

THE  
NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE

# The Mental Capacity Act in Practice: *Guidance for End of Life Care*



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# Foreword

*I am delighted to welcome NCPC's latest publication "The Mental Capacity Act in Practice: Guidance for End of Life Care". The objectives that underpin the Mental Capacity Act are also central to delivering good palliative and end of life care. This new guidance is immensely practical and will enable anybody reading it to understand what the MCA means for them and how it can be used to make real differences to the lives of all those it affects.*

*It follows NCPC's earlier "Guidance on the Mental Capacity Act 2005", which helped explain to organisations and professionals what they needed to do to prepare for this new legislation. This new guidance goes much further than that, with a clear and detailed explanation of the MCA set in the context of current practice. It offers advice and guidance not only to professional carers and organisations, but also to people for whom impaired capacity is or might one day become an issue, as well as their family friends and informal carers.*

*NCPC is one of the organisations that we have worked closely with in preparing and then implementing the MCA. As part of our implementation programme we have been very keen to provide opportunities for organisations to supplement the Code of Practice and other Government publications with their own guidance.*

*This publication is one of the projects we were very pleased to be able to support. Although it has been written by NCPC it is relevant to everyone affected by the MCA, not just people in palliative and end of life care. I recommend it to you.*



**Paul Gantley**

**Implementation Manager Mental Capacity Act  
Care Services Improvement Partnership / Department of Health**

# Introduction

## *The Mental Capacity Act and Palliative Care*

NCPC's Guidance on the Mental Capacity Act, published in October 2005, stated that "the Act will have a profound impact on decision-making in palliative care."

Two years later, with the benefit of many discussions, workshops and conferences, and with the MCA now in operation, it is apparent that this prediction was if anything an understatement. As our understanding of the MCA has developed over the last two years, NCPC has increasingly come to see the extent of the common ground between the principles and objectives underpinning the MCA and those that drive palliative care. At the heart of the MCA lies a genuine commitment to person-centred care, advance care planning, excellent communication, and valuing the choices of vulnerable people.

The MCA requires every carer, professional and informal, to give all practicable support to adults with impaired capacity in order to maximise their ability to make decisions about their own lives. If people lack capacity, decisions about their care must be made in their best interests, and will have to be justified on that basis if challenged. Good record-keeping will be required to evidence this. The result will be to drive up the quality of decision-making and, in so doing, to improve people's care.

Because the MCA is legislation, it must be complied with. It is not an option. This is a real opportunity for palliative care. To work with colleagues in other services and organisations on MCA-related issues is

to have the opportunity to engage them with and inform them about palliative care, and about ways in which tools such as those supported by the End of Life Care programme<sup>1</sup> might help them comply with their obligations under the MCA.

This is particularly important in the context of the forthcoming End of Life Care strategy, due for publication in the summer of 2008. It is anticipated that the strategy will emphasise the importance of good communication and advance care planning in developing good end of life care. By focusing on those, organisations and care providers will both find it easier to implement the MCA and help ensure that the strategy's objectives are met.

## *This publication*

Our guidance on the MCA, in October 2005, was one of the first pieces of specialist guidance published in the country. At that stage, although the MCA had been passed through Parliament, a great deal of further work needed to be done before it could become law. This new guidance takes into account all the developments since October 2005, including the publication of the Code of Practice and the establishment of the Independent Mental Capacity Advocate (IMCA) service; the new Court of Protection; and the Office of the Public Guardian. It goes into more detail than was possible in 2005. It explains the MCA in the context of the current developments in palliative care, and sets out NCPC's future work plans in relation to the MCA.

This guidance is principally written for professionals and organisations in all

settings that provide palliative care services, either within specialist services or as part of their day-to-day care. People working in specialist palliative care units, hospices, hospitals, care homes, and primary and community care will all find it relevant. However, it is also intended to help patients, care home residents and people who want to understand how they can influence their future care. We also hope that informal carers and family members will find it useful.

### *To whom does the MCA apply? - age limits & geography*

The MCA applies to every decision made by or on behalf of an adult aged 16 years or over with impaired capacity. The only exceptions to that are that individuals must be aged 18 or over to give a Lasting Power of Attorney to somebody else (see section 7) or to make an advance decision to refuse treatment (see section 4).

The MCA applies only to England and Wales.

### *Examples of people for whom impaired mental capacity might be an issue*

Examples of people who might either have impaired capacity or lack capacity altogether in relation to a particular decision include:

- People living with dementia
- People living with impaired cognitive function
- People living with learning disability
- People living with severe psychiatric disorders
- Older people experiencing frailty
- People who are experiencing delirium or confusion
- People with fluctuating capacity or consciousness
- People on medication which causes persistent, transient or fluctuating cognitive impairment
- People who are imminently dying and who no longer have full mental capacity
- People who are unconscious

These are examples of the people whom the MCA is intended to help and whose interests it protects.

***NB. In this publication, as in the Mental Capacity Act itself, "he" "him" and "his" refers to people of both sexes.***

# *The Code of Practice*

The MCA is accompanied by a lengthy and detailed Code of Practice. All paid and professional carers, as well as donees of Lasting Powers of Attorney, court appointed deputies, and Independent Mental Capacity Advocates, are under a statutory duty to “have regard” to it when acting in relation to a person who lacks capacity. That does not mean that the Code must be rigidly adhered to. It does however mean that anybody who departs from its guidance will need to be able to explain why if challenged. This reflects the MCA’s broad approach which is to ensure that decisions made on behalf of or about people lacking capacity are made for valid and explicable reasons.

The Code of Practice is available on-line, with a word-search facility<sup>2</sup>. It is a helpful

and accessible document from a teaching, reference and educational perspective. At almost 300 pages, it is also lengthy. People will be unable to remember all of it. Organisations should ensure that their members of staff have easy access to a copy of it so that they can consult it if necessary.

Unpaid informal carers are not under a statutory duty in relation to the Code of Practice. Nevertheless it contains valuable help, advice and guidance and they would be best advised to consult it where it is appropriate for them to do so.

The Code of Practice will be taken into account in the event of any civil or criminal proceedings about the Mental Capacity Act.

# 1. UNDERLYING PRINCIPLES (MCA section 1)

The MCA has 5 key underlying principles, which are set out in section 1 of the Act. These are:

## 1. *A presumption of capacity*

There is an assumption in favour of capacity. Every adult has the right to make his own decisions for himself, and so a person must be assumed to have capacity, unless it is established that he lacks capacity to make the decision in question.

## 2. *Individuals should be supported where possible so that they can make their own decisions*

A person must not be treated as being unable to make a decision unless all practicable steps to help him to do so have been taken, without success

## 3. *People have the right to make decisions which may seem eccentric or unwise to other people*

A person is not to be treated as unable to make a decision merely because he makes an unwise decision

## 4. *Best interests*

Acts done or decisions made on behalf of a person established to be lacking capacity must be in his best interests.

## 5. *People's rights and freedoms must be restricted as little as possible*

Before doing an act or taking a decision on behalf of someone you must consider whether the purpose underlying that act or decision can be achieved in a way that is less restrictive of that person's rights or freedom of action.

## *Commentary on the underlying principles*

*Although much of the MCA deals with what is to happen once a person has been assessed as lacking the capacity to make a particular decision for himself, these principles in section 1 are applicable at an earlier stage, and are intended to maximise an individual's capacity to make decisions for himself. Under the MCA, deciding that an individual lacks capacity for a particular decision is a determination of last resort, and should be done only when all practicable steps to help him make the decision himself have been taken but have not succeeded. The first 3 principles make this clear. They state that:*

- *The starting assumption is that people can make their own decisions for themselves*
- *People should be given every support to help them make their own decisions*
- *People can make unwise or eccentric decisions if they want to.*

*If challenged, health and social care professionals and other carers will have to be able to justify their decision that someone lacked capacity to make a particular decision and explain what steps they took to support that person and maximise his opportunity to take the decision for himself. This is intended to create a new culture of care, in which every effort is made to support individuals to help them in their decision-making. Further guidance on this is contained in section 2 below on assessing capacity.*

*The duty to act in the best interests of the person who lacks capacity is*

*also crucial. It means that **someone's inability to consent to particular treatment cannot be allowed to become a barrier to him receiving the treatment that he needs in his best interests.** This is a very important provision. Much of the campaigning impetus that helped bring the MCA into being came from the disability rights movement, which was driven by the belief that unwarranted superficial and paternalistic assumptions were too often being made about people's quality of life with the result that people living with disability did not receive treatment that was in their best interests. This is sometimes called "disability prejudice".*

#### **DISABILITY PREJUDICE - AN EXAMPLE**

*"I was born with spinal muscular atrophy, a so-called "terminal" condition. I cannot lift my head from the pillow unaided and I need a ventilator to help me breathe at night. I use a powered wheelchair and have a computer on which I type with one finger.*

*In January 2003 I was hospitalised with severe pneumonia in both lungs. On two separate occasions, doctors told me they assumed that if I fell unconscious I wouldn't want to be given life-saving treatment. I was so frightened of what might happen to me that I kept myself awake for 48 hours. My husband brought in a photo of me in my graduation gown and stuck it on the bed-head to remind the hospital staff that there was more to me than the shrivelled form they saw lying in front of them.*

*I was lucky: although I could barely breathe, I had an assertive husband insisting to the authorities that I had everything to live for. Imagine what it would be like if you were too weak to communicate. Or your relatives less positive about the quality of your life."*

*Jane Campbell, now Baroness Jane Campbell DBE, writing in The Guardian, 26 August 2003. At the time of writing she was a Disability Rights Commissioner. She is now an Equality & Human Rights Commissioner.*

*The third underlying principle, emphasising the right to make eccentric decisions, is an important one which illustrates well one of the key issues that should be understood about the MCA.*

*When the government drafted the MCA it was concerned about the relationship between the state and the individual, and in particular the need to protect vulnerable individuals against state interference or even abuse. Deciding without proper justification that somebody lacks the capacity to make a decision for himself is one way in which the state can interfere in an individual's life.*

*Instead the MCA is intended to ensure that each individual is properly assessed and that superficial judgements are not made about him. The mere fact that*

*somebody behaves in a way that others might find odd or eccentric does not of itself prove that he lacks capacity. Each of us has a right to make our own choices and decisions, even though others might consider them eccentric or unwise.*

*The fifth principle, that people should be restricted as little as possible, needs to be balanced with the principle that decisions should be made in a person's best interests. The final decision must always allow the person's best interests to be achieved.*

*These five principles are very important. Developing an understanding of these will help develop an understanding of the MCA. If you are ever uncertain about what to do under the MCA, applying these principles to the situation you are in may help you find a solution.*

## 2. ASSESSING CAPACITY (MCA sections 2-3)

The MCA sets out the following framework which must be applied when assessing whether a person has capacity to make a particular decision:

- **The diagnostic test.** A person lacks capacity if at the material time (i.e. the time that a particular decision has to be made) he is unable to make that decision for himself by reason of an impairment or disturbance of his mind or brain, whether on a temporary or permanent basis
- **The functional test.** A person is unable to make a decision if he cannot understand relevant information, retain that information, use or weigh

that information as part of making a decision, or is unable to communicate his decision by any means

- **Do not discriminate.** Lack of capacity cannot be established merely by reference to a person's age, appearance, or to any condition of his or aspect of his behaviour which might lead others to make unjustified assumptions about his capacity.

### Commentary on assessing lack of capacity

*The MCA sets out what approach needs to be taken when assessing capacity.*

*First, capacity must be decided on a decision by decision basis. Clearly somebody who is unconscious will not have capacity. However it will be the case for many people that they might have capacity to make some decisions, but not others. For example, a care home resident might have the capacity to decide what he wants to wear, eat or drink, where and with whom he wants to sit, and how he wants to spend his day. He might not have the capacity to make more complicated decisions, for example about his pension or investments. So long as a person is conscious, his capacity should not be determined in a blanket way, but must be assessed decision by decision.*

*That means that you need to identify the decision that has to be taken.*

*Then you need to assess whether the person has the capacity to make that decision for himself. The MCA contains a two-stage test (diagnostic and functional), and a prohibition.*

*The prohibition (in the third bullet point on page 9) is that you must not make judgements about somebody based on superficial appearances or particular diagnoses. You must not assume that somebody lacks capacity to make a particular decision simply on the basis of their age, their appearance, their condition, or an aspect of their behaviour. These are factors that can be taken into account, but they are not sufficient of themselves. People must be assessed on an individual and decision by decision basis. This is a very important aspect of the MCA - it is intended to ensure that people are not discriminated against simply because, for example, they are old, frail or happen to live with a particular condition, perhaps a learning*

*disability or dementia. There is a similar anti-discriminatory provision when it comes to assessing best interests. The practical effect of this is to emphasise the importance of person-centred decision-making, which will be very familiar to people working in palliative care.*

*Beyond the anti-discriminatory provision, the MCA's 2-stage test to assess capacity is as follows:*

- 1. Diagnostic: Is there an impairment or disturbance of the mind or brain which means that the person is unable to make a decision for himself?*
- 2. Functional: Is the person unable to make a decision for himself, because he is unable to understand, retain, use or weigh relevant information, or is unable to communicate by any means?*

*This means that when assessing capacity you need to determine first whether there is an impairment or disturbance of the mind or brain and then, if there is, whether it is sufficiently serious to cause the person to be unable to make the decision himself.*

*The majority of people who lack capacity will do so because they cannot understand, retain, use, or weigh information. They will have impaired comprehension, memory or judgement, or some combination of the three, which means that they are unable to make the decision in question even with support.*

*The final part of the functional test is about communication. The emphasis is on the word "any"; the person must be unable to communicate by any means.*

*The residual ability to blink with one eyelid is an ability to communicate. That illustrates the lengths to which carers are expected to go in order to support and communicate with individuals to enable them to make decisions for themselves.*

*We can see here the importance of the five underlying principles in section 1 of the MCA. The second of those states that individuals should be supported where possible so that they can make their own decisions. This means that people must be given all practicable support not only to communicate, but also to maximise their ability to understand, remember or assess information.*

*Examples of the sort of support and communication that may be helpful include: ensuring that the person has a hearing aid; providing appropriate technological support and equipment; using simple language or pictures; writing things down; seeking guidance or support from interpreters (signing or language), speech therapists, psychologists or psychiatrists, particularly in complex cases. It may also be that the individual's usual carers have developed ways of supporting and communicating with him. It may be necessary to repeat information several times to ensure that a person with a brain injury has retained it. Environment can be important. For example, somebody living with dementia might find it easier to make a decision in a calm and peaceful place without distractions. Remember also that lack of capacity can be temporary and that*

*capacity can vary or fluctuate. If a decision is not urgent, it may be possible to defer the decision until the person has regained capacity. If a person tends to be more alert at a particular time of day, and the decision can wait until then, use that time to ask him about the decision.*

*The nature of the support that might be appropriate will vary from person to person, and will depend on a variety of factors including the condition that he is living with. **Further guidance on helping people to make decisions themselves can be found in Chapter 3 of the Code of Practice.***

*If however, after having done what you can to support somebody, you nevertheless conclude that he lacks the capacity to make a particular decision, you will need to identify the decision in question, and record your reasons for assessing him as not having the capacity to make that decision himself. The extent of the notes will depend on how serious the decision is and on how difficult it was to assess the individual or decide where his best interests lie. If it was a low-level decision for somebody who clearly did not have capacity, a very short note will be sufficient. If it was a complicated and important decision, and it was difficult to decide whether the person had capacity, more detailed notes will be required.*

- **Further information on assessing capacity can be found in Chapter 4 of the Code of Practice. Practical guidance is set out in paragraph 4.49.**

### ASSESSING CAPACITY CHECKLIST

It might be helpful to ask the following questions when assessing capacity and recording a decision:

1. What decision has to be made?
2. Does the person have an impairment or disturbance of the mind or brain?
3. Is that impairment or disturbance sufficient to cause lack of capacity for the decision in question?
4. What support has been given to help the person make the decision for himself?
5. Does the person still lack capacity, even with all practicable support?

## 3. BEST INTERESTS (MCA section 4)

Once it has been established that someone (“P”) lacks capacity to make a particular decision, then somebody else (“D”) must make that decision on P’s behalf. Unless it is in a situation in which P has made a valid and applicable advance decision to refuse treatment (see further under section 9), **whoever makes that decision must make it in the best interests of the person concerned (P), not on the basis of the best interests of others.**

The MCA sets out a specific process that must be applied when assessing P’s best interests:

- a. D must not determine P’s best interests merely by reference to P’s age, appearance, or to any condition of his or aspect of his behaviour which might lead others to make unjustified assumptions about his best interests;
- b. D must consider all the relevant circumstances<sup>3</sup>; and
- c. In particular, D must take the following steps:
  - i. Consider whether, and if so when, P might have capacity for the matter in question

- ii. So far as reasonably practicable, permit and encourage P to participate, or improve his ability to participate, in the decision or action
- iii. Where the determination relates to life-sustaining treatment<sup>4</sup> D must not, in considering whether the treatment is in P’s best interests, be motivated by a desire to bring about his death.
- iv. Consider, so far as is reasonably ascertainable:
  1. P’s past and present wishes and feelings (and in particular any relevant written statement made by P whilst he had capacity);
  2. the beliefs and values that would be likely to influence P’s decision if he had capacity;
  3. any other factors P would consider if able to do so.
- v. Take account, if practicable, of views as to what would be in P’s best interests of:
  1. anyone named by P as someone to be consulted;

2. anyone engaged in caring for P or interested in his welfare;
3. any holder of a Lasting Power of Attorney;
4. any court appointed deputy.

### **Commentary on best interests**

The MCA sets out the process that must be followed when assessing a person's best interests. This applies to **anyone** taking a decision on that person's behalf, whoever they are, whatever the setting, and whatever the decision.

Just as with assessing capacity, there is a prohibition and a two-stage process.

The prohibition is the same anti-discriminatory provision as before. You must not make judgements about a person's best interests simply by reference to how old he is, what he looks like, what his diagnosis is, or how he behaves. You must assess him and do your best to understand him as an individual. The MCA and the Code of Practice tell us that **we must not make assumptions about somebody else's quality of life**. Decision-makers should not make negative assumptions simply because it may appear to them that somebody's life is of limited quality. Instead, best interests judgements must be based upon evidence gathered from the 2-stage process set out in the Act.

The **first step** of the 2-stage process is that you must **take into account "all relevant circumstances"**. That means you must consider any circumstances or factors that, in your professional judgement (if you are a professional carer), you consider to be relevant. This might include, for example, your assessment of the likely outcome of particular treatment options and your assessment of the benefits and burdens to that particular patient. For

*example: what is the probability that a proposed intervention will extend life, and if so, for how long?*

For the second stage, the MCA sets out a number of steps which you must go through, in addition to taking into account all the things that you consider relevant. This is a **compulsory** check-list.

#### **1. You must consider whether and when the person might gain capacity**

If the person has fluctuating capacity, with some periods during the day when he is more lucid than others, or is temporarily unconscious, consider whether the decision can wait until he regains capacity. If the decision is not an urgent one, and the person might regain capacity soon, then wait until he does so and then ask him what he wants to do - giving him support if necessary. It may be that treatment will be required to help someone regain capacity. For example somebody who is confused or delirious by reason of an infection might regain capacity after being given antibiotics. The decision to be made is whether it is in that person's best interests to be given antibiotics in that particular clinical situation (if the person is imminently dying this might not be the case).

#### **2. Permit and encourage the person to participate**

The fact that the person does not have capacity to make a particular decision does not mean that his wishes or what he finds burdensome should be ignored or that he should be excluded from what is going on. Where possible his views should be obtained, the decision should be explained, and he should be involved in what is happening. The fact that a person does not have the capacity to make a

particular decision does not diminish his humanity. He still needs to be treated with respect. Quite apart from being the right thing to do, this may also make it easier both to assess his best interests and then implement the decision that has been made.

### **3. Where life-sustaining treatment is in issue, you must NOT be motivated by a desire to bring about death**

The motivation must always be to identify the person's best interests and act accordingly. When making decisions about whether the benefit of commencing or continuing life-sustaining treatment is outweighed by the burden of the treatment, your concern must be to identify the person's best interests, and not to bring about his death. You must not make assumptions about the person's quality of life. The Act makes it clear that it does not change the law relating to assisted dying or euthanasia.<sup>5</sup>

This provision was included because of fears in some quarters that the MCA was introducing "euthanasia by the back door", particularly in relation to decisions about withdrawing or withholding artificial nutrition and hydration at the end of life. There is a clear ethical and legal distinction between discontinuing treatment for a dying patient in circumstances where to continue treatment would be burdensome and without benefit to the patient, and intervening to bring about death via lethal medication some days weeks or months before death would otherwise have occurred. These issues are often described in an ill-informed and confusing way in the media. It is important that staff have a clear grasp of the ethical issues involved so that they can explain clearly to patients, families and carers what is happening.

Confusion or uncertainty on the part of staff might lead to avoidable distress and worry on the part of others. Please refer to NCPC's Artificial Nutrition and Hydration - Guidance in End of Life Care for Adults<sup>6</sup> for further guidance on this issue.

The MCA states that life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. This decision will not just depend on the type of treatment. It will also depend on the circumstances in which the healthcare professional is giving it. For example, in some situations antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life<sup>7</sup>.

### **4. You must consider, so far as is reasonably ascertainable:**

- a. **The person's past & present wishes and feelings (including any written statement made by the patient whilst he had capacity)**
- b. **The person's beliefs and values**
- c. **Any other factors the person would consider if he was able to.**

This is a very important provision, which will have a significant impact on palliative and end of life care. The effect of it is to give legal weight to advance care planning. When assessing somebody's best interests, you must take their previously expressed views, beliefs, wishes, feelings and values into account. The MCA particularly emphasises any written statement, although clear and well-evidenced oral statements will also be helpful.

This means that a person's previously expressed wishes must be taken into account by anyone assessing their best interests. They cannot be ignored. So, for example, wishes recorded during an advance care

planning discussion, or in a Preferred Priorities for Care document, must be considered. If decision-makers decide that, despite a clearly expressed preference, the individual's best interests would be served by a different course of action being taken, they will need to be able to justify why they reached that decision.

The making of wide-ranging written statements about preferences for future care or treatment will significantly enhance a person's ability to express and exercise choice beyond loss of capacity, and will potentially be very useful to future carers. Such statements should be included in any care plans drawn up in relation to individuals.

For example, somebody who has been diagnosed with dementia might make a statement to the effect that all his life he has preferred taking a shower to having a bath, dislikes marmite and soft-boiled eggs, likes milk in his tea, finds woollen jumpers very itchy, has a long-held phobia of needles and fear of hospitals, the latter being caused by witnessing his grandmother dying a bad death, and so on. These likes and dislikes, if communicated to a carer, might make significant differences to that individual's everyday experience of care. Such statements would not be legally binding, but would certainly be helpful to those assessing his best interests.

Health and social care professionals and service providers will need to review current practice and consider their policy and approach to the making of such written statements, as well as to advance decisions refusing treatment.

**Please refer to section 11, on Advance Care Planning and the MCA, for further guidance.**

**5. You must take account, if practicable, of the views of:**

- a. Anyone named by the person as someone to be consulted**
- b. Anyone engaged in caring for the person or interested in his welfare**
- c. Any holder of a Lasting Power of Attorney or any Court Appointed Deputy**

When consulting any of these people about their views, it is vital to remember that you must consult them about their views about **what the person's best interests are**, and not about what they might want to happen. This is important because the best interests of an individual are not always identical with the wishes of friends or family. For example a person might want to be cared for at home, but his family might be reluctant for that to happen. The MCA is clear that it is the best interests of the patient which must form the basis of the decision, not those of the family.

**Families, carers, friends & "next of kin"**

In the past it was often thought, erroneously, that "next of kin" had legal rights when family members lost capacity to make decisions for themselves. In fact that was not the case. The MCA has changed that, and now states that "anyone caring for the person or interested in his welfare" must be consulted about his best interests where it is practicable to do so. The effect of this is to give legal recognition and status to family and carers. Families - or "the next of kin" - will almost invariably be amongst those who are either engaged in caring for the person or at least interested in his welfare. However the test is whether people are caring for the person or interested in his welfare; it is not about being a blood relative.

*The views of such people about what the person might have wanted and what his best interests are must be taken into account. If you decide not to follow what they say, because you consider the person's best interests require a different decision to be taken, you should record your reasons so that you can justify your decision if required.*

*It is important to note that **this provision does not give families or carers the right to decide**. That happens only where a person decides to give proxy decision-making rights under a Lasting Power of Attorney (see section 7 for further guidance). Nor does it mean that families, carers and other interested people must be heard in all circumstances. However it does mean that they must be consulted about where the person's best interests lie, if it is practicable to do. That will depend on the urgency of the decision to be taken and the availability of families and carers. In a medical emergency, consultation may not be practicable. Where a long-term care decision needs to be taken, it might be possible to contact family members living far away or even abroad.*

### **Consulting proxy decision-makers about best interests**

*The MCA says that anyone holding a Lasting Power of Attorney or a Court Appointed Deputy must also be consulted about best interests. This may seem confusing, because, as we shall see in section 7, these are people who have been appointed as proxy decision-makers to make decisions on the person's behalf if he lacks the capacity to make them himself. That being so surely they should be making the decisions, not just be consulted about them? However, what this provision means is that if there is such a proxy decision-maker, but their proxy authority does not cover the particular decision in question, they should nevertheless be consulted about the person's best interests as they might have insights to contribute from their own relationship and decision-making on behalf of the person.*

#### **BEST INTERESTS CHECKLIST**

**To summarise, when making a best interests decision, you must:**

- 1. Not make superficial judgements or discriminate on the basis of the person's age, diagnosis, appearance or behaviour;**
- 2. Take everything into account that you consider to be relevant;**
- 3. Make sure you have followed all the steps set out in the MCA and taken into account all the factors that you are required to (including the person's wishes, feelings, beliefs and values and the views of those close to or caring for him); and**
- 4. Make sure that you can justify the decision as being in the person's best interests.**

- **CHAPTER 5 of the Code of Practice contains further guidance about Best Interests.**

## 4. ADVANCE DECISIONS TO REFUSE TREATMENT (MCA sections 24-6)

The MCA contains a new statutory framework about advance decisions to refuse treatment.

If advance decisions to refuse treatment comply with all the tests set out in the MCA they will be binding, so must be respected as if the person who had made the advance decision had capacity and refused the treatment in question at the time the decision was required.

Advance decisions to refuse treatment are not confined to life-sustaining treatment, but may apply to any form of treatment. However, there are additional rules which apply to advance decisions to refuse life-sustaining treatment.

*In summary, the MCA's framework for advance decisions to refuse treatment is as follows:*

- i. The treatment being refused must be specified
- ii. Whilst it is possible to make an advance decision refusing a treatment in all circumstances (for example refusing a blood transfusion in all circumstances for religious reasons), if it is intended that the refusal should apply in some circumstances but not others, the circumstances in which that treatment is being refused should be specified
- iii. It is possible to specify either treatment or circumstances in layman's language; technical language is not necessary
- iv. An advance decision to refuse

treatment can be withdrawn or altered at any time whilst the person has capacity to do so. This need not be in writing, although it would be good practice to ensure that it is recorded and communicated to all those involved in the person's care

- v. An advance decision will be binding upon all carers, professional and informal, if it is "valid" and "applicable".

The MCA does not define what is "valid" or "applicable". Instead, it sets out the circumstances in which an advance decision to refuse treatment will be either invalid or inapplicable. By process of deduction, it should therefore be assumed that advance decisions to refuse treatment that do not fall into those categories will be valid and applicable.

An advance decision to refuse treatment is **not valid** if the person:

- i. has withdrawn it he had capacity to do so (withdrawals need not be in writing, but should be recorded as a matter of good practice as soon as practicable);
- ii. subsequently created a lasting power of attorney giving to somebody else the authority to refuse or give consent to the treatment that the advance decision relates to (creating such a lasting power of attorney would be clearly inconsistent with a previously made advance decision);
- iii. has done anything else clearly

inconsistent with the advance decision remaining his fixed decision.

An advance decision is **not applicable** to the treatment in question if:

- i. at the material time (i.e. when the decision about whether to refuse treatment is required) the person has capacity to give consent to or refuse the treatment in question, and so is able to make the decision himself;
- ii. the treatment in question is not the treatment specified in the advance decision;
- iii. any circumstances specified in the advance decision are absent;
- iv. there are reasonable grounds to believe that circumstances exist which the person did not anticipate when he made the advance decision and which would have affected his decision had he known.

Additional rules apply to **advance decisions in relation to life-sustaining treatment**:

- i. The person must state that the advance decision is to apply to the specified treatment even if his life is at risk;
- ii. The advance decision must be in writing, signed either by the person making the advance decision or by another on his behalf and at his direction, and signed by a witness.

The MCA states that life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. This decision will not just depend on the type of treatment.

It will also depend on the circumstances which exist at the time. For example, in some situations antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life<sup>8</sup>.

### **Commentary on advance decisions to refuse treatment**

#### ● **Determining whether the person has made a legally binding advance decision**

*It is very important that all carers, and in particular all professional carers, understand what the rules are to determine whether or not a particular statement refusing treatment is a legally binding advance decision to refuse treatment. Different legal consequences flow, depending on whether the person has made a binding advance decision to refuse treatment or whether he has made a non-binding statement.*

*If somebody without capacity has made a legally-binding advance decision refusing specified treatment it must be followed. The person has, in effect, taken responsibility for the decision from those treating him, and made the decision himself. Questions of best interests do **not** arise. If however the advance refusal is not legally binding it needs to be taken into account along with other factors. The decision must then be made in the person's best interests.*

*Carers are responsible for establishing that a statement purporting to be an advance decision to refuse treatment is binding under the MCA. This is particularly important for healthcare professionals who are likely to encounter the majority of advance decisions to refuse treatment. However, this*

*applies to all carers. Advance decisions to refuse treatment can apply to all kinds of treatment, not just serious or life-sustaining treatment. For example, a person might wish to refuse to use a particular type of dressing or pressure bandage which he has found uncomfortable.*

*It should not simply be assumed that a statement containing a refusal of treatment is binding. It must be assessed in the context of the treatment decision to be made and the circumstances that exist at the time. Remember that a document does not become a binding advance decision to refuse treatment simply because it carries a heading saying: "Advance Decision to Refuse Treatment" or "Living Will" or contains a declaration that it is legally binding. **It must be assessed against the tests for validity and applicability set out in the MCA as well as the special requirements for decisions refusing life-sustaining treatment.** If it complies with the MCA's requirements it will be binding. If it does not meet all the MCA's tests, for example because it does not sufficiently specify the treatment in question or some of the circumstances specified are absent, it will not be binding, regardless of what its heading states.*

*However, if a statement is not binding, that does not mean that it can simply be ignored. It is likely to be evidence of what the individual's wishes and values were before he lost capacity, and therefore must be taken into account when assessing his best interests.*

### ● **Terminology**

*In the past advance decisions to refuse treatment have also been*

*called "advance directives", "advance statements" or "living wills". However, those labels do not help with the most important question: is the refusal of treatment binding, or is it something that needs to be taken into account as part of the best interests assessment, but without being binding?*

*There will be a need to find language that distinguishes clearly between these different types of advance written refusals, so as to avoid confusion. One possible solution is to refer, as the MCA and the Code of Practice do, to binding advance decisions to refuse treatment as "advance decisions", and to all other types of statement, including non-binding advance refusals of treatment, as "statements of wishes" or "statements of preferences". "Decision" has a sense of binding finality about it, which "statement" does not.*

### ● **In practice**

*Advance decisions to refuse treatment become applicable only if the person does not have the capacity to make the decision for himself. If he has the capacity to make the decision he should be asked whether or not he wants the treatment and given any support and information necessary to help him make the decision.*

*The MCA distinguishes between advance decisions to refuse medical treatment, and advance requests to receive medical treatment. Only advance decisions to refuse treatment can be legally binding under the MCA, and then only if they are both valid and applicable. Requests for treatment, whether in advance or not, are evidence of the person's wishes and values and must be taken into account, but are not binding. The MCA does not*

*change the position that doctors are not obliged to offer treatment that would be futile or otherwise not in the patient's best interests.*

*A valid and applicable advance decision to refuse treatment will override the authority of the donee of a lasting power of attorney for that particular decision, unless the lasting power of attorney was made subsequently and confers authority on the holder to consent to or refuse treatment covered by the advance decision (see further in section 7 on Lasting Powers of Attorney). The key is the order in which the documents were created: a lasting power of attorney created subsequently to an advance decision, and referring expressly to the same treatment, would be inconsistent with the earlier advance decision and would therefore supersede it.*

*Responsibility for making an advance decision to refuse treatment and for making sure it is brought to the attention of his carers, including his healthcare professionals, lies with the person making the advance decision. Similarly, if he wishes to alter it or withdraw it, he needs to make sure that it is communicated to everyone whom he has told about it. Organisations and professionals will need to develop policies to ensure that advance decisions to refuse treatment, as well as any changes or withdrawals, are properly recorded and communicated. This is particularly important where an individual is transferred between services.*

### ● **Specific language and circumstances**

*It is still possible to create an advance decision refusing treatment that would be applicable in all circumstances.*

*However in the majority of cases, people will want to refuse treatment in some circumstances but not others. The MCA states that an advance decision will not be applicable if "any" of the circumstances that the patient has specified are absent. It should still be taken into account, but will not be binding.*

*It is not yet clear how "specific" language will have to be when describing the treatment or circumstances. Care will have to be taken when considering these issues. However, a statement such as "if I am dying I refuse any life-sustaining treatment" is likely to be insufficiently specific both as to circumstances and treatment. A person living with a progressive and incurable condition such as MND is arguably "dying" on one interpretation of language, even if death is not expected imminently. Language such as "any life-sustaining treatment" does not specify a particular treatment. The Code of Practice recognises that some treatment might be life-sustaining in some circumstances, but not others. Antibiotics are one example.*

*In practice it is likely to be considerably easier to create an advance decision refusing specific treatment in specific circumstances once there is a well-established diagnosis. It then becomes possible for an individual and his medical team to anticipate likely events and treatment options along the disease pathway, and to discuss what the individual's preferences and choices might be. That should be part of overall and continuing advance care planning discussions, if the patient wishes to discuss those issues. It would be good practice to ensure that an advance decision refusing treatment is reviewed*

regularly. Precisely how often will depend on individual circumstances.

Just as with wider advance care planning, making an advance decision to refuse treatment should be an entirely voluntary process; people are under no obligation to make an advance decision to refuse treatment. If they decide to do so, they should be advised to seek specific advice both about the treatment and circumstances in question, and the consequences if the advance decision is implemented.

People who are healthy and do not have a life-threatening diagnosis should exercise caution before making a decision that will bind their future medical team. It is not easy to anticipate or imagine when healthy how you might respond to the reality of living with a life-threatening condition.

People with advance decisions (or similar documents) that pre-date the MCA should be advised to review them to ensure that they meet the requirements of the MCA.

#### ● **Advance decisions to refuse treatment and CPR - discussion**

The impact of the MCA's provisions about advance decisions to refuse treatment on decisions about CPR (cardiopulmonary resuscitation) and DNAR (Do Not Attempt Resuscitation) decisions is complex. These decisions are of particular importance in end of life care for people at risk of cardio-respiratory arrest. Decisions should be made on the basis of an individual assessment of each person. It is good practice to make these decisions when there is time for proper consideration and review them as appropriate. It is extremely difficult

to make these decisions at the time of a cardio-respiratory arrest. If left until the moment of arrest, resuscitation is often attempted in circumstances in which it might not have been appropriate.

The British Medical Association, the Royal College of Nursing and the Resuscitation Council have recently published a new joint statement on Decisions relating to cardiopulmonary resuscitation<sup>9</sup>. This joint statement considers these issues in more detail than is possible here. Healthcare professionals should refer to the guidance contained in that statement.

The joint statement makes it clear that if the healthcare team considers that CPR has no realistic prospect of success (i.e. that it would not re-start the heart and breathing) and could only be burdensome to the person, it should not be attempted or offered<sup>10</sup>. This would apply regardless of the person's capacity. Whilst this decision by the healthcare team not to offer CPR must be recorded and, where appropriate, communicated to the person, it does not require a treatment decision to be made by the person. In these circumstances, the decision not to attempt CPR is made by the health care team, and is not an advance decision to refuse treatment made by the patient.

Where arguments about benefit and burden are more finely balanced, and the healthcare team is not in a position to say that CPR would be futile, the position is different. Where the person has capacity to make a decision about whether he wishes CPR to be attempted in the future there should be a discussion with him, and his views should be recorded and respected. If the patient lacks capacity, a decision needs to be

taken as to whether it would be in his best interests to attempt resuscitation in the event of a future arrest. That decision will be made when necessary by the healthcare team or, if applicable, a donee of a Lasting Power of Attorney who has the authority to make decisions about life-sustaining treatment (see section 7) according to the MCA rules.

In circumstances in which the healthcare team consider that it would or might be appropriate to attempt CPR, but a person with capacity decides that he wishes to refuse it should he lose capacity in the future, he is making an advance decision to refuse a potentially life-sustaining treatment. The rules relating to advance decisions refusing life-sustaining treatment therefore apply: the Do Not Attempt Resuscitation decision should be written, signed, witnessed and contain a statement that the advance decision to refuse CPR is to apply even though life is at risk as a result.

● **If in doubt**

*If healthcare professionals are satisfied that there is a valid and applicable*

*advance decision to refuse treatment in existence, they would be liable for assault if nevertheless they carried out or continued the specified treatment despite that advance decision. The position would be the same as if a competent patient had refused treatment, but they nevertheless administered it. However, if there is any doubt about whether an advance refusal is valid, applicable and therefore binding, life-sustaining treatment and other treatment to prevent the patient's condition from deteriorating can be provided whilst a decision is being obtained from the Court of Protection. The best advice can be summarised as: if in doubt, preserve life.*

- **Chapter 9 of the Code of Practice contains further guidance on advance decisions to refuse treatment. This includes a number of helpful case studies.**
- **NCPC and the End of Life Care programme will publish further detailed guidance, both for patients and professionals, on Advance Decisions to Refuse Treatment in the summer of 2008.**

## 5. LIABILITY & RESPONSIBILITY (MCA section 5)

The MCA gives the following protection for somebody (D) who has carried out an act in connection with the care or treatment of somebody (P) who lacked the capacity to consent to that act:

D will not be liable for the act in connection with the care or treatment of P if:

- a. he took reasonable steps to establish whether P had capacity in relation to the matter;
- b. he reasonably believed that P lacked capacity;
- c. he reasonably believed the act was in P's best interests; and
- d. it is an act to which P could have given consent if he had capacity.

The MCA does not have any impact on civil or criminal liability for negligence. In other words, if D decides that a particular act is in P's best interests, but does it negligently, he will still be liable for the consequences of negligence.

### *Commentary on liability and responsibility*

*It is important to understand where responsibility lies under the MCA. Is it with the person who determines capacity, who decides what course of action is in a patient's best interests, or is it the person who implements the decision? This is a particularly significant question in palliative care where decisions about care and treatment are often made in the multi-professional team context.*

*Under the MCA ultimate responsibility for decision-making rests with the person who has to implement the decision. The decision-maker is the implementer. So, for example, in a complex case, where a psychologist might have been consulted to advise on a patient's capacity, a specialist consultant considers that particular medication is required, and the nurse actually administers the medication, the nurse is the person with whom ultimate responsibility arises.*

*To understand why this is the case we need to look briefly at the law of consent. We need to consent to medical treatment, or to people dealing with our property. If we do not, the person who cuts us open with a scalpel would be guilty of assault (or worse!) and the person who takes and uses our money might be guilty of theft. The MCA puts carers in the position that they would have been in if the person for whom they are caring had consented to the activity in question. To be specific, the MCA states that if a carer reasonably believed that the person did not have capacity to make a particular decision, and the carer reasonably believed that the course of action was in the person's best interests, then the carer is absolved from civil or criminal liability as if the person had consented.*

*How does this work in a multi-professional team? Where there is consensus in the team about what is to happen, all should be well. The person responsible for implementing the decision will be supported by the professional judgements of their colleagues in the team.*

*If however there is no consensus, the MCA gives responsibility and authority to the person who implements the decision. That person must be satisfied about both capacity and best interests. The MCA provides a framework to enable us to identify where responsibility lies.*

*To take another example, if a palliative medicine consultant judged that it would*

*be in the best interests of a patient to have a peg tube inserted, but the gastroenterologist whose task it would be to insert the tube advised that this was not appropriate, the gastroenterologist's view would be decisive.*

- **Chapter 6 of the Code of Practice contains further guidance on liability and responsibility.**

## 6. RESTRAINT (MCA section 6)

The MCA originally stated that a person can be restrained only if that is necessary to prevent harm to him, and if that restraint is proportionate to the possible harm to him. The MCA at present does permit the deprivation of liberty of a person lacking capacity. However, the Mental Health Act 2007 has amended the MCA and introduced deprivation of liberty safeguards. These are due to come into force on 1 April 2009.

### **Commentary on restraint and the Bournemouth case**

*This provision needs to be read in conjunction with two of the underlying principles: that a decision made on behalf of somebody lacking capacity must always be in his best interests, and that the least restrictive option should be taken where possible.*

*The MCA does not include any reference to restraining P in order to prevent him from causing harm or distress to other people, for example other patients. The government's position in the legislative process was that this will remain an issue to be governed by reference to other law and in particular common law. Common law enables somebody to be appropriately restrained in order to prevent harm to him*

*or to others<sup>11</sup>. The MCA allows restraint only if that is necessary to prevent harm to him.*

*There is an overlap between the MCA and the Mental Health Acts on the issue of restraint. This was brought into focus by the Bournemouth case in which a man with autism who did not have the capacity to consent to being in hospital was not detained under the Mental Health Act, but admitted, as an informal or voluntary patient. However because he lacked the capacity to consent he was in fact admitted under common law in his best interests. The European Court ruled that the circumstances in which his best interests were being met were a deprivation of his liberty and he was thus unlawfully detained. The Government needed to introduce a process that would be compliant with European Human Rights legislation. As a result, the Mental Health Act 2007 amended the MCA, and introduced the new deprivation of liberty safeguards. These are intended to plug the Bournemouth gap. This new law will not come into effect until 1 April 2009.*

*<sup>12</sup>This is a complicated area of law which falls outside the scope of this publication. Guidance should be obtained from specialists where necessary.*

## 7. THIRD PARTY INVOLVEMENT IN DECISION-MAKING

The MCA introduces new ways in which third parties can be involved in decision-making, either as proxy decision-makers, or as advocates. These are:

1. Lasting Powers of Attorney
2. Court Appointed Deputies
3. Independent Mental Capacity Advocates.

### LASTING POWERS OF ATTORNEY (MCA sections 9-14)

The MCA contains detailed provisions in relation to powers of attorney. In particular it creates new Lasting Powers of Attorney (LPA), which replace the old Enduring Powers of Attorney (EPA). It is now no longer possible to execute a new EPA. However, EPAs that were made before the MCA came into force remain valid.

The most significant difference is that Lasting Powers of Attorney can apply to a person's welfare, which includes his health and social care, as well as to his financial affairs and property. The rules differentiate between these two types of LPA:

- a. A personal welfare LPA
- b. A property and affairs LPA

In summary the new provisions about LPAs are as follows:

- a. A person can whilst he still has capacity give another person (or

persons) an LPA to make decisions about all or some of the following:

- i. his personal welfare
  - ii. his personal property
  - iii. specified matters relating to his welfare or property
- b. People making decisions about him under an LPA are under a duty to make those decisions in his best interests. They are therefore bound by the rules relating to best interests
  - c. An LPA must be in a prescribed form<sup>13</sup>. It must be registered with the Office of the Public Guardian<sup>14</sup> before it can be used
  - d. An LPA in relation to someone's personal welfare will apply only if that person lacks capacity to make a decision covered by the LPA
  - e. An LPA in relation to someone's personal welfare can extend to giving or refusing consent to the carrying out or continuation of treatment, but will extend to life-sustaining treatment only if that is expressly contained in the LPA
  - f. A person making an LPA can give power of attorney to more than one person.

The person who is given authority to make decisions for somebody else under an LPA is sometimes called the **Donee** of the LPA, and the giver is sometimes called the **Donor**.

#### *Formalities*

LPAs are formal documents. They have to be in a prescribed form, copies of which

are available on the Office of the Public Guardian's (OPG) website (see section 15 of this document). There are separate forms for the personal welfare LPA and the property and affairs LPA.

LPAs have to be registered with the OPG before they can be activated. They can be registered either by the donor or the donee. A fee of £150 must be paid to the OPG on registration of an LPA. If you wish to register both a welfare LPA and a property and affairs LPA that means that a total fee of £300 must be paid. People in receipt of some welfare benefits can apply for a fee exemption. There is also a tapered fee remission scheme so that people with an income of up to £16,000 can apply for a reduction in the fees payable. Details are available on the OPG website.

### **Giving a Lasting Power of Attorney to somebody else**

*The ability to make a power of attorney covering personal welfare as well as property and affairs is a very considerable extension of the law. It will have a significant impact on health and social care.*

*People are under no obligation to give an LPA to anybody. They should do so only if they are satisfied that they can trust the person or people to whom they are giving the LPA. If you give somebody an LPA you are giving that person the authority to make important and intimate decisions on your behalf should you lose the capacity to make those decisions for yourself in the future. That is a significant responsibility both to give and discharge. Donees of LPAs may need support in making decisions about care and treatment, particularly complex ones or where they have been given*

*the express authority to make decisions about life-sustaining treatment.*

*It will be possible to specify what decisions you are giving the Donee the power to make. It will also be possible to give more than one person the power to make decisions, and to give different people the power to make different decisions on your behalf. So, for example, you might appoint one family member to make decisions about your property and affairs, and another to make decisions about your welfare. It is up to you.*

*The Donee of the LPA cannot make any decisions about life-sustaining treatment unless you have specifically stated that you want him to have that power.*

*LPAs are formal documents which need to be registered. It is not possible to make them verbally, or to write them down on a spare piece of paper. The OPG will stamp LPA documents to show that they have been registered.*

### **LPA & best interests**

*People making decisions as Donees of an LPA must make the decision in the best interests of the Donor. That means that they must go through precisely the same process as anybody else making a best interests decision, using the same 2-stage test. They will need to be able to justify their decision on best interests grounds if challenged.*

*If you are caring for somebody who has not got the capacity to make a particular decision for himself, and somebody else claims that they have the right to make decisions under an LPA, you should always ask to see the LPA document to make sure that it does give that person the authority to make the decision in*

question, and to check that the LPA document has been stamped by the OPG to show that it has been registered. If there is a doubt about the validity or registration of an LPA it is possible to apply to search the LPA register for a £25 fee.

**What happens if there is a disagreement between the donee of an LPA and a person's carers about where the person's best interests lie?**

The MCA gives the decision-making authority to the donee of the LPA, not to the professionals and other carers. However, the carers (whether professionals or not) may disagree with the donee's decision.

In practical terms, the best solution will often be for the carers to discuss their concerns with the donee of the LPA. It might be that the donee of the LPA has perfectly valid reasons for making the decision in question. That should be respected; the person decided to give the donee the LPA because he trusted the donee to make judgements about where his best interests lie, and wanted the donee to make that judgement rather than anyone else. As an alternative, it may be that the donee of the LPA needs additional support and information in order to understand more fully what the issues involved are. In many cases good communication should make it possible to clarify or resolve any concerns to everybody's satisfaction.

If there is genuine concern that the donee's decision cannot be justified by reference to best interests, the donee can be challenged. If discussion and meetings fail to produce resolution, ultimately an application can be made to the Court of Protection. **Chapter 15 of**

*the Code of Practice contains further guidance on resolving MCA-related disputes.*

- **Chapter 7 of the Code of Practice contains further guidance on Lasting Powers of Attorney.**

## COURT APPOINTED DEPUTIES (MCA sections 15-21)

The MCA enables the court to appoint a deputy to make decisions in relation to someone who lacks capacity to make those decisions for himself. In summary, the MCA's framework relating to deputies is as follows:

- a. The court may make declarations as to whether a person has or lacks capacity in relation to specified decisions or matters
- b. If the person lacks capacity in matters concerning his personal welfare or property, the court may either make decisions on his behalf, or appoint a deputy to make those decisions
- c. Like other decision-makers, the court is subject to the best interests provisions in taking decisions about the person, including the decision whether or not to appoint a deputy
- d. A deputy is also subject to the best interests provisions
- e. In principle, a decision by the court is to be preferred to a decision by a deputy, and powers conferred on a deputy are to be as restricted and for as limited a period as possible
- f. A deputy may not be given authority to refuse or consent to the carrying out or continuation of life-sustaining treatment in relation to the person.

## **Commentary on Court Appointed Deputies**

*This is a new statutory power and it will take some time to see how its use evolves in practice. The principles that will help the court decide whether to appoint a deputy to make decisions on behalf of a person include the following:*

- 1. The court can appoint a deputy only if the judge considers that it is in the best interests of the person who lacks capacity to make a decision for himself*
- 2. Where possible the court should make the decision itself, rather than appoint a deputy to do it instead*
- 3. If a deputy needs to be appointed, his appointment should be as limited in scope and for as short a time as possible*
- 4. The court does not have the power to appoint a deputy to make a decision about life-sustaining treatment. If a decision about that sort of treatment has come before the court, the court must make the decision itself.*

*Examples in which the court might decide to appoint a deputy include the following:*

- 1. Where it is necessary to sell a person's house or some of his property*
- 2. Where the person has financial assets that need to be managed*
- 3. Where there is a history of unresolved family disputes about the person's care and a deputy is required to make necessary and urgent decisions*
- 4. Where a series of linked welfare decisions needs to be made over a period of time and it is not*

*appropriate to require them all to be made by the court.*

*Nobody can be appointed a deputy without their consent. The court can appoint more than one person to be a deputy, and can specify which decisions each deputy has the power to make. More than one deputy might be required to make the same decision. Relatives, friends or professionals might be appointed as deputies, depending on the circumstances. If a professional is appointed, the court will need to make sure that there is no possible conflict of interest. For example care home managers should not generally be appointed as deputies to make financial decisions about a resident.*

*Further guidance about the Court of Protection and the Office of the Public Guardian can be found in section 10 below.*

- **Chapter 8 of the Code of Practice contains further guidance on the powers of the court, including the appointment of deputies.**

## **INDEPENDENT MENTAL CAPACITY ADVOCATES (MCA sections 35-41)**

Independent Mental Capacity Advocates (IMCAs) are a completely new type of statutory advocacy service. The IMCA role is to provide a safeguard for people who lack the capacity to make certain important decisions and have no-one else (other than paid staff) to support or represent them or be consulted. IMCAs are intended to protect people who have no family or friends who can be consulted about their best interests.

The MCA states that an IMCA **must** be instructed and consulted for such people whenever:

1. An NHS body is proposing to provide, withhold or withdraw serious medical treatment
2. An NHS body or local authority is making or changing arrangements for a person's accommodation either in hospital (if for more than 28 days) or a care home (if for more than 8 weeks).

An IMCA *may* also be instructed to support someone lacking capacity in relation to care reviews, if there is nobody else available to be consulted other than paid carers, or in adult protection cases, even if family or friends are involved.

The IMCA's role is **not** to make decisions, but to work with and support people lacking capacity, to make their views known to decision-makers, and to raise questions or challenge decisions which appear not to be in the person's best interests. They have the right to see relevant health and social care records.

### **Commentary on IMCAs**

*The most important thing about IMCAs is that they are **advocates, not decision-makers**. Their role is never to make a decision on behalf of a person. Instead they are there to represent the person for whom the decision is being made and to make sure that the decision is made in his best interests. The decision-maker must take any information provided by the IMCA into account when making the decision. If necessary the IMCA can call for a second opinion or challenge the decision before the court.*

*IMCAs are required only when particular*

*decisions about serious medical treatment or longer term place of care are being made by NHS bodies or local authorities. They are not required in cases where similar decisions are being made solely by independent or voluntary sector organisations. The reason for this is that the government was particularly concerned to protect vulnerable people against the state. IMCAs are not required for patients in voluntary hospices or privately-funded residents in independent care homes, unless that care is being funded or arranged by an NHS body or local authority.*

*As IMCA services take root and then begin to mature, IMCA consultations will be seen as good practice and other services will seek to take advantage of them. There will be a funding issue for non-statutory agencies that wish to consult IMCAs. Anecdotal evidence suggests that some voluntary hospices have already contacted their PCTs about making IMCA services available to them. IMCAs are not prevented from acting in response to such requests but will need to be authorised to do so by those who commission their services.*

### **What is "serious medical treatment"?**

*There is an issue about what "serious medical treatment" means, particularly in the context of end of life decisions about attempting CPR or about artificial nutrition and hydration (ANH).*

*Regulations define "serious medical treatment" (which includes stopping or withholding treatment, as well as starting it) as follows:*

- *Where there is a fine line between the likely benefits and the burdens to the patient and the risks involved;*
- *Where there is a fine balance between*

- choices of treatment; or
- *Where what is proposed is likely to have serious consequences for the patient.*

*The question is whether, at the end of life, where a patient is close to death and no recovery is possible, a decision to provide or withdraw ANH or to attempt or not to attempt CPR is a decision that would have “serious consequences” for that patient. Would an NHS body always need to consult an IMCA for such patients, if there is nobody else to consult?*

*The courts have not yet had an opportunity to rule on this. However, the Code of Practice suggests that, whilst withdrawing or withholding ANH might be considered serious, that will depend on the circumstances and consequences for the individual patient.<sup>15</sup>*

*In their 2007 guidance on CPR<sup>16</sup> the British Medical Association, the Royal College of Nursing and the Resuscitation*

*Council stated that, whilst there is still some uncertainty in this area, “an IMCA does not need to be called when it is clear to the medical team that CPR would not re-start the patient’s heart and breathing for a sustained period.”*

*NCPC takes a similar view. If it is clear that CPR would not succeed, or that ANH would have no benefit to the patient, then an IMCA need not be consulted. If however there is genuine uncertainty, and the decision is “finely balanced” then an IMCA must be consulted. If the decision needs to be taken out of hours, and an IMCA is not available, that should be recorded and the decision reached should be discussed with the IMCA service at the earliest opportunity. The MCA provides that serious medical treatment can provided if it is required “as a matter of urgency”, even if the NHS body or local authority has not been able to consult an IMCA.*

- **Chapter 10 of the Code of Practice contains further guidance on IMCAs.**

## 8. ILL-TREATMENT & NEGLECT (MCA section 44)

The MCA has created two new criminal offences: ill-treatment and wilful neglect. These can apply to anyone caring for a person lacking capacity. This includes donees of an LPA, or a deputy appointed by the court. The offences are punishable by up to five years' imprisonment.

### **Commentary on ill-treatment & wilful neglect**

*The MCA does not define what is meant by ill-treatment or wilful neglect. The court will have to decide what degree of misbehaviour or neglect is so serious that it should attract a criminal sanction.<sup>17</sup>*

*It is possible that single acts or omissions will be sufficiently serious as to amount to ill-treatment or wilful neglect. It is also possible that behaviour or neglect*

*which, as an isolated instance might not attract criminal proceedings, would do if it occurred more often.*

*Ill-treatment probably would not need to result in actual physical harm, but might include psychological abuse, for example repeatedly shouting at or distressing somebody. Wilful neglect might include repeated failure to provide care such as washing, or failing to support somebody who needs assistance in feeding themselves. There will be uncertainty over this until the court has the opportunity to issue some guidelines.*

- **Chapter 14 of the Code of Practice contains further guidance on issues of abuse including wilful neglect and ill-treatment.**

## 9. RESEARCH IN RELATION TO PEOPLE WITHOUT CAPACITY (MCA sections 30-34)

The MCA permits “intrusive research” (i.e. research that would be unlawful unless consent was given) to be carried out in relation to an individual who lacks the capacity to consent to that research, provided that safeguards are met. These safeguards include:

- i. The research has been approved by a local ethics committee;
- ii. The research is connected with an impairing condition that both affects the person lacking capacity and is attributable to the impairment or disturbance of his mind or brain;
- iii. The research would not be effective if carried out only in relation to people with capacity;
- iv. The research has the potential to benefit the person without imposing a disproportionate burden on him;

- v. If (iv) above does not apply, the research must be intended to provide knowledge of the person’s condition, but must not significantly interfere with his freedom of action or privacy, or be unduly invasive or restrictive.

### **Comment on provisions relating to research**

*The purpose of these provisions is to enable research to be carried out into the condition that may have caused somebody’s incapacity, whilst at the same time protecting him from non-consensual research into other conditions that he might have which are unrelated to his lack of capacity. By way of example, provided that the MCA safeguards are complied with, it would be permissible to research the causes of somebody’s dementia, but not his diabetes.*

## 10. COURT OF PROTECTION & PUBLIC GUARDIAN

The Act creates a new specialist Court of Protection, to deal with all issues relating to the welfare or financial decisions of adults lacking capacity. In the past, these issues were dealt with in separate courts. The court will be supported in its work by a new public office: the Public Guardian. The Public Guardian's role will include holding registers of Lasting Powers of Attorney and deputies appointed by the court, and directing Court of Protection Visitors to make reports to the Court of Protection in relation to individual cases.

The Code of Practice states that some treatment decisions are so serious that they must be referred to the court for a decision, unless the person has already made a Lasting Power of Attorney appointing somebody to make such decisions for them, or they have made a valid and applicable advance decision refusing treatment. In particular, the Court of Protection **must** be asked to make decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from a person in a

permanent vegetative state (PVS). Other examples of serious treatment include decisions about sterilisation or organ donation.<sup>18</sup>

Outside those very serious cases, in the event of genuine disputes and disagreements involving families, carers and professionals, or any combination of those, best practice will be to try all avenues of communication, information-sharing and dispute resolution first. Referral to the Court should ideally be a last resort.

*Please refer to the Code of Practice for further guidance and information as follows:*

- ***Role of the Court: Chapter 8***
- ***Role of the Public Guardian: Chapter 14***
- ***Settling MCA-related disagreements and disputes: Chapter 15***

Website details can be found in section 15 at the end of this document.

# 11. THE MENTAL CAPACITY ACT & ADVANCE CARE PLANNING

Advance care planning (ACP) has been defined as: *a continuing process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual's agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care. An ACP discussion might include:*

- *the individual's concerns*
- *their important values or personal goals for care*
- *their understanding about their illness and prognosis*
- *their preferences for types of care or treatment that may be beneficial in the future and the availability of these.*<sup>19</sup>

The overlap between the MCA and advance care planning is in relation to decisions about what is to happen when an individual loses capacity to make a decision for himself. Advance care planning is also used, whilst an individual retains capacity, to facilitate the provision and arrangement of appropriate services and equipment by anticipating the individual's needs and priorities in advance and planning accordingly.

The requirement in the MCA that an individual's wishes, feelings, beliefs and values must be taken into account when assessing his best interests, and its new rules about both advance decisions to refuse treatment and proxy-decision-making through Lasting Powers of Attorney, mean that the MCA

has a considerable impact on advance care planning. Its effect is to give legal status to a person's values and priorities when he loses capacity to make his own decisions. His wishes must be taken into account; they cannot be ignored.

Looking at it from a carer's perspective, advance care planning is a process by which an individual's priorities, preferences, wishes and values can be expressed, captured and recorded. Advance care planning is therefore a means by which organisations and carers can comply with their obligations under the MCA. This is because advance care planning can enable a documented framework to be put in place so that best interests decisions can be made in a way that is as well-informed as possible about the individual and what he would wish. A number of tools exist which can facilitate the advance care planning process, including the Gold Standards Framework, the Liverpool Care Pathway and the Preferred Priorities for Care document, all of which have been promoted by the NHS End of life Care Programme.

The effect of the MCA and advance care planning does not mean that a person's wishes must always be followed. It may be that in the particular circumstances their best interests mean that something else must happen, or that they have requested treatment that would not be in their best interests. However if a carer decides not to follow a person's wishes and preferences he will need to make sure that he is able to justify that decision if he is later asked to do so.

It should be emphasised that advance care planning is not a compulsory process - some individuals may not wish to do this, although it is best practice to offer it to them. Nor is what they say going to be immediately and permanently binding. People can always change their minds and, if they have the capacity to do so, will still be able to make every decision for themselves at the appropriate moment.

### *Organisational requirements*

Many health and social care professionals and service providers are already using one or more of the End of Life Care Programme's tools<sup>20</sup>. All professionals and organisations engaged in end of life care

should consider doing the same. This is not just a question of good practice; it will help them implement and comply with the MCA.

Practical questions about advance care planning include how to capture and record written statements from a person. What level of support does a person need to make them? What level of training needs to be given to staff about supporting people during advance care planning? What level of detail should advance care plans contain? In order to implement advance care planning organisations will need to consider staff training needs, particularly in relation to skills such as communication and assessment.

## 12. FROM AN INDIVIDUAL'S PERSPECTIVE: USING THE MCA TO EXPRESS AND PROTECT CHOICES

As we have seen above, the MCA provides a number of ways in which people can pro-actively take steps to express and, in some cases, protect their choices about their care and treatment should they lose capacity to make those decisions for themselves. It would be sensible for them to discuss these with any friends or family whom they wish to be involved as well as with their health and social care team as part of their overall advance care planning.

- **Nominating a friend or relative to be consulted about their best interests.** The MCA requires that the views of anybody whom a person has nominated must be taken into account when assessing his best interests. This is **not** the same as giving someone a formal Lasting Power of Attorney.
- **Identifying people who should not be consulted.** Although the MCA does not say so expressly, it is also possible for people with capacity to identify in advance anybody whom they do not wish to be consulted. So, for example, in the event of family breakdown, it would be possible to say that you do not want a particular person to be consulted about your best interests.
- **Making statements about their wishes, preferences, priorities and values.** These statements will not be binding, but must be taken into account. They can include both what the person would

and would not like to happen in the future. For example, an individual's treatment choices might be aimed at preserving mobility or speech for as long as possible, potentially overriding other considerations. The Preferred Priorities for Care tool is one means of recording these to ensure that they are clear and well-evidenced.

- **Appointing a proxy decision-maker under a Lasting Power of Attorney.** This is a formal process. If the LPA applies to the decision in question, the donee of the LPA will be the person who makes the decision, rather than one of the person's carers. The donee of the LPA must make the decision in the person's best interests, and can be challenged about that in the event of a disagreement.
- **Making an advance decision to refuse specified treatment.** This will be binding, provided that the decision is valid and applicable to the treatment and circumstances that exist at the time and that it accords, where appropriate, with the explicit requirements of the MCA about life-sustaining treatment.

*NCPC and the End of Life Care programme will be producing an introductory leaflet for patients about Advance Care Planning in the summer of 2008.*

## 13. WHAT THE MCA MEANS FOR FAMILY MEMBERS, CARERS & FRIENDS

As set out above, in the section on “best interests”, the MCA provides a framework for family members, carers and friends to be involved in decision-making about a person’s care. The MCA does this by stating that, when a decision needs to be taken about a person who lacks capacity, the decision-maker must take into account, if practicable, the views of anyone engaged in caring for that person or interested in his welfare as to what would be in that person’s best interests.

Provided that friends and family members can demonstrate that they are interested in somebody’s welfare, they, along with his carers, must be consulted if it is practicable to do so. Family members must be consulted not because they are blood relatives, but because they are interested in the person’s welfare. It is important to recognise that they must be consulted about their views of the person’s best interests, and not about what they might want to happen themselves. There are sometimes tensions and conflicts between a person’s best interests and the interests of those close to him, for any number of reasons.

Ways in which the MCA affects interested family members, carers and friends include the following:

- **Protected decision-making.** Until the MCA there was no legal framework for decision-making. That has now changed. Family members and carers will be protected in law if they can

show that they reasonably believed both that the person for whom they are caring did not have the capacity to make a particular decision and that the decision that they took was in the person’s best interests. This applies across the whole range of decisions, from minor decisions about everyday care to more significant ones such as place of residence.

- **They must be consulted where practicable.** If a decision needs to be taken about a person’s best interests, their interested family members and carers must be consulted if practicable. That means that the family’s and carers’ views about the person’s best interests must be taken into account along with all the other factors identified by the MCA. A person can also nominate one or more of his family members or carers to be consulted about his best interests.
- **Challenging decisions.** Family members and carers can challenge a decision made on behalf of the person they are caring for if they consider that it is not in the person’s best interests. Ultimately disagreements can be resolved before the Court of Protection. The MCA’s requirement that decisions must be in a person’s best interests means a person’s inability to consent to care or treatment cannot be a barrier to him receiving it if it is in his best interests. Family members and carers can use this to argue that the person for whom they are caring

should or should not have a particular treatment or care arrangement.

(N.B. It is important to distinguish between treatment that would be in somebody's best interests and treatment that would be futile. The MCA does not require health care professionals to provide treatment that would be of no benefit to a person without capacity.)

- **Appointment as an Attorney.** A person with capacity can give one or more people a Lasting Power of Attorney to make decisions about his property and finances or his personal welfare. This is a great responsibility, both to give and to receive. People should not be placed under pressure to give powers

of attorney to anybody. It must be a voluntary act, free from undue influence or coercion. If a person does decide to give authority under an LPA to another person, the donee of the LPA must make decisions in the donor's best interests.

- **Appointment as a Deputy.** An application can be made to the Court for one or more people to be appointed as a Deputy to make decisions on behalf of a person without capacity. The Court can only appoint a Deputy if it is in the person's best interests to do so, and the Deputy's authority should be as limited in scope and time as possible.

# 14. WHAT THE MCA MEANS FOR ORGANISATIONS

Organisations will need to **review their existing procedures and policies** across a wide range of activities to ensure that they comply with the MCA. This will include but is not limited to:

- Assessing mental capacity
- Assessing best interests
- Advance care planning
- Advance decisions to refuse treatment
- Decisions regarding potentially life-sustaining treatment e.g. artificial nutrition and hydration and cardiopulmonary resuscitation
- Written consent for treatment
- Protection of vulnerable adults

**New policies** will also be required to cover Lasting Powers of Attorney for personal welfare, as well as finance and property, court appointed deputies, and IMCA consultations.

The Hospice of the Good Shepherd, Chester, and Help the Hospices have developed a Mental Capacity Act Pro Forma document, which is intended to ensure that decisions made on behalf of somebody lacking capacity comply with the MCA. It includes sections on recording information about decision-making on capacity and best interests, as well as advance care planning, Lasting Powers of Attorney, IMCA consultations, and discussions with family and carers. Please see section 15 for a weblink to this document, which may be helpful.

Organisations will also need to ensure that their **workforce receives sufficient training** in MCA to enable them to comply

with it. This may include some volunteers as well as paid members of staff. If members of the workforce are directly involved in caring for or treating people with impaired mental capacity, they will need to be trained about the MCA. They will also need access to the Code of Practice.

NCPC and Help the Hospices have developed an e-learning tool about the Mental Capacity Act. This includes a presentation about the MCA, which can be used individually or in group work, together with case studies. It can be accessed on-line at <http://www.helpthehospices.org.uk/elearning/mca/index.html>

## **NCPC's FUTURE WORK**

- NCPC is carrying out an impact survey into the MCA, which has been sent to all adult hospices and specialist palliative care units and a sample of care homes. An initial questionnaire was sent out in October 2007, and the survey will be repeated in 2008. It includes questions both on policies and procedures and on workforce training. It will be used to help identify organisational needs in these areas and will inform NCPC's future work plans. Preliminary findings will be published in 2008. It would be of great help if all those who receive the 2008 questionnaire could complete and return it.
- NCPC will be holding an MCA-themed conference in each of its areas in

England during 2008 as part of its regular area events programme. These conferences will explain the impact of the MCA on palliative care, set the MCA in the context of current palliative and end of life care issues, and explain how it can be used to deliver Advance Care Planning, and drive improvements in care. Individual conferences will explore in detail issues such as cardio-pulmonary resuscitation, artificial nutrition and hydration, advance decisions to refuse treatment, and proxy decision-making. Further details will be

published in due course and will be made available at [www.ncpc.org.uk](http://www.ncpc.org.uk)

- NCPC and the NHS End of Life Care Programme will be publishing guidance on advance decisions to refuse treatment as well as information for patients about advance decisions to refuse treatment and advance care planning during 2008. These will be launched at a large conference. Details will be published in due course, and will be made available at [www.ncpc.org.uk](http://www.ncpc.org.uk).

## 15. FURTHER READING & WEBSITES

### NCPC publications

The following publications can be accessed via [www.ncpc.org.uk/publications](http://www.ncpc.org.uk/publications):

- Partridge R & Campbell C, *Artificial Nutrition and Hydration - Guidance in End of Life Care for Adults* (NCPC & the Association for Palliative Medicine) 2007
- *Artificial Nutrition and Hydration - Summary Guidance* (NCPC & the Association for Palliative Medicine) 2007
- *Advanced Care Planning: A Guide for Health and Social Care Staff* (NHS End of Life Care Programme, supported by NCPC) 2007
- NCPC's and help the Hospices' **MCA e-learning website** can be accessed at: <http://www.helpthehospices.org.uk/elearning/mca/index.html>

### Other publications

- The text of the **Mental Capacity Act** can be found at: [http://www.opsi.gov.uk/acts/acts2005/ukpga\\_20050009\\_en\\_1](http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1)
- The **Mental Capacity Act Code of Practice** can be ordered as a hard copy via TSO: [www.tso.co.uk](http://www.tso.co.uk). It is also available on-line at: <http://www.dca.gov.uk/menincap/legis.htm#codeofpractice>
- The **Department of Health** has published 5 sets of **training materials**, covering the following areas: a core set; mental health; residential accommodation;

community care and primary care; acute hospitals. These can be downloaded at: [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074491](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074491)

- **Decisions relating to cardiopulmonary resuscitation** (October 2007) British Medical Association, the Royal College of Nursing & the Resuscitation Council. Available on-line at: [www.bma.org.uk/ap.nsf/Content/CPRDecisions07](http://www.bma.org.uk/ap.nsf/Content/CPRDecisions07)
- The Hospice of the Good Shepherd's **Mental Capacity Act Pro Forma**: [http://www.helpthehospices.org.uk/servicedev/downloads/mental\\_capacity\\_act\\_proforma.pdf](http://www.helpthehospices.org.uk/servicedev/downloads/mental_capacity_act_proforma.pdf)

### Other websites:

- The **Department of Health's mental capacity site**: [www.dh.gov.uk/mentalcapacityact](http://www.dh.gov.uk/mentalcapacityact)
- **Office of the Public Guardian**: [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)
- **NHS End of Life Care Programme**: [www.endoflifecare.nhs.uk/eolc](http://www.endoflifecare.nhs.uk/eolc); [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)
- The **Gold Standards Framework**: [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)
- The **Liverpool Care Pathway**: [www.mcpcil.org.uk/liverpool\\_care\\_pathway](http://www.mcpcil.org.uk/liverpool_care_pathway)
- The **Preferred Priorities for Care plan**: [http://www.endoflifecareforadults.nhs.uk/eolc/eolc/current/files/F2110-Preferred\\_Priorities\\_for\\_Care\\_V2\\_Dec2007.pdf](http://www.endoflifecareforadults.nhs.uk/eolc/eolc/current/files/F2110-Preferred_Priorities_for_Care_V2_Dec2007.pdf)
- **Advance decisions to refuse treatment**: [www.adrtnhs.co.uk](http://www.adrtnhs.co.uk)

# ACKNOWLEDGEMENTS

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## NCPC

The National Council for Palliative Care (NCPC) is the umbrella organisation for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales and Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions. NCPC promotes palliative care in health and social care settings across all sectors to government, national and local policy makers.

NCPC runs regular regional and national conferences and workshops and publishes a quarterly magazine, a monthly e-mail briefing and topical publications on all aspects of palliative and end of life care.

# REFERENCES

- 1 The Gold Standards Framework; the Liverpool Care Pathway; the Preferred Priorities for Care tool
- 2 [www.dca.gov.uk/menincap/legis.htm#codeofpractice](http://www.dca.gov.uk/menincap/legis.htm#codeofpractice)
- 3 “Relevant circumstances” are defined as those circumstances of which D is aware, and which it would be reasonable to regard as relevant
- 4 “Life-sustaining treatment” is treatment that in the view of a person providing health care for P is necessary to sustain life: MCA section 4 (10)
- 5 See section 62 of the MCA
- 6 Partridge R & Campbell C, *Artificial Nutrition and Hydration - Guidance in End of Life Care for Adults* (NCPC & the Association for Palliative Medicine) 2007
- 7 See para 9.25 of the Code of Practice
- 8 See para 9.25 of the Code of Practice
- 9 *Decisions relating to cardiopulmonary resuscitation* (October 2007) British Medical Association, the Royal College of Nursing & the Resuscitation Council
- 10 “If CPR would not re-start the heart and breathing, it should not be attempted”: *Decisions relating to cardiopulmonary resuscitation* (October 2007) British Medical Association, the Royal College of Nursing & the Resuscitation Council
- 11 MCA Code of Practice para 6.43
- 12 For more information please go to: [www.dh.gov.uk/en/Consultations/Closedconsultations/DH\\_078052](http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_078052)
- 13 [www.publicguardian.gov.uk/forms/guidance\\_booklets.htm](http://www.publicguardian.gov.uk/forms/guidance_booklets.htm)
- 14 [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)
- 15 MCA Code of Practice para 10.45
- 16 *Decisions relating to cardiopulmonary resuscitation* (October 2007) British Medical Association, the Royal College of Nursing & the Resuscitation Council
- 17 The first prosecution under the MCA involved care home workers charged with leaving residents unattended in a locked car whilst they went to a betting shop for a long period. [www.thisiswiltshire.co.uk/news/headlines/display.var.1904366.0.carers\\_left\\_special\\_needs\\_trio\\_locked\\_in\\_car\\_for\\_3\\_hours.php](http://www.thisiswiltshire.co.uk/news/headlines/display.var.1904366.0.carers_left_special_needs_trio_locked_in_car_for_3_hours.php)
- 18 MCA Code of Practice, paragraphs 6.18 & 8.18-8.24
- 19 *Advance Care Planning: A Guide for Health & Social Care Staff* (2007) The End of Life Care Programme
- 20 The Gold Standards Framework; the Liverpool Care Pathway; the Preferred Priorities for Care tool: see [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk) under “Associated Documents”

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