



Mental Capacity Act 2005

Acute Hospitals Training Set



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Mental Capacity Act 2005

Acute Hospitals Training Set

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Foreword

I am pleased to introduce these excellent new training materials on the Mental Capacity Act 2005 (MCA). They have been developed by the University of Central Lancashire (UCLAN) and the Social Care Workforce Research Unit at King's College London, and provide in-depth information and guidance on what the new MCA will mean to people like you working in health and social care. The MCA will apply to everyone who works in health and social care and is involved in the care, treatment or support of people who lack capacity to make their own decisions or to consent to the treatment or care that is proposed.

The MCA puts the individual who lacks capacity at the heart of decision making and places a strong emphasis on supporting and enabling the individual to make their own decisions or involving them as far as possible in the decision-making process.

You will all have a vital role to play in the implementation of the MCA. Your role will begin in April when some parts of the MCA come into force – including the new Independent Mental Capacity Advocate (IMCA) service and the new criminal offences of ill-treatment or wilful neglect of a person who lacks capacity.

The MCA Code of Practice, recently passed by Parliament, provides the foundation of the training materials. It will be useful to become familiar with the Code, which explains how the MCA will work on a day-to-day basis. As you will know, because you work in a professional or paid capacity with people who lack capacity, you have a duty of regard to the Code. The training materials complement the Code and are a wide-ranging and comprehensive package, which, together with the Code, will ensure that you have the relevant knowledge and skills to meet the demands of the new MCA.

The new MCA will play an important part in safeguarding and protecting those people in society who lack capacity to do so for themselves. Working in health and social care, you will be playing a vital part in supporting and caring for some of the most vulnerable people in society, and I am confident that you will rise to the challenge posed by the new MCA.

The training is interactive and I know that you will be engaged and stimulated by the material. I hope that the training will leave you with a full understanding of your new role in relation to the MCA, and, most importantly, of your responsibilities to those in your care who lack capacity.

Rosie Winterton

Minister of State (Health Services)

Rose With

1 Introduction

1.1 Who is this training for?

This training is for staff working with the Mental Capacity Act 2005 (MCA) in acute hospitals in England and Wales. It is designed to be used as the basis for training sessions for staff working with people whose capacity to make particular decisions may be uncertain or questionable, and for training those working with people who wish to plan ahead or make their decisions in advance. It can be used in three main ways:

- as the basis for staff training sessions
- for individual learning and continuing professional development
- as a resource that staff can consult in the course of their day-to-day practice.

This set of materials is designed to cover the knowledge needed by those working in acute hospitals. The training focuses on how the MCA will be used in practice. You may also be interested in the other training sets. These are:

- a core set
- a mental health set
- a residential accommodation set
- a community and primary care set.

The training set comprises five learning hours for continuing professional development purposes and there is a certificate included at the back of this pack, which you can complete and forward to your professional training organisation or employer when you have worked through these materials.

1.2 Introducing the Mental Capacity Act

The MCA is being introduced in two phases.

In April 2007:

- the new Independent Mental Capacity Advocate (IMCA) service became operational in England only
- the new criminal offences of ill-treatment or wilful neglect came into force in England and Wales

- Sections 1–4 of the Act (the principles, assessing capacity and determining best interests), which are essential to how IMCAs do their work, also came into force but only in situations where an IMCA is involved and for the purposes of criminal offences. Sections 1–4 of the Act will not apply in any other situations until October 2007
- the Code of Practice for the Act was issued and should be followed by those who must have regard to it in situations where an IMCA could be involved.

In October 2007:

- all other parts of the Act come into force, including the IMCA service in Wales
- the Code of Practice will have statutory force for all of the Act, not solely in relation to where an IMCA is involved and/or the criminal offences.

The MCA is different from the Mental Health Act. Some people may be affected by both Acts. See the training set on mental health for further details.

1.3 Using this training

The case studies and exercises are included here for discussion and to show how the MCA and the Code of Practice will work in practice. They are not provided as examples of what **must** be done, because each assessment of capacity and best interests-led decision will be determined by individual circumstances.

This training is focused on the MCA and the Code of Practice. The assessment of capacity and the process of making decisions are described in the MCA and the Code of Practice. These can be found at: www.dh.gov.uk/mentalcapacityact

If you are using the PDF version of this training set you can move around it and to other documents mentioned in the text, such as the Code of Practice, by clicking on the underlined chapter headings or references. Where the PDF features recordings of the service users' and carers' quotations you can click on these to hear their words spoken.

In some places, this training set employs language and phrases used in the legislation. References to the relevant sections are included in the text. You can find an accessible glossary of relevant terms at the end of this training set.

This training has been developed in collaboration with service users, carers and practitioners who have provided some of the case examples we have used. The quotations included here express their opinions of the MCA. These are their views and are not a guide as to how the MCA will be applied in specific situations. We are grateful for their comments.

1.4 Background

The MCA has been developed to co-ordinate and simplify the law about the care and treatment of people who lack capacity. It is designed to protect the rights of individuals and empower vulnerable people. The MCA introduces new powers and new bodies to protect individuals and helps clarify what is expected of staff.

In the past, it was not unusual for some people, for example people with severe learning disabilities, severe or enduring mental health needs or dementia, to have decisions made for them. This resulted in numerous injustices, such as mass institutionalisation, loss of individuality, damage to self-esteem, involuntary sterilisation, loss of control of their own finances and loss of the right to vote.

1.5 Person-centred approach

The underlying philosophy of the MCA is to ensure that individuals who lack the ability to make specific decisions are the focus of any decisions made, or actions taken, on their behalf. This means that an individual approach that centres around the interests of the person, not the views or convenience of those caring for that person, should prevail. Staff should make every effort to ensure that patients and service users are supported to make as many decisions as possible for themselves.

Service users and carers consulted during the development of these training materials were very positive about the potential role of the MCA in enhancing the rights of people who lack capacity.

Marcus, the father of two adult children with mental health problems, said:

"The Act individualises the whole approach to principles in terms of protection of the individual. I also believe that the Act will enhance the workers' holistic approach."

Jenny, a mental health service user, commented:

"I think it is particularly good actually that it is in there that people can make decisions that are eccentric or that you disagree with, and it is good that it is stating that you have the assumption that you can make a decision unless it is proved otherwise, and it's good that they are intending to give people support to make decisions, and it's good that they are thinking of ways to ensure that when people do lack capacity that whatever's done on their behalf is in their interests."

Service users and carers also strongly emphasised the importance of the personal qualities of the staff working with people who are not able to make some decisions.

Marion, the mother of a young woman with profound and multiple disabilities, said:

"I would like staff to approach us with an attitude showing that they are open-minded."

Ade, a retired care worker who supports his adult child who has severe mental health problems and has been in hospital many times, reflected:

"I think the first thing professionals should have, probably a humane and understanding approach ... and, if professionals are to make an impact in alleviating suffering or whatever you want to call it, they need to have a unanimity of approach because there seem to be so many different approaches."

1.6 Which staff will be affected by the Mental Capacity Act?

The following staff have to take account of the MCA and the Code of Practice when acting in relation to a person who lacks, or may lack, capacity to make a decision (Code of Practice, Introduction, page 2):

• people working in a professional capacity, e.g. doctors, nurses, social workers, dentists, psychologists and psychotherapists

- people who are being paid to provide care or support, e.g. care assistants, home care workers, support workers, staff working in supported housing, prison officers and paramedics
- anyone who is a deputy appointed by the Court of Protection
- anyone acting as an IMCA
- anyone carrying out research involving people who cannot make a decision about taking part.

Exercise:

How do you currently manage issues of whether patients can make decisions in your work?

1.7 Defining mental capacity

Mental capacity within the context of the MCA means the ability to make a decision. A person's capacity to make a decision can be affected by a range of factors such as a stroke, dementia, a learning disability or a mental illness.

People with a mental illness do not necessarily lack capacity. However, people with a severe mental illness may experience a temporary loss of capacity to make decisions about their care and treatment.

A person's capacity may vary over time or according to the type of decision to be made. Physical conditions, such as an intimidating or unfamiliar environment, can also affect capacity, as can trauma, loss and health problems. A temporary lack of capacity will also include those who are unconscious or barely conscious, whether due to an accident, being under anaesthetic or as a result of other conditions or circumstances, such as being under the influence of alcohol or drugs.

All decisions about mental capacity should be guided by the five core principles (Mental Capacity Act, Section 1; Code of Practice, Chapter 2).

BOX 1

The five core principles

- 1. A person must be assumed to have capacity unless it is established that they lack capacity.
- 2. A person is not to be treated as unable to make a decision unless all practicable (doable) steps to help them to do so have been taken without success.
- 3. A person is not to be treated as unable to make a decision merely because they make an unwise decision.
- 4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests.
- 5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

BOX 2

Example

Peter is a 60-year-old man who is admitted to hospital for investigations for abdominal pains. Peter had a stroke two years ago and is extremely claustrophobic. His speech is slurred and difficult to understand and he gets a little confused when he is very tired. The medical staff want to do an abdominal CT scan on Peter but this will require him to lie flat in an enclosed space, something that Peter will not consider. He refuses to consent to the procedure.

The potential implications of his decision are explained to Peter and, as it is clear that he understands what the doctors have explained, it is his right to decide not to have the CT scan. He refuses to consent to the treatment, having weighed up the implications of his decision. Staff must respect his decision.

Remember that a person is entitled to make an unwise decision.

At this point, you have:

- learnt why the MCA was introduced
- identified which staff will be affected by the MCA
- been alerted to the importance of the Code of Practice
- been introduced to the five core principles of the MCA.

2 The Mental Capacity Act and the care process

Staff should make an assessment of whether a person does or does not have capacity to consent to care or treatment. Staff cannot know whether they are acting with the person's consent, or whether they are acting without consent if they do not do this assessment.

An assessment of capacity to make a decision is therefore an integral part of any assessment about healthcare or treatment. You should assume a person has capacity to make a specific decision unless there is evidence to show otherwise. Any relevant preliminary screening forms or standardised tools should include questions that consider matters of capacity. The trigger for an assessment of capacity is that a decision has to be made.

2.1 When is an assessment of capacity required?

As stated in the principles of the Mental Capacity Act (MCA), you should always assume a patient has capacity to make a decision, but doubts about a person's capacity may occur because of:

- the person's behaviour
- their circumstances
- the concerns raised by someone else.

Box 3 below identifies people in your hospital from whom you may wish to seek advice or help if you are unfamiliar with the MCA or the processes that are in place.

BOX 3

Sources of advice or help

- Clinical psychologist
- Psychogeriatrician
- Nurse consultant
- Specialist nurse, e.g. in dementia care or liaison psychiatry
- Senior nurse

2.2 Assessing capacity

This process needs to be integrated into your usual assessment procedures. For many staff, it will become part of the single assessment process.

There are two questions to be asked if you are assessing a person's capacity (see Box 4).

BOX 4

The two-stage test of capacity

(Code of Practice, 4.11–4.13)

- 1. Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?
- 2. If so, is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision?

This two-stage test must be used and your records should show it has been used.

Remember: an unwise decision does not of itself indicate a lack of capacity.

2.3 How is capacity assessed?

(Mental Capacity Act, Section 3; Code of Practice, 4.49–4.54)

The presumption is always that a person has capacity to make a decision. Deciding that a person lacks capacity is a serious decision. A formal, clear and recorded process should be followed where an important decision is to be made. Day-to-day assessments of capacity may be relatively informal but should still be written down or otherwise recorded if a new decision about capacity in a particular situation is being made.

Any assessment of a person's capacity **must** consider the following factors:

- whether they are able to understand the information
- whether they are able to retain the information relating to the decision to be made
- whether they are able to use or weigh that information as part of the process of making the decision.

The person has to be able to do all three to make a decision and they have to be able to communicate that decision. This could include alternative forms of communication, such as sign language, blinking an eye or squeezing a hand, when verbal communication is not possible.

2.4 Who assesses capacity?

Anyone caring for or supporting a person who may lack capacity could be involved in the test to assess capacity. This will include family members and carers as well as health and care staff. The more significant the decision, the greater the number of people likely to be involved. Expert testing by doctors or psychologists will be required in some cases but, even when used, may not be the only form of assessment. Who you involve depends on individual circumstances. Specialist or expert opinion may be helpful sometimes, but knowledge of the person concerned, for example that of family and friends, is very important.

2.5 Record keeping

All professional staff – that is, nurses, doctors, physiotherapists, social workers and so on – involved in the care and treatment of a person who may lack capacity to make a decision should keep a record of long-term or significant decisions made about capacity. The record should be made in the place where you regularly note down details about a service user or patient, such as a care plan, file or case notes and case records. The record should show:

- what the decision was
- why the decision was made
- how the decision was made who was involved and what information was used.

Such records will provide evidence for staff if they face any challenges and help them to demonstrate why they had a reasonable belief in the person's lack of capacity.

For healthcare assistants or support staff helping patients who lack capacity to make day-to-day decisions, no formal assessment procedures or records are required. So for Mrs Begum, a patient in the orthopaedic ward who is not able to decide what food she wants and so is helped to choose by a healthcare assistant, it is sufficient for the healthcare assistant to record:

Mrs Begum was helped to decide her choice of meals for the day.

For Mrs Davis, who has a brain injury following a traffic accident and who is given intravenous pain relief for severe post-operative pain, it is sufficient for the nurse to record:

Mrs Davis appears to be in pain and the doctor has prescribed intravenous pain relief. She is not communicative and appears unable to respond to my questions. The pain relief has been administered via the pump and it appears to have settled Mrs Davis.

Care plans should show that capacity to make decisions about these activities has been assessed at some point and that such decisions are being made in the patient's best interests, and are being regularly reviewed until such time as the person gains the capacity to refuse or consent for themselves.

2.6 Best interests decisions and acts

(Code of Practice, 5.1–5.69)

Where a patient has been assessed as lacking capacity to make a particular decision, that decision can be made on their behalf. The person making that decision has to act in the patient's 'best interests'. The MCA requires any decision or act made on behalf of a person who lacks capacity to be made in that person's best interests.

BOX 5

Example

Bess is a 78-year-old widow who lives with her son and daughter-inlaw. Bess has dementia, is very hard of hearing, and her ability to understand information varies on a day-to-day basis and depending on the circumstances.

In the last two weeks Bess has collapsed twice. Bess's GP thinks she may need a pacemaker so refers her to a cardiologist for an assessment. Before the appointment arrives, she collapses at home. An ambulance is called, but when it arrives she has recovered and refuses to get into the ambulance.

Exercise:

You are a member of the ambulance crew. What do you do?

The senior paramedic makes a best interests decision that Bess should go to hospital and persuades Bess to get into the ambulance. At the accident and emergency department, Bess is seen by a cardiologist who confirms that she needs a pacemaker. She remains confused and is becoming increasingly distressed. She clearly does not fully understand what a pacemaker is and what the procedure will involve, even though staff are taking her hearing impairment into account.

Exercise:

How would you assess her capacity to make a decision about the operation?

Who would you involve in the assessment? Who might you seek advice from?

Discussion:

As Bess is not confused all the time, it would be good to delay the procedure until Bess is less confused and able to make the decision herself. If this is not possible, it may be necessary to assess Bess's capacity to consent to the operation. It is likely that Bess's GP and her son will be involved, as they are the people who know Bess well.

At this point, you have:

- learnt when an assessment of capacity is required
- been introduced to the two-stage test of capacity
- identified what needs to be considered when assessing capacity
- noted the importance of recording the process of assessing capacity and decision making
- noted that best interests decisions and acts can be made on behalf of a person who lacks capacity to consent.

3 Decision making

Reference is made in the Code of Practice (**Chapter 5**) to the 'decision maker'. This is the term for the person who decides whether to take action in connection with the care or treatment of an adult who lacks capacity or who is contemplating making a decision on that person's behalf. Who the decision maker is therefore depends on the particular circumstances and the decision to be made.

Where the decision involves medical treatment for someone who lacks capacity, the doctor or healthcare professional carrying out the treatment is the decision maker even if a number of professionals, for example in a multidisciplinary team, have been involved in the decision. Where nursing care is provided, the nurse is the decision maker. For most day-to-day actions or decisions, the decision maker will be the person most directly involved with the patient at the time. Outside hospital, that is likely to be a care worker or family member, but remember that most people have capacity to make most decisions themselves.

3.1 Healthcare and treatment decisions

In acute hospital settings, determining or working out whether healthcare or treatment options are in the best interests of an individual who lacks capacity is likely to be a key issue.

The Mental Capacity Act (MCA) requires any decision or act made on behalf of a person who lacks capacity to be made in that person's best interests. Decisions may be made under the MCA by people appointed to do so, such as attorneys, deputies and the Court of Protection. However, decisions will often be made by staff involved in the care and treatment of the person concerned. Staff can also undertake most acts in connection with care or treatment that are made on behalf of a person who lacks capacity to consent if those acts are in a person's best interests.

The MCA does not define best interests but identifies a number of factors that must be considered when determining the best interests of individuals who have been assessed as lacking capacity to make a particular decision or consent to acts of care or treatment. There are a number of steps involved in deciding what a person's best interests are. The MCA makes it clear that, when determining what is in someone's best interests, you must not base the decision on the person's age or appearance or make unjustified assumptions based on their condition.

The factors that must be taken into account when determining what is in someone's best interests are set out in the best interests checklist (*Mental Capacity Act, Section 4*; *Code of Practice, 5.13*).

BOX 6

Determining best interests – the statutory (legal) checklist

- Avoid making assumptions about someone's best interests merely on the basis of the person's age, appearance, condition or behaviour.
- Consider a person's own wishes, feelings, beliefs and values and any written statements made by the person when they had capacity.
- Take account of the views of family and informal carers.
- Can the decision be put off until the person regains capacity?
- Involve the person in the decision-making process.
- Demonstrate that you have carefully assessed any conflicting evidence or views.
- Provide clear, objective reasons as to why you are acting in the person's best interests.
- Take account of the views of any independent mental capacity advocate (see Part 8 of these materials).
- Take the less restrictive alternative or intervention.

3.2 Legal decisions and common law tests of capacity

There are some issues that you may come across in hospital that are about decisions that do not relate to healthcare and treatment. Perhaps you have seen a person decide to get married while an inpatient or someone who suddenly thinks that they need to make their will. Your role is not to make decisions here about the person's mental capacity; there are common law tests that apply. In the case of a person who wants to make a will, for example, a legal practitioner is the best person to test capacity to make a will, not you. You may be asked to give your professional opinion but it is the legal practitioner who makes the decision about capacity.

BOX 7

Example

You are on nights and Mrs Jenkins calls you to talk about making her will. She is a bit confused about time and place, but seems very keen that her money should go to her sister, not her brother. You are not sure if she is capable of making a decision at this time. What should you do?

Answer:

You should reassure Mrs Jenkins and tell her that she can make arrangements to call her solicitor in the morning. It is not your job to assess her capacity to make this decision. You should record your discussion in the notes, not just because it is a useful safeguard, but also because it may alert other staff to Mrs Jenkins' possible worries about her operation and her prognosis.

3.3 Protection from liability (being sued or sacked) (Mental Capacity Act, Section 5; Code of Practice, Chapter 6)

When carrying out acts of care and treatment in the best interests of a person who lacks capacity, staff will be legally protected. This means that they will be protected through Section 5 of the MCA against legal challenges, providing that they:

- have taken reasonable steps to assess the person's capacity to consent to the act in question
- reasonably believe that the person lacks capacity to consent
- reasonably believe that the act they are carrying out is in the person's best interests.

However, staff will not be protected if they act negligently.

Eileen, an older person who has been undergoing medical treatment in hospital, said:

"I do think it is right that [paid] carers should be protected from legal liability if their actions are based on a 'proper' assessment."

3.4 Making best interests decisions in practice

The following are examples that explore best interests decisions. They can be used for discussion in small groups or reflected on by individuals.

BOX 8

Example

Consent to healthcare treatment – blood transfusion

Rebecca is knocked unconscious while being assaulted and robbed of her rucksack. She is rushed to hospital by ambulance. Rebecca has sustained head injuries and a stab wound and has lost a lot of blood so the casualty doctor arranges an urgent blood transfusion, believing this to be necessary to save her life and therefore in her best interests. When her relatives are finally located, they say that Rebecca's beliefs mean that she would have refused all blood products.

- Did the doctor behave appropriately?
- Did the doctor act against Rebecca's best interests?

Discussion:

There was no prior indication of who Rebecca was, or what her beliefs were, as her rucksack had been stolen. The doctor therefore had reasonable grounds for believing that his action was in his patient's best interests and so was justified in taking that action. If, however, a document had been available that confirmed her refusal of blood products (a valid and applicable advance decision to refuse life-sustaining treatment – see Part 5 of these materials), the doctor would have been acting unlawfully if he had authorised a blood transfusion. Here, the doctor was the decision maker, even though the nurses were involved in the treatment. If the situation had been less urgent, the doctor should have taken time to locate and consult relatives or others who knew Rebecca.

Source: Adapted from the Code of Practice

Decisions about rehabilitation

The next example is a composite of several similar cases, as this is a reasonably common scenario in brain injury rehabilitation units. If you are reading this by yourself for continuing professional development, we suggest you work through the section stage by stage rather than reading it all at once.

If you are a trainer, it may be helpful to give some of the information relating to this example to course participants prior to the training day, with a view to them coming to discuss the issues with other participants. Several alternative outcomes are described in order to reflect on the issues involved.

BOX 9

Example

Background information

Sue, aged 34, suffered a brain injury in a road traffic accident three months ago. Prior to her accident, Sue had been working full time as a sales executive. She lived alone. At the time of her injury she was admitted to her local district general hospital and made a good physical recovery. Unfortunately, she continued to show confusion and disorientation and her cognitive recovery was slow. She was assessed at the local hospital by a member of the rehabilitation team as suitable for transfer to the rehabilitation unit. Members of her family were supportive of the need for further specialist input but were concerned about the distance of the unit from their home. An assessment was carried out to determine whether Sue was capable of consenting to or refusing the proposed treatment at the rehabilitation unit.

Initial assessment on acute medical ward

This consisted of a semi-structured screening interview with Sue (conducted by a psychologist), a cognitive screening test, information from ward staff concerning her behaviour and progress on the ward, and a brief interview with family members.

Jane, the night sister, left a message to say that each night when she had been on duty Sue had generally slept well but was very disorientated if she woke during the night.

The psychologist's opinion was that Sue was not oriented to time or place. She was not able to focus her attention on the interview for more than a couple of minutes. Opportunities to write or draw were provided but she made no attempt to pick up the offered pen. She did not focus on any written or pictorial material provided. She did not demonstrate any understanding of what had happened to her or of any problems she might have that required further treatment.

BOX 9 (continued)

On the basis of this information, the consultant – the decision maker – decided that Sue was not able to understand in simple language what the treatment was, its nature and purpose, and why it was being proposed. She was not able to retain the information given to her, and was not engaging in a meaningful communication about her medical condition. She was considered, therefore, to be incapable of consenting to or refusing treatment at this stage, but it was recognised that her condition was likely to improve and that her ability to consent to treatment should be reviewed.

Exercise:

What do you remember about the two-stage test?

- 1. Does Sue have an impairment or disturbance in the functioning of her mind or brain?
- 2. If so, is the impairment sufficient that Sue lacks the capacity to make the particular decision about her need for rehabilitation in the specialist unit?

Using the best interests checklist shown in Box 6, the consultant decided that it was in Sue's best interests to be transferred to the rehabilitation unit. He talked this decision through with her family but took into account the fact that he was not able to wait for Sue to regain capacity as the place at the rehabilitation unit would not be available for long. Shortly after her move, Sue was interviewed again by the psychologist who had carried out the initial assessment. She reported that the position about meaningful consent had not changed since the decision 10 days before. All clients within the unit were given an information pack and the opportunity to discuss this with a member of staff on arrival. The pack contained information about the unit, the nature of the rehabilitation process, the rules and regulations of the unit and the complaints procedure. Where clients could give consent, they were asked to give their agreement to comply with the programme. In this instance, it was felt that Sue's signature on the form would not be meaningful informed consent, but again it was recognised that her condition was likely to improve and it was agreed to monitor her progress at the weekly multidisciplinary meeting.

BOX 9 (continued)

Exercise:

Consider the following questions to assess whether Sue had capacity to consent to the rehabilitation programme?

Write down how you would assess:

- Sue's ability to understand and retain information relating to the decision to be made
- Sue's ability to use or assess the information while considering the decision
- Sue's ability to communicate the decision by any means.

Naomi, her key worker, said:

"I would talk to her in simple language, ask her who she is and where she is, see if she can focus on written information or pictures, find out if she knows what has happened to her, find out if she understands about the rehabilitation unit and what has been said."

Three weeks after admission

During her stay in the unit, a more detailed assessment of Sue's condition was carried out using a range of assessment tools. Structured and functional observations by the multidisciplinary team covered daily living skills, social and problem-solving skills and community skills (including road safety and use of transport). The assessments showed that Sue was making good progress. She now understood that she needed to remain on the unit so that she could continue to improve and made the decision to remain on the unit. An assessment confirmed that she was now able to make her own decision as to whether or not she stayed.

Critical reflection

Informed consent in relation to medical or psychological intervention involves the knowledge, understanding and retention of the information – all of which can be seriously compromised by brain injury. This was evident during the early stages of Sue's treatment. If Sue had continued to lack capacity but had been compliant with treatment, Sue's case might have fallen into the category of the Bournewood decision (see Part 6.3 of these materials).

At this point, you have:

- clarified the role of the decision maker
- learnt the key elements of consultation and engagement when establishing a person's best interests
- seen these principles applied to some complex cases.

4 Medical treatment and the Court of Protection

4.1 The Court of Protection

The Court of Protection is a specialist court with powers to deal with matters affecting adults who may lack capacity to make particular decisions. The Court is able to hear cases at a number of locations in England and Wales. It covers all areas of decision making under the Mental Capacity Act (MCA) and can determine whether a person has capacity to take a particular decision, whether a proposed act would be lawful, whether a particular act or decision is in a person's best interests, and the meaning or effect of Lasting Power of Attorney (see Part 5 of these materials) in disputed cases. It is able to be involved in investigations of abuse, including financial issues.

The Court of Protection plans to be an accessible, regional court. It aims to be informal and quick. It takes over the duties of the former Court of Protection and matters regarding healthcare and personal welfare that were previously dealt with by the High Court. The Court charges a fee for applications – information on fees and forms are available on the Court's website at: www.guardianship.gov.uk or www.publicguardian.gov.uk (from October 2007).

It is expected that the Court of Protection will only be involved where particularly complex decisions or difficult disputes are raised.

Either the Court of Protection or the Family Court may deal with health and welfare decisions concerning 16 and 17-year-olds who lack capacity to make particular decisions (see Part 11 of these materials).

4.2 Court of Protection deputies

(Mental Capacity Act, Section 16(4)(a))

The MCA requires the Court to make a decision where possible. However, the Court might decide that it is appropriate to appoint a deputy. Deputies are appointed by the Court of Protection to make ongoing decisions on behalf of a person who lacks capacity to make those decisions.

A deputy can be appointed to deal with financial matters and/or personal welfare. The appointment of a deputy could take place, for example, where no Lasting Power of Attorney exists or there is a serious dispute among carers that cannot be resolved in any other way. The appointment of a deputy is limited in scope (what it can do) and duration (time). This is to reflect the principle of the less restrictive intervention.

A deputy can be a family member, or any other person (or in property and affairs cases a trust) the Court thinks suitable.

A deputy must act with regard to the Code of Practice, in accordance with the MCA's principles and in the person's best interests.

4.3 Court of Protection visitors

These are individuals appointed by the Lord Chancellor who provide independent advice to the Court and the Public Guardian. They will have a role in the investigation of allegations of abuse of a person who lacks capacity. Their visits will include checks on the general well-being of a person who lacks capacity. They will also help and support attorneys and deputies.

Further information and guidance on their role and how to contact them will be provided by the Office of the Public Guardian as it becomes more established. These details are likely to be included in local adult protection policies and procedures.

4.4 Medical treatment requiring court approval

Prior to the MCA coming into force, the courts decided that some decisions relating to the provision of medical treatment were so serious that in each case an application should be made to the Court for a declaration that the proposed action was lawful.

Cases involving any of the following decisions should therefore be brought before the Court of Protection:

- the proposed withholding or withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state
- cases involving organ or bone marrow donation by a person lacking capacity to consent
- cases involving the proposed non-therapeutic sterilisation of a person lacking capacity to consent to this (e.g. for contraceptive purposes)
- all other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests.

BOX 10

Example

Louise is a profoundly disabled young woman, aged 23, who has cognitive and physical impairments. She lives in a nursing home with 15 other residents. One night she is found in bed with one of the other residents. Her parents do not agree on what should happen. One parent feels that sterilisation would be in her best interests on health and emotional grounds while the other doesn't. The Court of Protection always has to decide if sterilisation is in a person's best interests as it is for contraceptive and therefore non-therapeutic reasons. Louise's case must therefore be decided by the Court.

If medical treatment requiring court approval is being considered for an individual and staff are unclear about what steps need to be taken, it is important that senior staff within the trust or hospital are aware of this and legal advice is sought. Ward staff are advised to contact the senior nurse and make them aware of the situation. Box 11 includes a list of other staff within the hospital who are also likely to be involved in such a process and whom you may need to alert if the senior nurse is not available.

BOX 11

Medical treatment requiring Court approval

Trust staff who should be aware of the process:

- senior nurse
- consultant caring for the patient
- medical director
- trust solicitor (who can be called on by all of the above).

At this point, you have:

- clarified the role of the Court of Protection
- been alerted to the roles of Court of Protection deputies and visitors
- learnt when medical treatment requires approval from the Court of Protection.

5 Planning for future care and treatment

5.1 Advance decisions to refuse treatment

(Mental Capacity Act, Section 24; Code of Practice, Chapter 9)

People can make advance decisions to refuse treatment under common law; these are sometimes called 'advance directives' or 'living wills'. You may have come across them in the past, but the Mental Capacity Act (MCA) formalises them and sets up clearer arrangements for them. It is likely that more people will make these, given the publicity surrounding the introduction of the MCA.

Karen, who has severe physical disabilities, felt that advance decisions could be used even more widely in the future:

"I think everyone should have an advance decision regardless of impairment or even if you've not got an impairment. And I think it's really important for people to talk about it and I think that a very important part of this Act is that people start to talk about it, because people don't."

A person aged 18 years or over who has capacity has, under the MCA, a legal right to **refuse** specified medical procedures or treatment in advance, intending that refusal to take effect when they no longer have capacity to refuse procedures or treatment, unless it is being undertaken for treating a mental disorder under the Mental Health Act 1983. No individual, whether or not they have capacity, has the right to demand specific forms of medical treatment. However, requests for specific forms of treatment or expressions of wishes or preferences made in advance by a person who subsequently lacks capacity to consent to treatment should be taken into account (in particular those that are written down) in deciding what treatment would be in that person's best interests.

The MCA states that an advance decision to refuse treatment must refer to a specified treatment(s) and may set out the circumstances when the refusal should apply. A statement that indicates a general desire not to be treated would **not** constitute an advance decision, but an advance decision refusing all treatment in any situation (for example, where a person explains that their decision is based on their religion or personal beliefs) may be valid and applicable.

When are advance decisions valid and applicable?

(Code of Practice, 9.40)

An advance decision is valid when:

- it is made when the person has capacity
- the person making it has not withdrawn it
- the advance decision is not overridden by a later Lasting Power of Attorney that relates to the treatment specified in the advance decision
- the person has acted in a way that is clearly consistent with the advance decision.

An advance decision is applicable when:

- the person who made it does not have the capacity to consent to or refuse the treatment in question
- it refers specifically to the treatment in question
- the circumstances to which the refusal of treatment refers are present.

An advance decision to refuse life-sustaining treatment is applicable when:

- it is in writing, including being written on the person's behalf or recorded in their medical notes
- it is signed by the person making it (or on their behalf at their direction if they are unable to sign) in the presence of a witness who has also signed it
- it is clearly stated, either in the advance decision or in a separate statement (which must be signed and witnessed), that the advance decision is to apply to the specified treatment, even if life is at risk.

But an advance decision is not applicable if the circumstances are different from those that may have been set out in the advance decision or there are reasonable grounds for believing that circumstances now exist that the person did not anticipate when they made the advance decision and that would have affected their decision had they been able to anticipate them (e.g. new treatment for their condition has been introduced).

BOX 12

Quiz

Which of the following do you think are advance decisions allowed by the MCA?

- 1. I do not want to have any treatment if I get dementia.
- 2. I do not want to be given artificial feeding if my condition has reached the stage where I'm unable to swallow.
- 3. I do not want to be given antibiotics if I am in a persistent vegetative state.
- 4. I want to be given everything possible even if I am considered to be dying.
- 5. I do not want to be given blood transfusions in any circumstances.

Answers:

If all other legal requirements are in place, numbers 2, 3 and 5 would usually be recognised as advance decisions because they are clearly refusing a specific procedure or treatment.

Number 1 would not be a valid and applicable advance decision because it does not clearly specify the treatment being refused. However, this type of expression of wishes or preferences made in advance by a person who subsequently lacks capacity to consent to treatment should be taken into account (in this case the sentiment would have more weight because it has been written down) when deciding what treatment would be in that person's best interests.

Number 4 is not an advance decision because it is requesting treatment rather than refusing it. However, as with the above answer (number 1), the feeling behind the statement should be taken into account when deciding what treatment would be in that person's best interests.

Responsibilities of health professionals

Healthcare professionals should be aware of the possibility that a patient may have made an advance decision to refuse treatment. When discussing treatment options, advance decisions should be discussed if appropriate.

If there are concerns about the ability of an individual to make a decision and healthcare professionals are alerted to the existence of a relevant written or oral advance decision, or have reasonable grounds to believe that one exists, the professional should, if time permits, make reasonable efforts to find out what that decision was. Reasonable efforts might include having discussions with the patient's relatives and carers, looking in the patient's clinical notes held in the hospital or contacting the patient's GP.

Once healthcare professionals who are considering treatment have been informed of the existence of an oral advance decision or presented with a written advance decision, they need to consider:

- whether it is an advance decision within the meaning of the MCA
- whether it is valid
- whether it is applicable to the treatment.

Conscientious objections

Some staff may have moral or religious grounds for not wishing to be involved in withdrawing or withholding life-sustaining treatment. They must make this known as soon as possible and the patient who has made the advance decision must be offered the option to be cared for by someone else. While staff do not have to do anything that goes against their beliefs, they need to arrange care for their patient from other staff.

Establishing the validity of the advance decision

An advance decision to refuse treatment is not valid if the patient has:

- withdrawn it (this does not need to be in writing)
- subsequently created a Lasting Power of Attorney which gives authority relating to the treatment specified in the advance decision
- done something clearly inconsistent with the advance decision.

Example

Neela, a retired woman, whose friend died after prolonged hospital treatment, made a signed and witnessed advance decision refusing any treatment to keep her alive by artificial means. A few months later, she is seriously injured in a diving accident and is paralysed from the neck down and is only able to breathe with artificial ventilation. Initially, she remains conscious and is able to consent to treatment while being taken to hospital. She participates actively in a rehabilitation programme. Some weeks later she loses consciousness. It is at this point that her written advance decision is located, though she has not mentioned it during her treatment.

What do you do?

- 1. Accept the advance decision that indicates that Neela does not wish to have treatment that will keep her alive by artificial means.
- 2. Use artificial means to keep her alive.

Discussion:

Neela's previous consent to treatment and involvement in rehabilitation place considerable doubt on the validity of the advance decision because it is clearly inconsistent with her actions prior to her lack of capacity, which suggests that answer 2 – use artificial means to keep her alive – would be appropriate.

Example

Patricia is a retired teacher with strong religious beliefs about the value of life. She is increasingly worried that as a single older woman, with a number of disabilities, including communication difficulties after a stroke, no one will be able to make her views known to medical and nursing staff if she is ever admitted to hospital and faced with emergency treatment. She draws up a document saying that she wants to be resuscitated and given life-saving treatment if she is in such circumstances. She takes copies of it when she goes to an outpatients' appointment for her pre-operative assessment. The doctor is concerned about the legality of the document.

What should the hospital staff do?

Discussion:

Staff need to be clear about the validity of any document and should seek advice if they are unsure. In Patricia's case, the document is not valid as an advance decision because she is requesting a specific treatment (resuscitation) rather than refusing a treatment or procedure. No individual, whether or not they have capacity, has the right to demand specific forms of medical treatment. However, in deciding Patricia's resuscitation status, Patricia's request must be taken into account by the medical team, particularly as Patricia expressed her wishes in a relevant written statement.

Example

Clare is a 64-year-old woman with breast cancer. After surgery, chemotherapy and radiotherapy, she made an advance decision saying that she did not wish to have any further chemotherapy or radiotherapy at any time. Clare's husband Raj and her GP are aware of her decision.

Five years later, when Clare is found to have extensive metastasis, she is admitted to the local hospice for palliative care. Her condition deteriorates rapidly and she fluctuates in and out of consciousness. The consultant thinks that Clare may benefit from a small dose of radiotherapy.

Exercise:

You are the nurse in charge and you are aware of the advance decision. What do you do?

Discussion:

It is important to establish that the advance decision is both valid and applicable. If the staff are sure that the conditions for establishing the validity of Clare's advance decision have been met (outlined earlier), then her refusal must be respected.

Establishing the applicability of the advance decision

Once the validity of the advance decision has been established, staff must determine whether it is applicable to the current situation.

Example

Michael is HIV positive and some years ago began to experience AIDS-related symptoms. Though willing to consent to standard treatment, for instance during a bout of pneumonia, he was initially unwilling to try the new retro-viral treatments, saying he didn't want to be a guinea pig for the medical profession. He made an advance decision refusing specific retro-virals if he lacked capacity to give or refuse consent in the future. Five years later, he is suddenly admitted to hospital seriously ill and is drifting in and out of consciousness. The medical team considers that retro-viral drugs are the most appropriate form of treatment but is aware that Michael has made an advance decision refusing specific retro-virals if he lacks capacity. The doctor examining his advance decision is concerned about its applicability because new retro-viral options have been developed since Michael made his advance decision.

What should the doctor do?

- 1. Accept the advance decision and not administer the new retro-viral drugs?
- 2. Discuss developments in the use of retro-viral drugs with Michael's partner and her concerns about the advance decision?

Discussion:

Having discussed this situation with Michael's partner, it is agreed that Michael's decision would not be applicable now due to advances in medical science and that there are reasonable grounds for believing that, were he aware of the developments in this field, this would have affected his decision to refuse all retro-virals. The doctor decides that the advance decision to refuse is therefore not applicable to the new retro-virals and gives him those retro-virals as part of his treatment.

As this example illustrates, an advance decision is not applicable if circumstances now exist which the person did not anticipate at the time they made the advance decision and which would have affected their decision had they been able to anticipate them (e.g. new treatment).

Exercise:

How would you tell Michael what has happened? Think about whose role this is and what support he and his partner might need. Who is responsible for this?

Example

Amy is a 76-year-old woman admitted to hospital with a urinary tract infection. She is usually fit and well but is currently extremely confused and agitated. When Tom, her son, comes to visit he asks the house officer to write in her notes that if her heart stops she should not be resuscitated because she always said that if she was ever admitted to hospital she did not want any heroic treatment.

What should you do?

- 1. Accept what Tom says about his mother's advance decision and agree that Amy should not be resuscitated if her heart stops?
- 2. Explain to Tom that an advance decision to refuse life-sustaining treatment that is not written down, signed and witnessed is not legally binding?
- 3. Say that you do not have evidence for what Amy wants and so will make decisions in her best interests?

Discussion:

There are two issues that should be considered here. Firstly, this advance decision is not applicable because it has not been written down, signed and witnessed so it cannot be used in this situation because it is a refusal of life-sustaining treatment. Tom should be consulted about his mother's treatment but he does not have any legal authority to make decisions on her behalf. Secondly, where possible, decisions about resuscitation should be delayed until Amy is well; it is unlikely that her confusion will continue once her infection has cleared. So the answers in this case are 2 and 3. How would you convey this information to Tom at a time when he is likely to be upset or anxious?

5.2 Lasting Powers of Attorney (LPA)

(Mental Capacity Act, Sections 9 to 14; Code of Practice, Chapter 7)

Under a Lasting Power of Attorney (LPA) an individual can, while they still have capacity, appoint another person to make decisions on their behalf about financial, welfare or healthcare matters. The person making the LPA chooses who will be their attorney. They can allow the attorney to make all decisions or they can choose which decisions they can make.

LPAs replace Enduring Powers of Attorney (EPAs), which were established by the Enduring Powers of Attorney Act 1985, which gave power to the attorney to manage property and financial affairs (not healthcare and welfare) on behalf of the donor. At the onset of the donor's incapacity, the attorney must register the EPA with the Public Guardian in order for their authorisation under the EPA to continue. No new EPAs can be set up after the Mental Capacity Act is implemented, but existing EPAs will continue to be valid whether registered or not (Code of Practice, Chapter 7). Donors can choose to replace their existing EPA with an LPA.

Guidance on LPAs can be found at: www.guardianship.gov.uk or www.publicguardian.gov.uk (from October 2007).

The key point is that an attorney acting under an LPA has the authority to make decisions on behalf of the person who made the LPA, if they can no longer make these decisions for themselves. An attorney is not there simply to be consulted. However, on other matters concerning the person that have not been specified in the LPA, staff should seek the views of the attorney. Attorneys must act in accordance with the Code of Practice.

In order to be valid, an LPA must be registered with the Public Guardian and on the prescribed form. There are two different LPAs to cover a range of circumstances. These are:

- personal welfare (which includes healthcare decisions)
- property and affairs (financial matters).

The person making the LPA is the **donor**, who donates or hands over responsibility to make decisions under specified circumstances. The person appointed to make the decisions under the LPA is the **donee**, also known as the **attorney** in the Code of Practice. One attorney may hold a number of LPAs for different people. A person (donor) can choose one or a number of

people to hold an LPA. An attorney could be a family member, friend or professional, such as a lawyer. The Code of Practice advises that health and social care staff should not act as attorneys unless they are also close relatives of the person who lacks capacity.

5.3 Lasting Powers of Attorney authorising healthcare decisions

An LPA that authorises the attorney to make personal welfare decisions generally also includes the authority to give or refuse consent to medical treatment or make other healthcare decisions, unless such decisions are specifically excluded by the donor when creating the power. This means that when creating or updating a care plan for a donor who has appointed an attorney to make healthcare decisions, or in deciding what particular treatment would be in the donor's best interests, healthcare professionals must consult the attorney. The attorney, if it is a decision for which they have the authority, must then decide to refuse or consent.

An LPA relating to personal welfare will not authorise an attorney to give or refuse consent to treatment in the following circumstances:

- · When the donor has capacity to make their own treatment decisions
- When there is an advance decision to refuse treatment which is valid and applicable in the particular circumstances.
 - However, if, after making the advance decision, the donor created an LPA conferring authority on the attorney to give or refuse consent to the treatment specified in the advance decision, this has the effect of making the advance decision invalid and the attorney's decision would then take precedence.
- An attorney has no power to consent to or refuse life-sustaining treatment, unless the LPA document expressly authorises this. If the donor wishes to authorise their chosen attorney to make decisions about the carrying out or continuation of life-sustaining treatment in circumstances where the donor lacks capacity to make such decisions, then the donor must include a clear statement to this effect in the LPA document.

When an attorney is involved in giving or refusing consent to medical treatment on behalf of the donor, they must always act in accordance with the MCA's principles and any decisions must be in the donor's best interests. It is important to note that an LPA can describe treatment that the individual does not want but it cannot give attorneys the power to demand a particular treatment that healthcare professionals do not believe to be clinically necessary or appropriate. If a personal welfare LPA is in place but does not include the authority to make the decisions that now need to be made, health and social care staff will make the necessary best interests decisions but they should consult the attorney.

In order to be **valid**, an LPA must be set out on the right form and registered with the Office of the Public Guardian before it can be used. An LPA is a formal, legal document. A personal welfare LPA will only take effect when a person has lost capacity to make a particular decision, and the LPA has to be registered with the Office of the Public Guardian. If it is not registered, it cannot be used. An LPA concerning financial matters will take effect immediately it is registered unless the donor specifies that it should not take effect until they lose capacity to make these decisions.

BOX 18

Example

Catherine has always been very concerned about doctors resuscitating people who she thinks are unlikely to ever enjoy a good quality of life if resuscitation is successful. Catherine and her husband John experienced this with her father, who lived for a number of months after being resuscitated but had a very poor quality of life in their eyes and they always wished they had 'let him go'.

Having seen her father in this position, she is clear that she would not wish to be resuscitated if it was likely that her quality of life would be poor. Catherine discusses this issue with her husband whom she trusts more than anyone else and knows he will respect her wishes if the circumstances arise. She therefore asks him to act as her attorney to make welfare (including healthcare) decisions on her behalf, should she lack capacity to make her own decision at any time in the future. Having obtained the information from the website of the Office of the Public Guardian, Catherine makes a personal welfare LPA, appointing John to make all her welfare and healthcare decisions, and includes a

BOX 18 (continued)

specific statement authorising him to ensure that she is not to be resuscitated if her quality of life is likely to be poor. Catherine registers the LPA with the Office of the Public Guardian.

Catherine is involved in a car accident and after extensive surgery suffers major organ failure. She is extremely unwell and her prognosis is poor. One night when John comes to visit her on the ward he asks the staff nurse if the doctors have decided whether she will be resuscitated. On finding out that Catherine will be resuscitated if her heart stops, John informs the nurse that he has an LPA, including refusals on his wife's behalf of life-sustaining treatment, and that he will not consent to her being resuscitated if her heart stops.

Exercise:

You are the staff nurse on duty. You have not come across anyone with an LPA before and on contacting the house officer you find that she is also not familiar with these. You are unsure about what to do next, as John is becoming increasingly upset about his wife's condition and feels that he is letting her down.

What do you do?

Discussion:

The important thing is to seek advice from someone who does know about LPAs. Box 19 gives examples of staff who may be able to help you.

Staff to contact

- Senior nurse
- Night sister
- Night practitioner
- Consultant
- The staff member on call for the hospital

It is important to establish the legality of the LPA. To be legally binding it needs to have been registered at the Office of the Public Guardian and the contents need to be applicable to the decision being made. Providing these requirements are met and that Catherine lacks capacity (you need to ensure that the two-stage test applies (see Part 2.2 of these materials), it is lawful for John to request that she should not be resuscitated.

Exercise:

How will you record this? Who needs to know? Can you think of ways to support John, for example asking him if he would like to have a visit from the hospital chaplain or religious/faith leader? Would he like to contact other family members or friends?

Exercise:

Where will information on LPAs be kept in your workplace? Who can access it? If any patients had any questions about LPAs, which of the following would be able to help in your area of work:

- Patient Advice and Liaison Services (PALS)
- Community Legal Service
- patient forum
- Department of Health website
- local advocacy services
- any other local organisations or groups?

At this point, you have:

- learnt to recognise when an advance decision is valid and applicable
- learnt when an LPA is valid
- discovered that LPAs can only be used to state what treatment an individual does not want.

6 Restraint and loss of liberty

(Mental Capacity Act, Sections 5 and 6; Code of Practice, 6.11–6.19)

6.1 Limitations on restraint

In circumstances where restraint needs to be used, staff restraining a person who lacks capacity will be protected from liability (for example, criminal charges) if certain conditions are met. There are specific rules on the use of restraint, whether verbal or physical, and the restriction or deprivation of liberty, as outlined in the Code of Practice, 6.11–6.19 and 6.40–6.53 and Department of Health and Welsh Assembly Government guidelines (www.dh.gov.uk/assetRoot/04/06/84/61/04068461.pdf and http://new.wales.gov.uk/docrepos/40382/40382313/childrenyoungpeople/childrenfirst/603793/framework-rpi-e.pdf?lang=en).

If restraint is used, staff must reasonably believe that the person lacks capacity to consent to the act in question, that it needs to be done in their best interests and that restraint is necessary to protect the person from harm. It must also be a proportionate or reasonable response to the likelihood of the person suffering harm and the seriousness of that harm. Restraint can include physical restraint, restricting the person's freedom of movement and verbal warnings, but cannot extend to depriving someone of their liberty (the difference between restraint and deprivation of liberty is discussed in Part 6.3 of these materials).

Restraint may also be used under common law in circumstances where there is a risk that the person lacking capacity may harm someone else.

6.2 Conditions that may justify the use of restraint

Since the Mental Capacity Act (MCA) has the best interests of people who lack capacity as one of its key principles, the use, or threat, of any sort of force or restriction of liberty is generally not permitted. However, the practicalities of caring for and providing protection for people who lack capacity are also recognised, and in particular that some forms of restraint may be justifiable to protect the person who lacks capacity. Box 20 sets out the two conditions set out in the MCA which, if satisfied, may provide protection from liability to staff and others who need to use restraint.

Conditions that may justify restraint

- The first condition is that the person taking action must reasonably believe that it is *necessary* to do an act which involves restraint in order to *prevent harm* to the person lacking capacity.
- The second condition is that the act is a proportionate response (in terms of both the degree and the duration of the restraint) to the likelihood of the person suffering harm and to the seriousness of that harm.

The word 'proportionate' is important and generally means that it is not excessive or no more than absolutely necessary. For example, if a nurse thinks that a person is getting out of bed and it is very unsafe to do so, then a verbal request followed by an instruction would be proportionate at first, rather than putting up cot sides immediately.

When might restraint be 'necessary'?

It is the person doing the act (carrying out restraint) who needs to give clear and unbiased reasons to justify their belief that restraint is necessary, i.e. that the person being cared for is likely to suffer harm unless some sort of physical intervention or other restraining action is taken. The restraining act must be necessary in order to prevent harm – not simply to enable staff to do something more quickly or easily. Where restraint is necessary to prevent the person from coming to any harm, only the minimum of force or other type of restraint may be used and for the shortest possible time.

Example

Mr Dafydd Benson is a 77-year-old retired surgeon who has a heart condition and is unsteady on his feet. He also has dementia. He is admitted to an acute hospital for tests following frequent falls. Mr Benson is clearly distressed by his surroundings and very confused. He is concerned that as he cannot find the operating theatre he will be late starting morning surgery. Mr Benson has been wandering around the ward all morning. The nurses are concerned that he will fall and hurt himself.

The ward sister contacts Mr Benson's daughter, who is able to come and sit with him, but he still remains agitated. They also move him to a single room but this does not appear to calm him and Mr Benson falls as he attempts to leave the ward. He sustains a slight laceration injury on this occasion.

Concerned that Mr Benson will fall again and seriously injure himself, and after discussion with his daughter, the on-call doctor prescribes Mr Benson a small dose of sedative to calm him and reduce his agitation.

Discussion:

Staff treating Mr Benson need to be clear why they thought it was necessary to restrain Mr Benson and that their response was proportionate to the situation.

In this case, staff will be able to explain why they reasonably believed that it was necessary to restrain Mr Benson using a sedative and that their action was proportionate to the situation as they had tried a number of approaches to calm the situation prior to using drug treatment (contacted his daughter to sit with him and moved him to a side room).

Example

Mr Arthur Roberts is a 65-year-old man with no fixed abode. He is brought into the busy accident and emergency department having been found collapsed in the street. He is known to be a diabetic and is admitted to the medical assessment unit for monitoring. He is confused.

On arriving on the unit he smells strongly of alcohol and stale urine. It is not long before the patients who are close to Mr Roberts complain to the nurses about the smell. Some of them insist that Mr Roberts has a bath. The nurses feel that, despite his confusion, it is safe for Mr Roberts to have a bath and ask him if he would like one. Despite being confused, he is very clear that he does not want a bath. The nurses do their utmost to try and persuade Mr Roberts but he refuses to talk to them. A bath is not necessary for medical reasons. The other patients are extremely unhappy about the situation and their relatives make strong representations to the nurses and threaten to complain.

Exercise:

What do you do?

- 1. Bath Mr Roberts despite his protests and resistance?
- 2. Respect his wishes?

Discussion:

The only way it will be possible for the nursing staff to bath Mr Roberts is to physically restrain him. While it is clear that the situation on the ward is difficult to manage, in particular because of the other patients' and relatives' complaints, under the terms of the MCA it will be difficult to argue that a bath involving restraint is necessary to prevent harm to Mr Roberts. The staff decide that it would not be in his best interests to bath him and so the use of restraint would be inappropriate and unlawful.

It is unlikely that they would have been protected from liability if they had decided to go ahead and bath Mr Roberts.

Exercise:

How would you record what is happening? Would you contact anyone outside the unit?

Section 5 of the MCA, which provides protection from liability in certain circumstances as discussed above, will not protect staff from liability for any action they take that conflicts with a decision made by someone acting under a Lasting Power of Attorney or by a deputy appointed by the Court of Protection.

6.3 Bournewood decisions and safeguards

BOX 23

The Bournewood Case

This legal case tested the boundary between appropriate restraint and the loss of human rights under Article 5 of the European Convention on Human Rights – the right to liberty.

The patient was in hospital and lacked capacity to say whether he would stay in hospital or accept treatment. He did not seem to be objecting. He was not detained under the Mental Health Act 1983.

The European Court determined that "the key factor in the present case [is] that the healthcare professionals treating and managing the applicant exercised complete and effective control over his care and movements". It found that "the concrete situation was that the applicant was under continuous supervision and control and was not free to leave".

The Government is seeking to amend the MCA because of this case. The distinction between restraint and the loss of liberty, which took this case to the European Court, is "one of degree and intensity, not one of nature and substance". Any deprivation of liberty can only be lawful if accompanied by safeguards such as those surrounding detention under the Mental Health Act 1983.

The Department of Health (December 2004) and the Welsh Assembly Government (January 2005) have issued guidance and a briefing sheet which should already be included in service providers' policies. At the time of writing, the Government is taking legislation through Parliament to establish a new set of safeguards in the MCA for people who need to be deprived of their liberty in their best interests and who cannot make the necessary decisions for themselves.

At this point, you have:

- confirmed that restraint is a last resort
- learnt when restraint might be necessary
- been alerted to the Bournewood Case and the need to seek advice in such circumstances.

7 Confidentiality and access to personal information

(Code of Practice, Chapter 16)

People making decisions on behalf of people who lack capacity will often need to share personal information about the person lacking capacity. This information is required in order to ensure that decision makers are acting in the best interests of the person lacking capacity.

When releasing information, the following must be considered:

- Is the person asking for the information acting on behalf of the person who lacks capacity?
- Is disclosure in the best interests of the person who lacks capacity?
- What kind of information is being requested?

Remember that access to personal information must be in accordance with the law. Disclosure of, and access to, information is regulated by:

- the Data Protection Act 1998
- · the common law duty of confidentiality
- professional codes of conduct
- the Human Rights Act 1998.

The NHS Code on Confidentiality provides the following guidance:

"Where the patient is incapacitated and unable to consent, information should only be disclosed in the patient's best interests and then only as much information as is needed to support their care."

However, attorneys with a Lasting Power of Attorney are entitled to any information as if they were the person lacking capacity, as long as they are acting within the scope of their authority.

Example

Reg has given his son William a personal welfare LPA. Reg is in hospital for surgery following a gastro bleed and is now unconscious and in a critical condition. William wants to see his father's notes, as he is worried about the care that he has received. The nurse is concerned that in the notes there is mention of Reg's history of treatment for syphilis, a long time ago, and she is not sure that William should see this information.

What should she do?

Discussion:

As Reg has given William a personal welfare LPA that includes making healthcare decisions on his behalf, William is entitled to access those records that are relevant to the concerns that he has about his father's treatment. It should not be necessary to provide information relating to the syphilis as this is not relevant to the case, but if this is not possible practically, staff should counsel or prepare William that there may be information in the records about past medical history that he is not aware of.

Key point:

Reg made the LPA knowing what it meant and understanding that this might mean that information about his medical history would be shared with his attorney (William).

At this point, you have:

- identified the questions to ask when sharing information
- noted that attorneys with LPAs are entitled to information.

8 Independent mental capacity advocates

(Mental Capacity Act, Sections 35 to 41; Code of Practice, Chapter 10)

The Mental Capacity Act (MCA) introduces a duty on the NHS and local authorities to involve an **independent mental capacity advocate (IMCA)** in certain decisions. This ensures that, when a person who lacks capacity to make a decision has no one who can speak for them and serious medical treatment or a move into accommodation arranged by the local authority or NHS body (following an assessment under the NHS and Community Care Act 1990) is being considered, an IMCA is instructed.

The IMCA has a specific role to play in supporting and representing a person who lacks capacity to make the decision in question. They are only able to act for people whose care or treatment is arranged by a local authority or the NHS. They have the right to information about an individual, so they can see relevant health and social care records.

The duties of an IMCA are to:

- support the person who lacks capacity and represent their views and interests to the decision maker
- obtain and evaluate information, both through interviewing the person and through examining relevant records and documents
- obtain the views of professionals and paid workers providing care or treatment for the person who lacks capacity
- identify alternative courses of action
- obtain a further medical opinion, if required
- prepare a report (that the decision maker must consider).

In England, regulations have extended the role of IMCAs so they may also be asked to represent the person lacking capacity where there is an allegation of or evidence of abuse or neglect to or by a person who lacks capacity. In adult protection cases, an IMCA can be appointed even though the person has family or friends.

Similarly, the regulations also allow IMCAs to contribute to reviews for people who have been in accommodation arranged by the local authority or NHS body or who have been in hospital for more than 12 weeks and who have nobody else to represent them.

The local authority or NHS body may instruct an IMCA to represent the person lacking capacity in either adult protection cases or accommodation reviews if they consider that it would be of 'particular benefit' to the person.

The National Assembly for Wales has also extended the role of IMCAs in Wales, to cover accommodation reviews and adult protection cases.

BOX 25

IMCAs always represent the interests of:

those who have been assessed as lacking capacity to make a
major decision about serious medical treatment or a longer-term
accommodation move, if they have no one else to speak for them
other than paid carers, and if their care or accommodation is arranged
by their local authority or NHS.

IMCAs may represent the interests of:

- those who have been placed in accommodation by the NHS or local authority, and whose accommodation arrangements are being reviewed, and/or
- those who have been or are alleged to have been abused or neglected or where a person lacking capacity has been alleged or proven to be an abuser (even if they have friends or family).

An IMCA is not a decision maker for the person who lacks capacity. They are there to support and represent that person and to ensure that decision making for people who lack capacity is done appropriately and in accordance with the MCA.

In England, the local authority area where a person currently is (e.g. in hospital) is responsible for making the IMCA service available. In Wales, local health boards have this responsibility. If the decision is about treatment, the relevant NHS body must instruct an IMCA, if it is about a move it will be either the local authority or the NHS body.

Example

Ethel is admitted to hospital following a fractured femur. She has been living in a care home for people with dementia and this is closing as the owner is retiring. She has no known relatives or friends and her fees for the home are paid for by a local authority some distance away. She is medically fit for discharge and the local authority is undertaking an assessment. One lunchtime, a man arrives on the ward and says he is from a local advocacy group and is the IMCA for Ethel (it appears that social services have made the referral to the local IMCA service on Ethel's behalf). He wants to see her notes and to talk to her.

- What do you do?
- What rights does he have?
- Can Ethel refuse to see him?
- How do you record his visit?

Discussion:

The ward staff need to satisfy themselves that the IMCA is who he says he is, and once this is confirmed the IMCA is entitled to look at relevant parts of Ethel's notes and take copies if they are relevant to the situation (decision) that he is supporting her with.

If Ethel does not wish to see the IMCA then there is no reason why she should, but the IMCA's role to represent and support her and to ensure that any decisions are made appropriately and in accordance with the MCA remains the same.

The IMCA's visit and involvement in Ethel's care should be recorded in the place where you regularly record details about a patient's care, such as a care plan, file or case notes.

Where is information about the IMCA service kept on the ward or in your workplace?

To contact an IMCA, look for details on the IMCA website.

At this point, you have:

- noted that there is a duty to instruct an IMCA in certain circumstances
- identified who an IMCA can represent
- noted that an IMCA is not a decision maker
- confirmed that the local authority or local health board where the person is currently living is responsible for commissioning the IMCA service
- identified who instructs an IMCA
- noted that the IMCA's report must be considered.

9 Protection

(Code of Practice, Chapter 14)

This part of the Code of Practice describes the way in which professionals and people acting with formal powers under the Mental Capacity Act (MCA) (i.e. attorneys and deputies) need to work with agencies responsible for the protection of vulnerable adults. All health and care settings, such as hospitals, should have their own formal protocols and procedures for the protection of vulnerable adults (adult protection policy) and staff's responsibilities under the MCA are being incorporated into them.

Staff need to know what safeguards are available for those affected by the MCA so that they can inform service users and carers about opportunities to raise complaints and resolve disputes. They also need to feel confident that their concerns will be addressed.

9.1 New criminal offences of ill-treatment or wilful neglect

The MCA creates new criminal offences of ill-treatment or wilful neglect (MCA, Section 44; Code of Practice, Chapter 14).

BOX 27

It is now a criminal offence if the following people ill-treat or wilfully neglect anyone in their care:

- people who have the care of a person who lacks capacity
- an attorney under a Lasting Power of Attorney (formerly an Enduring Power of Attorney)
- a deputy appointed by the court.

Allegations of this offence are dealt with under adult protection procedures and may involve the police at an early stage. The penalty for these criminal offences is a fine and/or a sentence of imprisonment for up to five years.

Isabel said:

"I was pleased to see that the Act introduces new criminal offences of ill-treatment or neglect of a person. I'm so pleased to see that within the Act because we've found it very difficult to pinpoint how some retribution can take place and this makes it a criminal offence. It's a step forward."

Example

Dot is an 89-year-old woman who lives with her daughter Val, who is her main carer. Dot has dementia and is visually impaired. She is admitted to the accident and emergency department with severe constipation, necrotic pressure sores and severe dehydration. The nurse caring for Dot is highly concerned about Dot's welfare because she appears to be very neglected. She makes a careful record of what she has seen.

The nurse alerts the charge nurse and they contact the police and the local adult protection service. A joint police and adult services (formerly social services) investigation is carried out. An independent mental capacity advocate (IMCA) may be involved to represent Dot's interests and views. The accident and emergency nurse makes a statement and is required to provide evidence at the court hearing when Val is committed for trial for the neglect of Dot. Adult services make alternative arrangements for Dot's care.

9.2 The Public Guardian

The MCA creates a new public office – the Public Guardian – with a range of functions that contribute to the protection of people who lack capacity. These functions include:

- keeping a register of Lasting Powers of Attorney and Enduring Powers of Attorney
- monitoring attorneys
- receiving reports from attorneys and deputies
- keeping a register of orders appointing deputies
- supervising deputies appointed by the Court
- directing Court of Protection visitors
- providing reports to the Court
- dealing with enquiries and complaints about the way deputies or attorneys use their powers
- working closely with other agencies to prevent abuse.

The Office of the Public Guardian will offer a telephone helpline service and support to people raising concerns about the actions of decision makers.

At this point, you have:

- been alerted to the new criminal offences of ill-treatment or wilful neglect
- been reminded of the need to refer to local adult protection procedures
- been alerted to the role of the Office of the Public Guardian.

10 Research

(Mental Capacity Act, Sections 30 to 34; Code of Practice, Chapter 11)

There are clear rules about involving people in health and social care research studies when they are not able to consent to taking part. A family member or carer (the consultee) should be consulted about any proposed study. People who can be consultees include family members, carers, attorneys and deputies, as long as they are not paid to look after the person in question and their interest in the welfare of the person is not a professional one. If they say that the person who lacks capacity would not have wanted to take part, or to continue to take part, then this means that the research must not go ahead.

If there is no such person who can be consulted, the researcher must find someone who is not connected with the research who can fulfil this role instead. Guidance will be available to researchers about how to go about this. Again, if the consultee says that the person would not have wanted to take part or continue to take part, the research must not go ahead.

The research has to be approved by the relevant research ethics committee. A researcher must stop the research if at any time they think that one of the MCA s31 requirements is not met (i.e. the research must relate to an impairing condition, have potential to benefit the person lacking capacity or be intended to provide knowledge about the same or a similar condition). This means that the researcher needs to understand the basis on which the research approval is given and ensure not only that the research is approved but that these requirements continue to be met throughout the period of the research. It is good practice for staff to ask to see evidence that the research has received approval.

If the person who lacks capacity appears to be unhappy with any of the activities involved in the research, then the research must stop.

NB: There are separate rules for clinical trials.

Example

A nurse working in the outpatients department is doing a study of elder abuse and wants to look at the files of people attending the memory clinic support group, all of whom have dementia. She has received ethical approval for this from the relevant research ethics committee, and agreement from the relatives (consultees) of the group's members when the members were not able to consent to take part.

In this case, the nurse will be able to undertake the study using the consent procedures that she has committed herself to and that have been approved.

At this point, you have:

- established that research can go ahead if it has approval from a relevant research ethics committee
- noted that if the individual appears unhappy with any aspects of the research, it must stop
- confirmed that if a consultee says the research must not go ahead because the person would have objected, then the research cannot proceed.

11 Children and young people

(Code of Practice, Chapter 12)

11.1 Young people under the age of 16

The Mental Capacity Act (MCA) does not usually apply in relation to children younger than 16 who do not have capacity. Generally, people with parental responsibility for such children can make decisions on their behalf under common law. However, the Court of Protection has powers to make decisions about the property and affairs of a person who is under 16 and lacks capacity within the meaning of the MCA (see Part 2.2 of these materials) if it is likely that the person will still lack capacity to make these types of decision when they are 18.

BOX 30

Example

Maisie was 9 when she was in a car accident and sustained severe injuries causing permanent brain damage and health problems. She was awarded a significant amount of money in damages in the personal injury claim taken by her parents on her behalf. She is unlikely to recover sufficiently to have capacity to be able to make financial decisions for herself when she reaches 18. The Court of Protection makes an order appointing Maisie's father as deputy to manage her financial affairs and the family makes arrangements to adapt their home so Maisie can return there.

11.2 Young people aged 16 and 17

The MCA overlaps with provisions made under the Children Act 1989 in some areas. There are no absolute criteria for deciding which route to follow. An example of where the MCA would be used would be when it is in the interests of the young person that a parent or, in some cases, someone independent of the family is appointed as a deputy to make financial or welfare decisions.

This could apply when a young person has been awarded compensation and a solicitor is appointed as a property and affairs (financial) deputy to work with a care manager and/or family members to ensure that the award is suitably invested to provide for the young person's needs throughout their lifetime.

Another example would be where the Court of Protection is asked to make a best interests decision where there is a dispute between those with parental

responsibility for a young person and those treating or caring for the young person and the dispute cannot be resolved in any other way.

Under the MCA, only people who have reached the age of 18 can make Lasting Powers of Attorney (LPAs), advance decisions and wills. While 16 and 17-year-olds who have capacity may give or refuse consent to treatment at the time it is offered, they cannot make advance decisions. However, any views or preferences they express when they have capacity should be considered when making a best interests decision.

A 16 or 17-year-old who lacks capacity to consent can be treated under Section 5 of the MCA. The person providing care or treatment must follow the MCA's principles and act in a way that they reasonably believe to be in the young person's best interests. Parents, others with parental responsibility or anyone else involved in the care of the young person should be consulted unless the young person does not want this or this would otherwise breach their right to confidentiality. Any known views of the young person should also be taken into account. If legal proceedings are required to resolve disputes about the care, treatment or welfare of the young person aged 16 or 17 who lacks capacity, these may be dealt with under the Children Act 1989 or the MCA.

BOX 31

Example

Kaley is 17 and has severe learning disabilities. She has a blood-clotting disorder that makes her prone to haemorrhaging. Kaley's wisdom teeth are impacted and causing her severe pain. The teeth can be removed only under a general anaesthetic. Her parents agree that she needs a dental extraction but they are Jehovah's Witnesses and refuse to consent to a blood transfusion. The dental surgeon feels that Kaley's safety could be severely compromised if she does not receive a blood transfusion if she haemorrhages during the surgery or post-operatively. The dental surgeon does not feel that this would be in Kaley's best interests so she asks the medical director to set in place an application to the Court of Protection. This is because the date of the operation has not been confirmed and may be after Kaley's 18th birthday.

At this point, you have:

- confirmed that the MCA generally applies only to people aged 16 and over
- discovered that the Court of Protection can be involved in decisions about someone under 16 if they are likely to continue to lack capacity to make those decisions when they reach 18
- learnt that only people of 18 and over can make LPAs and advance decisions under the MCA
- clarified that a 16 or 17-year-old who lacks capacity can be treated under the MCA.

12 How will the Mental Capacity Act change practice?

The service users involved in the development of this training set were generally very positive about the Mental Capacity Act (MCA). However, they wanted the MCA to be fully implemented and were keen that checks and balances are sufficiently strong to protect individuals.

A key aim of the MCA is to co-ordinate and simplify a complex area of law. Interviews with service users and carers suggest that the MCA could help staff improve their practice with patients and service users.

Users and carers hoped that the MCA would encourage staff to acknowledge the dignity and right to make choices of people lacking capacity. They emphasised that all service users want to be treated with warmth and respect.

Karen, who has severe physical disabilities, describes the qualities staff need to work with the MCA:

"They'd have to be very patient, be willing to listen, be willing to explore ways to communicate; particularly at that stage when they're trying to make decisions, they want to be sure they're making decisions based on what the person lacking capacity would really want, not what the professional thinks might be easier for a friend, social services or whatever."

Marcus, the father of two adult children with mental health problems, says:

"Professionals should not ignore the reality of what is happening to people. It's not about a quick fix; it's about being patient and sympathetic. It's about a relationship too. Never mind if you are at the most vulnerable point of your life like having an illness, it's even worse if you're not treated with dignity and respect and empathy."

The introduction of the MCA provides an ideal opportunity for staff to look again at their practice and find new ways of listening to patients and enabling them to make choices and decisions.

In conclusion, you have:

- learnt the key elements of the MCA
- reflected on the implications for your own practice
- listened to the hopes and views of service users and carers about the way in which the MCA will improve practice.

Glossary

Advance decision – allows an adult with capacity to set out a refusal of specified medical treatment in advance of the time when they might lack capacity to refuse it if it is proposed. If life-sustaining treatment is being refused, the advance decision has to be in writing, signed and witnessed, and has to include a statement saying that it applies even if life is at risk.

Attorney – the person an individual chooses to manage their assets or make decisions under a Lasting Power of Attorney or Enduring Power of Attorney.

Best interests – the duty of decision makers to have regard to a wide range of factors when reaching a decision or carrying out an act on behalf of a person who lacks capacity.

Capacity – the ability to make a decision.

Contemporaneous – at the same time. Any person with capacity can refuse treatment at the time it is offered. An advance decision means accepting that what that person wanted some time ago is what they want now.

Court of Protection – where there is a dispute or challenge to a decision under the Mental Capacity Act, this Court decides on such matters as whether a person has capacity in relation to a particular decision, whether a proposed act would be lawful, and the meaning or effect of a Lasting Power of Attorney or Enduring Power of Attorney.

Court-appointed deputy – an individual appointed by the Court of Protection to make best interests decisions on behalf of an adult who lacks capacity to make particular decisions.

Decision maker – someone working in health or social care or a family member or unpaid carer who decides whether to provide care or treatment for someone who cannot consent; or an attorney or deputy who has the legal authority to make best interests decisions on behalf of someone who lacks the capacity to do so.

Donor – the person who makes a Lasting Power of Attorney to appoint a person to manage their assets or to make personal welfare decisions.

Enduring Power of Attorney (EPA) – a power of attorney to deal with property and financial affairs established by previous legislation. No new EPAs can be made after the Mental Capacity Act 2005 is implemented, but existing EPAs continue to be valid.

Independent mental capacity advocate (IMCA) – an advocate who has to be instructed when a person who lacks capacity to make specific decisions has no one else who can speak for them. They do not make decisions for people who lack capacity, but support and represent them and ensure that major decisions regarding people who lack capacity are made appropriately and in accordance with the Mental Capacity Act.

Lasting Power of Attorney – a power under the Mental Capacity Act that allows an individual to appoint another person to act on their behalf in relation to certain decisions regarding their financial, welfare and healthcare matters.

Public Guardian – this official body registers Lasting Powers of Attorney and court-appointed deputies and investigates complaints about how an attorney under a Lasting Power of Attorney or a deputy is exercising their powers.

Useful sources and references

Further information is available in the training sets that accompany this material. Links to more information and reference to the Mental Capacity Act (MCA) and Code of Practice are included in the text where relevant. The following list includes other articles or books that may be of interest.

Department for Constitutional Affairs Range of material including the

statutes and an easy read summary of the MCA available on the website: www.dca.gov.uk/legal-policy/mental-

capacity

Department of Health website:

www.dh.gov.uk/mentalcapacityact

Welsh Assembly Government Guidance issued for Wales available

on website:

http://new.wales.gov.uk/topics/ health/nhswales/healthservice/mental _health_services/mentalcapacityact/

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Joint Royal Colleges Ambulance

Liaison Committee

website: www2.warwick.ac.uk/fac/med/research/hsri/emergencycare/jrcalc_2006/clinical_guidelines_

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