoms.

This principle is about finding the least restrictive alternative. Of course, you should also think about whether you need to act or make a decision at all. If you must, remember that your decision must still be in the person's best interests.

Section 3: Step 1 - Help with decision-making

This section looks more closely at the second principle:

You should not treat someone as being unable to make a decision until all practicable steps to help and support them to make a decision have been taken, without success.

Think of this as the first step. It is very important to offer all practicable help and support to a person who you think may lack capacity first, before you decide that person lacks the capacity to make the decision.

What is meant by practicable?

You need to offer what help and support is possible and appropriate, bearing in mind:

- the individual circumstances of the person making the decision;
- the nature of the decision which needs to be made; and
- the time available to make it.

What do you need to do?

Simply put, as a primary care clinician, you need to present relevant information to the person who may lack capacity in a way that they will best understand:

- Identify what information is relevant to the decision that you want to help the person to make.
- Identify the person's needs and abilities and match the information you convey to these.
- Communicate the information in a way that the person will find easiest to understand.
- Explain the advantages and disadvantages of making the decision in question (and of making no decision at all).

What communication strategies can I use in my consultations?

You can use pictures, objects and illustrations.

You should use simple language and break down information into smaller pieces that are easier for the person to understand.

You can speak to people who know the person well, to find out what methods of communication they best respond to.

Remember to bear in mind specific cultural, ethnic and religious factors that can shape a person's way of thinking, behaviour, way of communication or factors *they* consider to be relevant.

You can engage the help of people whom the person trusts (such as a carer, social worker or designated support worker). If you do, remember that you can only share as much information about the person as is in their best interests (see section 5).

Check the person understands what you have told them, after a brief period. You may repeat information several times if you feel this is necessary.

Address specific communication or cognitive problems (using sign language, visual aids, computers, Makaton).

Choose an environment where the person is most at ease and time of day when the person is most alert.

Step 1 – Help with decision-making

Try this simple checklist

1. Are you clear about the decision that has to be made?
2. Can the decision be postponed until a time when the person is better able to participate?
3. Have you given the person all relevant information to help them make an informed decision?
4. Have you covered all important information?
5. Have you explained the risks and benefits of the decision in a balanced way?
6. Have you explained the consequences of making no decision at all?
7. Have you considered whether the person may need support from a friend or family member whom they trust?
8. Have you considered whether you may need more specialist medical advice from elsewhere?
9. Does the person feel at ease? Is the time of day and environment right?
10. Have you thought about and (if appropriate) explored the most effective way of communicating information to the person so that they will receive it in a way that they will best understand?
11. Have you tried all possible and appropriate means of communication?
12. Speak to people who know the person about the best form of communication for them.
13. Use simple language and (if appropriate) images.
14. Break down important information into smaller, easier to understand points.
15. Would the use of an advocate improve communication?
16. Be aware of cultural, ethnic or religious factors that may shape the way the person behaves, thinks or communicates.

CASE STUDY 1

Mrs Brown has early dementia. Her daughter accompanies her to an appointment for a 'flu immunisation and the practice nurse needs to explain the implications.

Context

This example is concerned with Step 1 of the *Guidance*, help with decision making.

Principle

In order to fulfil the second principle, the practice nurse should make sure that she does not treat Mrs Brown as being unable to decide whether to have a 'flu immunisation until all practicable steps to help and support her to make her own decision have been taken, without success.

This means the practice nurse:

- has to clearly understand the decision that she will support Mrs Brown to make; and
- will offer Mrs Brown all possible help and support that is appropriate, bearing in mind Mrs Brown's individual circumstances (her early dementia) and the nature of the decision which needs to be made ('flu immunisation).

Practice

To achieve this and to fulfil the guidance in the Code, the practice nurse needs to present relevant information to Mrs Brown in a way that she will best understand. This will involve the practice nurse:

- identifying what information is relevant to Mrs Brown's decision;
- identifying Mrs Brown's needs and abilities and thinking about how to match relevant information to these;
- importantly, communicating relevant information in a way that Mrs Brown will find easiest to understand:
- this may involve using simple language and breaking down information into smaller pieces that are easier for Mrs Brown to understand;
- the practice nurse will check to see whether Mrs Brown understands why she is at the surgery (to have a 'flu immunisation);

- the practice nurse may ask Mrs Brown's daughter how she might best explain to Mrs Brown why she needs a 'flu immunisation (to help to protect her against 'flu).
- explaining to Mrs Brown the advantages and disadvantages of making the decision and of making no decision at all, in a balanced way.

The practice nurse may repeat information to check that Mrs Brown understands what is being proposed, if she considers this is necessary. She should check Mrs Brown's understanding of the decision after a brief period by asking Mrs Brown to tell her what she understands will happen. Assuming that the practice nurse and Mrs Brown's daughter are satisfied that she understands and agrees to having a 'flu immunisation, the nurse should clearly record Mrs Brown's decision and the steps taken to reach it.

Section 4: Step 2 – Assessing capacity

If you have taken all practicable steps to help and support a person who you think may lack capacity to make a decision, without success, you can assess their capacity.

Remember:

- there is an assumption that every person over the age of 16 years has capacity to make their own decisions, unless there is evidence to the contrary (principle 1); and
- a person who needs help to make or communicate a decision does not necessarily lack the capacity to make it.

What do we mean by “capacity”?

A person’s capacity means the ability to make a decision (including consenting to treatment). You will be responsible for assessing the person’s capacity to make a specific decision at a specific time if you are responsible for carrying out the particular medical or related treatment to which the decision relates.

Assessing capacity

The test for assessing capacity is in 2 stages:

Does the person have an impairment of, or a disturbance in the functioning of, the mind or brain?

If no, the person has capacity.

If yes, the person may lack capacity. You must move onto stage 2.

Does the impairment or disturbance mean that the person is unable to make a specific decision, at the time they need to?

If no, the person has capacity.

If yes, the person lacks capacity.

Your clinical records should show that the 2 stage test was used.

Impairment of, or a disturbance in the functioning of, the mind or brain.

This means there is an impairment of the person’s mind or brain, or a disturbance that affects the way the person’s mind or brain works. Examples of an impairment or disturbance may include (but is not limited to) the following: dementia, significant learning disabilities, brain injury, concussion following a head injury, the effects of a

stroke, brain tumours, physical and medical conditions that cause confusion, drowsiness or loss of consciousness, neurological disorder, conditions associated with some forms of mental illness, delirium and the effects of drug or alcohol use.

Inability to make a specific decision

The impairment or disturbance must affect the person's ability to make a specific decision at a specific time. This part of the test only applies if you have given the person all practicable help and support to make that decision themselves, without success.

The person is unable to make a specific decision at the time they need to make that decision if any one of the following four criteria is satisfied, namely the person is unable to:

- communicate their decision by any means;
- understand relevant information about the decision to be made;
- retain that information in their mind long enough to make the decision themselves; or
- use or weigh up that information as part of the decision-making process.

If any one of these is satisfied, the person is unable to make a particular decision.

Balance of probabilities

When you assess capacity, your view should be based upon the balance of probabilities test (meaning more likely than not).

Temporary or fluctuating capacity

From time to time, you may come across people whose lack of capacity is temporary, or which fluctuates. What is relevant is the person's ability to make a specific decision at a specific time. However, in some cases it may be possible to postpone the decision until a later time, when you think the person may have capacity to make it.

Remember that the person's circumstances may change so in some cases you may need to repeat or review an assessment of capacity for different decisions.

Reasonable belief

It is important only to have a reasonable belief that a person lacks capacity to make a decision, if you have assessed them. Broadly speaking, you will hold a reasonable belief if you have:

- started with the assumption of capacity (principle 1); and
- followed the 2-stage test for assessing capacity properly.

Not only will this help to empower and protect vulnerable people, but this will also help to provide you with protection should your decision be challenged. You need:

- to be able to give reasons why you decided that a person lacked capacity to make a specific decision at a specific time; and
- to be able to provide objective evidence to support that belief.

Record keeping

We will guide you through the process of record keeping when assessing capacity in section 8.

Step 2 – Assessing capacity

Try this simple checklist

1. Have you taken all practicable steps to help and support the person to make the decision, without success?
2. Can the decision be postponed until a time when the person is better able to participate?
3. Have you started from the assumption of capacity in adults over the age of 16 years, unless there is evidence to the contrary?
4. Does the person have an impairment of or a disturbance in the functioning of the mind or brain?
5. Does the impairment or disturbance mean that the person is unable to make a specific decision, at the specific time they need to (disregard the person's ability to make decisions in general)? In particular, consider:
 - Is the person able to communicate their decision by any means?
 - Is the person able to understand, retain (for as long as is required) or use and weigh up the information you have given them, to reach a decision?
6. Where the assessment of capacity relates to a decision with particularly serious consequences for the person, have you considered whether there is a need for a more thorough assessment of capacity (to be carried out by someone with particular expertise, for example)?
7. Before you act, do you consider that you now have a reasonable belief that the person lacks capacity to make the decision or agree to the act of care or being proposed?
8. Have you recorded your assessment and reasons (the more complex the assessment or the more serious the consequences of your assessment for the person, the more comprehensive should be your record)? Would this withstand a challenge to your decision?
9. Have you made sure that your decision about the person's capacity is not based simply upon the person's age, appearance (physical appearance, characteristics, dress (including religious dress)), assumptions about their condition or any aspect of their behaviour?

CASE STUDY 2

Mr Kotecha, 82, who has advanced dementia and diabetes, is cared for at home by his wife. The community nurse was asked to visit to advise on his occasional incontinence. The nurse found that Mr Kotecha had an untreated leg ulcer which, if left untreated, would put Mr Kotecha at significant risk. The nurse knows Mr Kotecha well and doubts his ability to make his own decision about treating the leg ulcer. Assume that Mr Kotecha is able to communicate with the nurse.

Context

This example is concerned with Step 2 of the *Guidance*, assessing capacity.

Principles

The decision relates to treating Mr Kotecha's leg ulcer. Although Mr Kotecha's community nurse doubts his ability to make a decision for himself, she should start from the position of assuming that Mr Kotecha has the capacity to make this particular decision, unless there is evidence to show that he lacks the capacity to do so (first principle). Even if the nurse has to help Mr Kotecha to make the decision, this does not necessarily mean that he lacks the capacity to make it.

The nurse should not treat Mr Kotecha as being unable to make the decision until all practicable steps to help and support him to make it have been taken, without success (second principle). Only if this is the case should the nurse assess Mr Kotecha's capacity to make the decision using the two-stage test.

Practice

Does Mr Kotecha have an impairment of or a disturbance in the functioning of the mind or brain?

There must be an impairment of Mr Kotecha's mind or brain, or some disturbance that affects the way his mind or brain works. Mr Kotecha has advanced dementia, so this part of the test is fulfilled.

Does the impairment or disturbance mean that Mr Kotecha is unable to make a specific decision, at the specific time they need to?

The nurse must disregard Mr Kotecha's ability to make decisions in general. The impairment or disturbance must affect Mr Kotecha's ability to make a specific decision at a specific time. The nurse will ask Mr Kotecha some simple questions to begin, such as "*What is your name and date of birth?*" and "*Where are you now?*" The nurse will give Mr Kotecha some simple information about the nature of his leg ulcer and will ask Mr Kotecha to repeat that information.

In relation to the decision that needs to be made, the nurse should decide on the balance of probabilities (more likely than not) whether Mr Kotecha is able to:

- understand relevant information about the decision;
- retain that information in his mind long enough to make the decision himself; or
- use or weigh up (evaluate) that information as part of the decision-making process.

If Mr Kotecha cannot do any of these three things, he is treated as being unable to make the decision.

The nurse's decision about Mr Kotecha's capacity must not be based merely upon his age, appearance, assumptions about his condition or any aspect of his behaviour. The nurse will ask Mr Kotecha's wife whether her husband has good days and bad days (occasions when Mr Kotecha might be able to make a decision about treating his leg ulcer). Mrs Kotecha confirms that he does not. The nurse decides that Mr Kotecha lacks capacity to make this decision and clearly records her assessment with reasons.

Section 5: Step 3 – Best interests

This section is concerned with the fourth principle:

Any act done or decision made on behalf of a person who lacks capacity must be done or made in their best interests.

There is no definition of the best interests of the person who lacks capacity. This is because a person's best interests will vary according to a number of factors in any given situation. But the MCA 2005 tells you what different factors you should consider applying when working out a person's best interests. Critically, you should focus upon the best interests of the person who lacks capacity.

Whose decision?

You will be the decision-maker for medical and related treatment (investigations and procedures, nursing care) if you are responsible for carrying out the particular treatment of procedure in question (even if the decision to deliver it was reached after consultation with other staff).

What should I take into account?

You need to take into account all relevant circumstances when deciding whether a proposed decision or act is in a person's best interests. Relevant circumstances are defined as those things which you, as decision-maker, are aware of and which it would be reasonable to regard as relevant.

What does this mean in practice?

Consider whether it is likely (on the balance of probabilities) that the person will regain capacity to make the decision in question, at a later time. If this is likely, consider postponing the decision until then.

As far as reasonably practicable, you should permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in making the decision affecting him.

As far as you are able to do so, consider all relevant circumstances. This means identifying things like:

- The person's past and present wishes and feelings (including any relevant statement of wishes and feelings made by him when he had capacity);
- The beliefs and values that would be likely to influence his decision if he had capacity; and
- Other factors that the person would take into account, if he were able to do so.

As far as it is practicable and appropriate to do so, you are also under a duty to consult and take into account the views of:

- Anyone the person has named as someone to consult in relation to the decision in question or similar issues;
- Anyone involved in caring for the person;
- Anyone interested in the person's welfare (such as near relatives and friends);
- An attorney (if the person has made a personal welfare or a financial power of attorney); or
- Any court-appointed deputy.

If you are making a decision about major medical treatment and the person has no-one whom you can consult within the categories above, an Independent Mental Capacity Advocate must be consulted.

What else do I need to do?

You need to check that the decision or act proposed must be the least restrictive of the person's rights and freedom of action (principle five).

You need to weigh up all of these factors in order to work out what is in the person's best interests.

What about confidentiality?

This is explored in greater detail in Section 9 below. Even though you are under a duty to consult others, you must still respect the person's right to privacy. This means you need to take care when sharing information about them with others.

Are there any other considerations?

Yes. These relate to decisions that come before the Court of Protection, court appointed deputies, attorneys appointed under a personal welfare LPA and advance decisions to refuse medical treatment.

Some healthcare and treatment decisions are so serious that in each case, an application should be made to the Court of Protection for a declaration that the proposed action is lawful, before it can be taken. The Court of Protection will only be involved where particularly complex decisions or difficult disputes are involved, for example where there is a doubt or dispute about whether a particular treatment will be in the person's best interests. If there is a need for on-going decision making powers and there is no relevant LPA, the court may have appointed a deputy to make future healthcare decisions so it is very important to check this.

An attorney appointed under a registered personal welfare LPA will be the decision-maker on all matters relating to the care and treatment of the donor who now lacks

capacity. Unless the LPA imposes conditions or restrictions of the attorney's authority (it is very important to check for these), the attorney will have the authority to make decisions about the personal welfare of the donor who now lacks capacity. This includes the ability to consent to or refuse medical examination and treatment. An attorney does not have the power to consent to or refuse life-sustaining treatment unless the LPA document expressly authorises this.

A valid and applicable advance decision to refuse medical treatment represents an exception to the best interests principle. The advance decision must be respected when the person lacks capacity, even if you consider that the decision to refuse treatment is not in their best interests. We look at advance decisions in more detail in section 7.

An attorney appointed under a registered personal welfare LPA cannot consent to specific treatment if the donor has made a valid, applicable advance decision to refuse that treatment. However, if the donor (when he had capacity) made a personal welfare LPA after the advance decision and gave the attorney the right to consent to or refuse this treatment, the attorney can choose not to follow the advance decision.

Step 3 – Best interests

Try this simple checklist

1. Have you taken all practicable steps to help and support the person to make the decision, without success?
2. Can the decision be postponed until a time when the person is better able to participate?
3. Identify and consider:
 - evidence of the person's past and present wishes and feelings (whether or not in the form of a written statement);
 - evidence of the person's beliefs and values (religious, cultural, moral, political) which are likely to have influenced the decision in question; and
 - any other factors of which you are aware and which, objectively, it would be reasonable to regard as relevant
4. Have you consulted others for their views about what may be in the person's best interests and to obtain any information about the person's wishes and feelings, beliefs and values (anyone named by the person, carers, near relatives, friends, any attorney or a court appointed deputy, or (in relation to major medical treatment) any IMCA appointed)?
5. Have you made sure that your decision about the person's best interests is not based simply upon the person's age, appearance (physical appearance, characteristics, dress (including religious dress)), assumptions about their condition or any aspect of their behaviour?
6. Have you considered whether there are other options that may be less restrictive of the person's rights and freedoms?
7. Have you weighed up all of these factors in order to work out what is in the person's best interests?

CASE STUDY 3

Miss Grey is 18 and has severe learning difficulties. She sees her General Practitioner (GP) accompanied by Mrs Grey, her mother, to discuss her heavy periods. After some discussion, the GP suggests that the oral contraceptive pill may offer the best treatment for Miss Grey's heavy periods. Mrs Grey is worried about her daughter taking the oral contraceptive pill and seems opposed to the suggestion. Assume that the GP has assessed Miss Grey's capacity to make a decision about the most appropriate form of treatment for her heavy periods, after taking all practicable steps to help and support her to make her own decision (without success). He has concluded that she lacks capacity to make a decision about this.

Context

This example is concerned with Step 3 of the *Guidance*, best interests.

Principles

In order to fulfil the fourth and fifth principles, the GP should make sure that any act done or decision made on behalf of Miss Grey:

- is done or made in her best interests; and
- is the least restrictive of her basic rights and freedoms.

Of course, the GP should:

- think about whether he needs to act or make a decision at all. If he must, the decision must still be in Miss Grey's best interests; and
- have taken all practicable steps to help and support Miss Grey to make the decision, without success.

Practice

Any decision to offer the oral contraceptive pill should be clearly indicated. The GP should ask Mrs Grey:

- whether her daughter has ever expressed a view on controlling her heavy periods or taking the pill (whether or not such expression is in the form of a written statement);
- whether her daughter has any beliefs and values that need to be considered (religious, cultural, moral) which are likely to have influenced the decision if she had the capacity to make it; and
- as her daughter's carer and mother, what she considers should happen to her daughter and why. While the views of Miss Grey's mother are

important in working out what course of action would be in Miss Grey's best interests, the decision must not be based upon what Mrs Grey would prefer. It must be based upon the best interests of Miss Grey.

The approach is now more holistic. The GP should try to find ways to involve Miss Grey in the decision and should consider any other factors which he is aware of and which, objectively, it would be reasonable to regard as relevant. As with the assessment of a person's capacity, the GP's decision must not be based merely upon Miss Grey's age, appearance, assumptions about her condition or any aspect of her behaviour. The GP should also consider whether there are other options that may be less restrictive of Miss Grey's rights and freedoms. The GP decides that offering Miss Grey the oral contraceptive pill is in her best interests and is the least restrictive option for controlling her heavy periods. This is the GP's advice to Mrs Grey. He clearly records his assessment of Miss Grey's capacity to make this decision and the factors he has taken into account to determine Miss Grey's best interests (reasonable belief).

Section 6: Protection for acts of healthcare or treatment

There is now statutory protection if you, as a primary healthcare clinician, perform an act of healthcare or treatment where it is in the best interests of the person who lacks capacity to consent to it. You must take certain steps to receive this protection. This statutory protection does not apply to any act giving rise to civil liability for negligence or to any criminal liability.

Why is there protection?

It allows actions to be taken to make sure that a person who lacks capacity to consent receives treatment that is in their best interests.

What is covered?

Healthcare and treatment includes things like providing nursing care, carrying out diagnostic examinations and tests, providing professional medical treatment and prescribing or giving medication, providing emergency care, carrying out other necessary medical procedures and therapies and arranging to refer someone to hospital for an assessment or for treatment.

What steps must I take to receive protection?

There are broadly two steps that you need to satisfy:

1. Before performing the act of healthcare or treatment, you must have taken reasonable steps to establish the person lacks capacity in relation to the act proposed. Reasonable steps means taking all practicable and appropriate steps to help people make a decision about an action themselves (see Section 3); and
2. Applying the two-stage test of capacity (see Section 4).

When performing an act of healthcare or treatment, you must reasonably believe that:

- The person lacks capacity in relation to the matter; and
- It is in the best interests of the person for the act to be performed.

If you satisfy these two steps, you can treat the person as if he had capacity to consent to treatment and had so consented (subject of course to ascertaining first whether the decision is one that must or ought to be referred to the Court of Protection, whether there is a court-appointed deputy, a registered personal welfare LPA or a valid, applicable advance decision to refuse specific medical treatment).

If your decision is challenged, you have to be able to provide some objective reasons that explain why you reasonably believe that the person lacks capacity to consent to the act proposed so it is vital that you clearly record your reasonable belief with reasons.

Emergency treatment

In emergency situations, you have less time to come to a conclusion about the steps above so it will almost always be in the person's best interests to give urgent treatment without delay (this is subject to separate requirements about advance decisions).

Section 7: Advance decisions to refuse medical treatment

A person who is 18 years of age and over and has capacity can refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment.

Do advance decisions only relate to refusals of treatment?

Yes. It is not possible for a person to compel a healthcare professional to treat them in a particular way, whether or not in advance.

Are these different from statements of wishes and feelings?

Yes. Valid advance decisions are about the refusal of medical treatment and bind medical staff. Statements of wishes and feelings are non-binding, but should be taken into account when working out the best interests of a person who lacks capacity. Either expression may be communicated to you verbally, but there are certain formalities associated with an advance decision to refuse life sustaining medical treatment (please see below).

What are the requirements of an advance decision?

The person making an advance decision must be 18 years of age and over and must have the capacity to make an advance decision.

To be effective, an advance decision must:

- exist;
- be valid; and
- be applicable to the circumstances under which it is considered.

Is an advance decision a formal document?

An advance decision need not be a formal document. Unless the advance decision includes a refusal of life-sustaining medical treatment (see below), it can be communicated verbally or put in writing.

An advance decision need only be in the words of the person making it, as long as it is clear about what treatment is being refused.

Life-sustaining treatment

An advance decision to refuse life-sustaining treatment must:

- be in writing;
- be signed by the person making it and witnessed; and
- contain the words “even if life is at risk”. If these words are contained in a separate document, that document must also be signed and witnessed.

As a medical professional, can I witness the document, if asked?

Yes, you can. You are only witnessing the signature and the fact that it concerns the wishes in the advance decision.

What should people include in an advance decision?

An advance decision:

- must state precisely what treatment is to be refused (an expression of a general desire not to be treated is not enough)
- may set out the circumstances when the refusal should apply (although not obligatory, it is helpful to include as much detail as possible)
- will only apply at a time when the person lacks capacity to consent to or refuse the treatment specified.

What about decisions refusing all treatment in any situation?

An advance decision refusing all treatment in any situation may be valid and applicable (for example, this may be based on a person’s personal or religious beliefs).

How do advance decisions relate to personal welfare Lasting Powers of Attorney (LPA)?

A registered personal welfare LPA may entitle an attorney to refuse medical treatment on behalf of a donor who has lost capacity to refuse. A registered personal welfare LPA only becomes valid when the donor lacks the capacity to make decisions about personal welfare (which can include healthcare and medical treatment decisions, subject to any conditions or restrictions to areas where they would not wish the attorney to have the power to act).

There are three situations:

1. a personal welfare attorney cannot consent to treatment if the donor made a valid and applicable advance decision to refuse that medical treatment after the date the LPA was signed;
2. a registered personal welfare LPA which gives the attorney the right to consent to or refuse specific medical treatment, made after the advance

decision, allows the attorney to choose not to follow the advance decision;
and

3. an attorney has no power to consent to or refuse life-sustaining treatment unless the LPA document expressly authorises this.

What else do I need to be aware of?

As a primary care worker, you may find the following helpful:

- Where appropriate, when discussing treatment options with a person who has capacity, you may consider asking whether there are any specific kinds of treatment they do not wish to receive if they should ever lack capacity in the future.
- An advance decision that is regularly reviewed and (where necessary) updated is more likely to be valid and applicable to current circumstances.
- Clearly record a verbal advance decision in a person's healthcare records. The record should also state:
 - o the treatment to be refused and the circumstances in which it will apply;
 - o that the decision should apply if the person lacks the capacity to make treatment decisions in the future;
 - o details of any people present with you when you recorded the verbal advance decision in the healthcare records; and
 - o whether you heard the decision, took part in it or are simply aware that it exists.

Protection

As a primary healthcare professional, you will be protected from liability if you:

- stop or withhold treatment from a person who lacks capacity because you reasonably believe that a valid, applicable advance decision exists; or
- treat a person who lacks capacity because, despite having taken all practical and appropriate steps, you do not know or are not satisfied that a valid and applicable advance decision exists.

It is good practice for all healthcare practitioners to record their decision and the reasons for it. It is important to remember, however, that in the absence of a valid and applicable advance decision, you must still treat in accordance with the patient's best interests.

Try this simple checklist

1. Identify whether the person has expressed an advance decision to refuse medical treatment?
2. Is the person 18 years of age or more and do they have capacity to make an advance decision to refuse medical treatment (remember the assumption of capacity in adults – principle 1)?
3. Does the advance decision state precisely what treatment is to be refused (a statement giving a general desire not to be treated is not enough)?
4. Does the advance decision set out the circumstances under which the refusal should apply (this is not mandatory, but it is helpful to include as much detail as possible)?
5. Has the person sought or been offered advice about making an advance decision? It is good practice to record any discussion about this in the person's healthcare records.
6. If an advance decision has been expressed verbally, has the person been offered the opportunity for their advance decision to be recorded in their healthcare records? Where possible, a verbal advance decision should be so recorded to prevent confusion in the future.
7. If the person makes an advance decision to refuse life-sustaining treatment, is the advance decision in writing, signed by the person making the advance decision, signed by a witness and contains the words "*even if life is at risk*"?
8. Have you advised the person to regularly review their advance decision, to make sure it is kept up to date?

Section 8: Record keeping and dealing with challenges

Record keeping

Good record keeping is at the heart of the MCA 2005.

Assessing capacity and record keeping

When you assess a person's capacity to make a decision, you must keep a formal, clear record, particularly where this concerns long-term or significant plans about capacity. The more significant the decision or consequences of that decision, the more formal the assessment.

You must record your decision, your reasons, who you consulted and what information you took into account (in other words, you describe how you reached your reasonable belief and this will also help you if your decision is ever challenged, or reviewed by the Court of Protection). Your record is evidence of your reasonable belief.

Although it should not be necessary to record assessments of capacity for minor, everyday decisions, a care plan should reveal that the person's capacity to make these kinds of decision has been assessed and there is intention to review capacity periodically. You should assess and record a person's capacity to make decisions about their healthcare or treatment. This also means that you do not assume a person's lack of capacity is permanent. If a new decision about capacity is being made, this must also be recorded.

Keep a clear record of your assessment of a person's capacity to consent to proposed treatment. Some Primary Care Trusts have a proforma for healthcare professionals to complete. A person's capacity to agree to the provision of services will be assessed as part of the care planning processes for health and social care needs, and this assessment must be recorded. It may not be necessary to record every intervention, but there would have to be provision to review that person's capacity periodically.

Best interests and record keeping

Record any act of healthcare or treatment for a person who lacks capacity (such as performing diagnostic examinations and tests, giving medical treatment and nursing care, arranging admission to hospital for assessment or treatment, giving medication, taking blood samples, therapies or emergency care).

This is because you need to be able to identify evidence in the clinical notes that you reasonably believe that the decision or act proposed is in the best interests of the person who lacks capacity.

Whilst you need not clearly record very minor decisions, you should assess and record the best interests of a person whom you have assessed as lacking the

capacity to make a particular decision about their healthcare or treatment. Similarly, a record should be made wherever any care or treatment proposed is substantial or long term.

Any potentially contentious decision may be discussed at a Significant Event Auditing meeting. Colleagues will want to review your decision in the light of the Code and the checklists in this *Guidance*. Their support may be invaluable in reflecting on the event, understanding the implications of the MCA 2005 and offering support should there be a challenge.

Dealing with challenges

From time to time, decisions about whether a person lacks capacity, or whether a proposed decision or act is in the best interests of a person, may be challenged. Decisions may be challenged by, for example, an Independent Mental Capacity Advocate, a family member or carer, or even the person whose capacity you assessed.

Challenges to your assessment of capacity

If someone wishes to challenge your assessment of capacity, they should raise it with you. If the challenge comes from the person whose capacity you assessed, they may need support from family, friends or an advocate.

The person challenging your assessment of capacity is entitled to ask you why you believe the person lacks capacity to make a specific decision and for objective evidence to support that belief. You need to be able to show that you have had regard to the Code and have applied the key principles (see section 2 above).

Challenges to your 'best interests' decision

As decision-maker, you may be faced with people who disagree about what is in the person's best interests. While you are under a duty to consult and take views into account, it is your responsibility to decide what is in the best interests of the person. Some of those people may disagree with your decision. Where you are faced with conflicting views and depending on the amount of time you have available, you may want to adopt this strategy:

- Review your best interests checklist with everyone involved (including the person who lacks capacity). Explain how you have come to your view. You may be able to show those who disagree with your view, why you have reached your decision.
- Consider a meeting so that everyone involved can talk about their concerns.
- Consider alternative forms of conflict resolution, such as mediation (please see below).
- You may not be able to resolve conflicting views. Ultimately, the responsibility for working out a person's best interests is yours.

Conflict resolution

There are many ways to resolve disagreements. It is better to try to resolve disagreements informally. Often, by simply explaining the reasons for your decision, it is possible to avoid a more serious disagreement.

Ways to resolve disagreements include:

- Revisiting the assessment (whether an assessment of capacity or best interests)
- Seeking a second opinion
- Following the local NHS complaints procedure
- Mediation

Mediation is a non-adversarial and voluntary process. A mediator is independent and acts as a facilitator. A mediator works with the parties to identify their concerns and helps them to resolve areas of disagreement. Parties who take part in mediation have a real stake in the process and a mediator empowers them to resolve the dispute themselves. This is why mediation is often very successful.

When any form of conflict resolution is employed, it is very important not to lose sight of what is in the person's best interests.

Section 9: Confidentiality and sharing information

From time to time, you will encounter issues about the disclosure of personal information involving patients who lack capacity to make a particular decision. The MCA Code provides some useful guidance on how to share information. This *Guidance* is in addition to (and does not replace) common law, statutory provisions (for example, the Data Protection Act 1998) and your own professional guidance about disclosure of and access to confidential information and should be read in conjunction with that.

The NHS Confidentiality Code of Practice

Under the NHS Code on Confidentiality, where the person lacks capacity and is unable to consent to acts of care or treatment, confidential information should only be disclosed in the patient's best interests and then only as much information as is needed to support their care (*Annex B – Confidentiality decisions*).

Attorneys

An attorney appointed under a LPA who requests confidential information about the donor is legally entitled to this, as if they were the donor, providing the attorney is acting within the scope of his authority and the information applies to decisions the attorney has the legal right to make. You should ask to see proof of identity and appointment. The attorney should treat the information confidentially.

Where a third party requires confidential information, an attorney appointed under a registered personal welfare LPA will determine if the confidential information can be disclosed. You must consult the attorney before sharing confidential information with a third party.

If for some reason it is not possible for you to speak to the attorney about disclosing confidential information to a third party (it may be the case that urgent treatment is necessary) you must still act in the best interests of the donor and advise the attorney of the disclosure as soon as possible.

Independent Mental Capacity Advocates (IMCAs)

An IMCA who is appointed to represent a person who lacks capacity is entitled to see that part of a person's medical records as is relevant to the decision in question. The Primary Care Trust will have contact details for your nearest IMCA service.

Assessment of capacity

You may need to share information with others about the person, to help you to assess their capacity. Where possible:

- try to obtain the person's permission to share relevant information with others. Give the person a full explanation of why this is necessary. Explain the risks and consequences of revealing or not revealing information to others; and

- if the person is unable to give permission, you may still be able to share relevant information to help you accurately assess capacity if it is in the best interests of the person to do this.

Where your assessment of capacity has involved discussions with third parties in order to fulfil your statutory obligation to have regard to the Code (for example, you may have discussed the person with other healthcare professionals, or perhaps with relatives or close friends), it is advisable to record the fact of your discussions in the person's medical records as well. This has the advantage of not only delineating and recording the extent of your inquiry but also to help you to show how you formed a reasonable belief that the person lacks capacity, should your decision ever be challenged.

Best interests

You must balance the right to privacy of the person who lacks capacity against your duty to consult with and take into account the views of others.

If you must discuss confidential information with others in order to fulfil that duty, make sure:

- that you only seek the views of those whom it is appropriate to consult (see Section 5 above);
- that it is in the best interests of the person to discuss this, or there is some other lawful reason to do so; and
- only reveal as much information as is relevant to the decision to be made.

You need to be able to justify your decision to discuss confidential information with others. In all cases, it is good practice to keep a clear and accurate record of the process of working out the person's best interests for each relevant decision, *including* who you consulted and what particular factors were taken into account.

Try this simple checklist

Sometimes, third parties may request information from you:

1. Always consider first whether the person who lacks capacity nevertheless has the capacity to agree to that information being disclosed. The following steps assume this to be the case.
2. Always consider whether the person making the request has lawful authority to ask for the confidential information (for example, is the person a validly appointed attorney or court appointed deputy?)
3. Are you satisfied that the person making the request is acting in the best interests of the person?
4. Are you satisfied that the person making the request needs the information to act properly?
5. Are you satisfied that the person making the request will respect confidentiality?
6. Are you satisfied that the person making the request will keep the information for no longer than is necessary?
7. If you decide, based upon the best interests and needs of the person who lacks capacity, that information should not be revealed to the person's carer, the Code encourages you to try to resolve the matter initially through discussion with the carer.
8. If you reveal information, consider asking a person to whom you lawfully reveal information about another to confirm that they will keep that information confidential.
9. If you have provided that person with a written record, it is good practice to ask that person to keep the confidential information safe. You may also ask them to keep the information no longer than is necessary for the reason requested.

Glossary of terms

Advance decision to refuse medical treatment: this is a decision made by an adult with capacity to refuse specific medical treatment in advance. The decision will apply at a future date when the person lacks the capacity to consent to or refuse the treatment specified in the advance decision. It has the same effect as a contemporaneous refusal of specified medical treatment.

Attorney: this is a person who has been appointed under either a Lasting Power of Attorney or (prior to October 2007) an Enduring Power of Attorney. An attorney has the legal right to make decisions on behalf of the donor, providing these decisions are within the scope of their authority. There are now personal welfare and financial Lasting Powers of Attorney.

Best interests: Any act done or decision made on behalf of a person who lacks capacity must be done or made in their best interests. Section 4 of the MCA 2005 sets out a non-exhaustive checklist.

Capacity: this describes a person's ability to make a specific decision at a specific time.

Decision maker: this is a person who is responsible for deciding what is in the best interests of a person who lacks capacity.

Deputy: this is a person appointed by the Court of Protection with ongoing legal authority to make particular decisions on behalf of the person who lacks capacity. Deputies for personal welfare (including healthcare) decisions will only be required in the most difficult cases where important and necessary actions cannot be carried out without the court's authority or there is no other way of settling the matter in the best interests of the person who lacks capacity to make particular welfare decisions.

Donor: this is a person who makes a Lasting Power of Attorney to appoint a person to manage their assets or to make personal welfare decisions or (prior to October 2007) an Enduring Power of Attorney.

Enduring Power of Attorney (EPA): this is a power of attorney created under the Enduring Powers of Attorney Act 1985 to deal with property and financial affairs. Existing EPAs continue to be valid.

Independent Mental Capacity Advocate (IMCA): this is a person who supports and represents a person who lacks capacity to make a specific decision, where that person has no one else who can support them. They make sure that major decisions for a person who lacks capacity are made in accordance with the Mental Capacity Act.

Lasting Power of Attorney (LPA): this is a power of attorney created under the Mental Capacity Act 2005. It enables a person initially with capacity to appoint another person to act on their behalf in relation to decisions about the donor's financial and / or personal welfare (including healthcare) at a time when they no longer have capacity. An LPA must be registered with the Office of the Public Guardian before it can be used.

Mediation: a voluntary, facilitative process that assists parties to reach a mutually acceptable outcome.

Statement of wishes and feelings: a person with capacity may express their wishes and feelings about their future medical treatment, where they would choose to live, how they would wish to be cared for, in the event they lose capacity in the future. These are non-binding but should be used by relevant professionals to decide what is in the best interests of a person who lacks capacity.

Validity (of an advance decision): An advance decision will not be valid if the person who made it has since withdrawn his decision and, at the time he withdrew his decision, had capacity to do so; or he has made a personal welfare Lasting Power of Attorney (LPA) after the date of his advance decision which confers authority upon the attorney to give or refuse consent to the treatment to which the advance decision relates; or has done anything else which is *clearly inconsistent* with the advance decision

Resources

Electronic resources

Mental Capacity Act 2005:

http://www.opsi.gov.uk/ACTS/acts2005/ukpga_20050009_en_1

You can download a copy of the Mental Capacity Act 2005 free of charge.

Code of Practice: <http://www.justice.gov.uk/guidance/mca-code-of-practice.htm>

You can download a copy of the Code of Practice free of charge.

Department of Health Training Materials:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074491

There are some very helpful training sets published by the Department of Health which are available to download free of charge, including a core training set and a community care and primary care training set.

Department of Constitutional Affairs:

www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet03.pdf

There is an excellent publication entitled *Making decisions: a guide for people who work in health and social care* which is published on the DCA website.

Websites

Collingham Healthcare Education Centre:

www.chec.org.uk

Office of the Public Guardian (including information about the Court of Protection):

www.publicguardian.gov.uk