MAKING DECISIONS FOR PEOPLE WHO LACK CAPACITY
Mental Capacity Act 2005

ETHICAL ISSUES

This is one of a series of resource materials for clinical ethics committees providing explanation and discussion of the sections of the Mental Capacity Act which are particularly relevant to their work.

This section differs from the more explanatory sections covering different areas of the Act. It is intended to explore in some depth some of the ethical issues for which the Act provides a regulatory framework. It is intended to facilitate understanding of the ethical basis of the Act and to show that within the framework of guidance provided by the Act there is still a need for good ethical judgement, for example in the determination of best interests.

Key ethical principles informing the Act

- Respect for valid choice
- Best interests principle
- Liberty of movement
- Avoidance of harm
- Doctrine of necessity

1. Priority given to valid patient choice

1.1: What is valid choice?
It has long been a principle of English law that an adult with capacity has the right to refuse any treatment, even life-saving treatment. This principle is endorsed and extended by the MCA.

Valid patient choice, either to refuse a treatment on offer or to choose between treatments on offer, trumps all other considerations. A valid choice is one made by a patient with capacity who is properly informed and who chooses voluntarily (without coercion).

1.2: Respecting valid choice is not the same as acting in a patient’s best interests
The concept of best interests, both as explained within the MCA and in most philosophical accounts, is logically distinct from valid choice.

On most analyses of best interests (see section 2 below), including that in the MCA, it is (logically) possible for a person to make a valid decision that is against his best interests. A person can be mistaken, for example, about what is best for him; or can make a valid decision knowing that it is unlikely to be in his best interests. ‘When the Gods want to punish us they answer our prayers’ (Oscar Wilde, An Ideal Husband, Act 2). A person might for example validly choose to take risks, or to pursue a life of gambling, even though, on any account, this is not in the person’s best interests. Thus, the assessment of the validity of a choice does not depend on whether the choice itself is in the person’s best interests.

Under the MCA valid patient choice is given priority over other considerations, including what is in a patient’s best interests.
1.3: Respecting valid choice is not the same as respecting patient autonomy
It might reasonably be thought that the MCA’s position on respecting valid choice can itself be seen as identical with respecting patient autonomy. The concept of autonomy however is not straightforward, and respecting what a patient says (e.g. her refusal of treatment) and respecting her autonomy may, on occasions, be different.

One key issue in the analysis of autonomy is what conditions need to be met for a person's decisions and actions to be autonomous, i.e. truly her own. Three aspects have been the focus of recent analysis.

a) To be autonomous one must make evaluations. The ideal of the autonomous person is the person who forms desires for how her life is to go (life plans) and can act on those desires. In order to create such a life plan for ourselves we need to make evaluations, in particular about what kind of life we think we should live, or that we think might be best for us.

b) Evaluations should be rational. In the ideal of autonomy day-to-day decisions should be rational, i.e. consistent with the person's life plans. If a desire, or choice, is not based on a rational evaluation then it is not autonomous. This is one reason why respecting a person's autonomy is not always the same as respecting her choice.

c) Desires higher in the hierarchy should be respected. A person may have a simultaneous conflict in desires. For example, a person addicted to alcohol may simultaneously desire alcohol and desire not to have the desire for alcohol. The desire for alcohol is a 'first-order' desire and the desire not to desire alcohol is a 'second-order' desire. Some have argued that respecting autonomy implies respecting the higher (second-order) desire on the grounds that it is the one that is part of the life plan.

English common law has developed the idea that patients can refuse treatment for reasons which are rational or irrational or for no reason, as long as they have capacity. Irrational decisions, or decisions made for no reasons at all, might therefore be valid decisions but would not necessarily be autonomous decisions (according to most accounts of autonomy).

1.4: The assumptions underlying the assessment of capacity (MCA section 1(3)
The MCA gives a particular account of what it is to have, or to lack, capacity – an account that has been developed in common law jurisdictions (such as English and US law). This notion of capacity is not value free. It plays a crucial ethical role in that it determines when a person’s refusal of medical treatment should be respected and when it may be overridden in the patient’s best interests. The notion of capacity in the MCA has the following three features:

a) The assessment of capacity is specific to the specific decision, so that a person may have the capacity to make one decision (e.g. to live in her own home) but lack capacity to make another decision (e.g. to have an operation for bowel cancer).

b) With regard to a specific decision a person either has capacity or lacks capacity: there are no degrees of capacity.
c) The account of capacity is almost exclusively intellectual. A person has capacity if he: understands the key information, retains it, can use or weigh the information as part of the process of making the decision, and communicate the decision.

The first feature – a) above – is widely accepted.

What about the second feature? Imagine a person whose intellectual abilities are gradually deteriorating due to Alzheimer’s disease. Is it plausible that there is a moment when that person’s capacity with regard to a particular decision flips from full capacity to no capacity? Some argue that it is not plausible and that capacity must have degrees from full capacity, through partial capacity to no capacity. Even if the underlying concept is a graded one, however, it might be that in practice it is best for the law to take an all-or-none approach. For example, suppose a patient who was refusing beneficial treatment was assessed as having partial capacity. Should we then give partial weight to her refusal? In theory this might make sense: it might mean that the refusal would be balanced against the likely harm of not giving the treatment, and a decision made. In practice this may be too complex and the binary approach to capacity may be more workable and effective.

The third feature – the almost exclusive focus on intellectual abilities – has received the most criticism. There are situations, particularly in the context of mental disorder, where a patient may refuse beneficial treatment not because he fails to understand, retain and use the information but because the way in which he uses the information is affected by the mental illness. A depressed person, for example, may give little weight to the risk of death in not receiving treatment for a physical illness because he does not put much value on carrying on living. A patient with anorexia may refuse treatment not because she fails to understand the risk of death, nor because she wants to die, but because she values remaining thin to such an extent that she would prefer to risk death than put on weight. A drug addict might refuse treatment because the addiction means that he cannot choose to avoid the substance to which he is addicted. Thus mental illness may affect both values and agency and thus the decision, without interfering substantially with intellectual abilities. It is not clear how to interpret the criterion: ‘to use and weigh that information as part of the process of making the decision’ in these types of case. The Code of Practice (4.2.2) briefly discusses anorexia and suggests that a person may have a ‘compulsion to eat’ that is too strong to ignore and (by implication) that she therefore lacks the ability to weigh up the information and lack capacity. This suggests that lack of agency might be a reason for lack of capacity under the MCA. Whatever the interpretation of the law, and this may need to wait for court decisions, there remains an important and difficult issue as to what is ethically right in these situations. When is capacity compromised and when is it right to override treatment refusal?

1.5: A duty to take active steps to promote valid patient choice
The emphasis given to valid patient choice, in the MCA, is greater than was clear in prior common law in that health professionals have a duty to try and ensure, if at all possible, that the patient can make valid choices. If a patient lacks capacity then health professionals must not treat in best interests until they have done whatever can be done to enable the patient to have capacity. Respecting valid patient choice is therefore not simply a passive duty (that if the patient is able currently to make a valid choice that must be respected) but it is an active duty (that a patient currently unable to make a valid choice must be helped to do so if at all possible).
1.6: Advance decisions

The principle that an adult with capacity has the right to refuse any treatment (see above, section 1.1) relates to *contemporaneous* decisions. The MCA extends this principle to cover decisions made now about situations in the future (when the patient lacks capacity). It does this by giving the same weight to an advance decision as it does to a contemporaneous decision (e.g. to refuse treatment) as long as that advance decision is ‘valid and applicable’. The position taken by the MCA is that a valid and applicable advance decision, just like a contemporaneous capacitous decision, may or may not be in the patient’s best interests but it should be respected in any case as part of respecting patient choice.

There has been much ethical debate concerning advance decisions. There are reasons for considering the extension from contemporaneous to future decisions problematic although these are not discussed in the MCA, nor in the Code of Practice.

There are two reasons against giving as much weight to an advance decision as to a contemporaneous decision. First, in the case of contemporaneous decisions, if a person is making what seems to others a foolish decision, health professionals can go to considerable lengths to ensure that the decision really is what the person wants. Second, the experience of illness can change people’s values in ways important to the decision. For example, anecdotal evidence suggests that a person following a stroke may have different views about life-extending treatment than she had when healthy and imagining a future scenario in which she suffers a stroke.

Health professionals may doubt the ‘validity and applicability’ of an advance decision refusing a treatment that they believe is strongly in the patient’s best interests. For an advance decision to be valid it would have to have been completed by the relevant person at a time when he had capacity and was informed of the relevant information. For the decision to be applicable the circumstances and treatment that actually arise would need to have been specified. It will often be the case that there will be some uncertainty over at least one of these elements. For an example of a problematic case see section 2.5 below.

2. If no valid choice then primacy given to best interests

2.1 The principle of best interests (MCA section 1(4))

The MCA gives a particular account of best interests. It does not, however, define best interests, nor does it provide a criterion for judging best interests. Instead it gives a checklist of issues that should be considered (or at least ascertained) in making the judgment about best interests. The Code of Practice states that this checklist is not complete and that the agent may need to take further unspecified issues into account.

2.2 Three different accounts of best interests (well being) in the philosophical literature

The philosophical concept most closely allied to best interests is *well-being*. A person’s best interests are served by maximising his well-being. There are several different accounts of well-being in the philosophical literature. The MCA does not address these nor state which of these accounts underlie the legal concept of best interests. The judgment of best interests based on the checklist items may differ depending on which accounts of well being are adopted or given most prominence.

Three accounts of well-being are as follows.

a) *Mental state theories*
According to mental state theories, well-being is defined in terms of mental states. At its simplest (hedonism) it is the view that happiness or pleasure is the only positive mental state, and unhappiness or pain the only negative one. The theory can be enriched (and complicated) by allowing a greater plurality of states of mind as contributing to well-being, although this raises the problem of which mental states these should be.

The idea is that at any one time it is meaningful to say that a person is experiencing a certain level of ‘happiness’ (or whatever mental state is relevant) and that this might change over time. At the moment, for example, I might rate this ‘moment happiness’ at say level 4 on a scale where 0 is neither happy nor sad, negative values are more sad than happy, and 10 is the happiest that I can be. Perhaps this evening over supper my rating will rise to 6; and tomorrow as I face the beginning of another day at work my rating will be -2. My overall ‘happiness’ over a year would then be the integral of my level as it changes over time. Suppose we were to ask whether it is in my best interests to go for job A or job B. The answer would be determined by working out the integral of my states of happiness over the rest of my life were I to choose job A, or job B. My best interests would be served by choosing that job that gave the higher figure to these integrals of moment happiness. Of course these figures are difficult to work out and judgments and guesses have to be made. But the point is that what is at the root of the question of best interests is choosing that path that, all things considered, is likely to lead to the highest overall rating for these moment to moment levels of happiness (or whatever states of mind are considered relevant to judgments of well-being).

b) Desire fulfillment theories
According to desire fulfillment theories, well-being consists in having one's desires fulfilled. It is plausible that to maximize a person's well-being we ought to give the person what they want. If desire fulfillment theories are to provide a plausible account of well-being, it is necessary to restrict the relevant set of desires. On one view only those desires pertaining to life as a whole count as relevant in the analysis of well-being. These are desires that relate to a person's life plan. I might have a strong desire to achieve a certain outcome in my life. I might for example want to write a book on the Mental Capacity Act. Fulfilling this ambition may be important to me. On this view it might be strongly in my best interests that I do this. But it does not follow from this that writing this book will maximise my ‘hedonic’ pleasure. It may be that taking more holidays instead of writing the book would increase the overall integral of my moment happinesses. So the desire-fulfillment theory and the mental state theory are not the same. They are alternative conceptions of the basis for best interests.

c) Objective list theories
According to objective list theories best interests are multidimensional and, more importantly, the dimensions are determined not by each individual but are seen as intrinsic to the concept. On this view certain things contribute to a person’s best interests whether or not they are desired, or lead to pleasurable mental states, for example engaging in deep personal relationships, rational activity and the development of one's abilities. Things that might, on this view, act against best interests include being betrayed, deceived, or gaining pleasure from cruelty.

Suppose, for example that we are judging the best interests for a particular person of two different ways of living. The first is that the person lives a life with no deep personal relationships. His work is mundane and he has no significant hobbies. But he is reasonably content. The second life is one in which the person lives a life of deep personal relationships and has a complex and worthwhile job. But the second life also has greater variation in hedonic pleasure and more ups and downs. Overall let us suppose the second life gives less hedonic
pleasure. On the objective list theory of well being it might be argued that living the second life is in the person’s best interests – even though the overall integral of happiness is less - because it is a richer life.
2.3 Applying the three theories of well-being to the case example

Is it in Mrs K's best interests to give the IV antibiotics or not? On a mental state theory of best interests (well-being) the issue is about her moment to moment experience. It appears that currently her moment to moment happiness is positive: that overall the sum (integral) of her pleasure is positive. It is not easy to judge this over the whole time between now and when she dies but there seems no overriding reason to believe that the overall sum will be negative, if she is treated with antibiotics. Given the clear pleasures that she seems to currently enjoy it seems likely that saving her life now will lead to more overall pleasure than if her life now ended. On the mental state view her prior values, disvaluing the state of dementia are not relevant.

On the desire fulfilment theory we presumably need to take into account her former desires before dementia. So if we withhold antibiotics we are contributing to her well being since we are fulfilling her earlier desires. There is then a question of whether she has any current desires that are relevant to the judgment of best interests. She appears to enjoy watching TV and walking round the garden, but does she have a desire to do these things? The answer depends on how we count desires and to what extent desires, in the sense in which they contribute to well being, are conscious and intellectually assessed desires or simply what drives behaviour towards a particular action. If the desires that are most important are the intellectually held desires that relate to life plans then the former pre-dementia desires would seem the most significant. On this view it is probably in the person’s best interests to withhold IV antibiotics allowing the person to die because this maximises the fulfilment of those desires.

On an objective list theory it may be the case that a life without dementia is objectively rated as giving much greater well being than a life with dementia. This is not on the grounds that the integral of moment happiness is greater but that living without dementia contributes more to a person’s objective well-being than living with dementia. Living without dementia, however, is no longer a possibility for that person. The rest of the person’s life will be in a state of dementia so the question is whether living with dementia is overall worse than no life at all. The answer

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**Box 1  Case example: Mrs K**

Mrs K has moderately severe Alzheimer’s disease, as had her mother. She cannot recognise her close relatives. She is generally cheerful and appears to enjoy watching TV ‘soaps’ although it is unlikely that she can follow the plots. She enjoys wandering around the nursing home garden smelling the flowers. She enjoys cups of tea and mealtimes.

Mrs K has contracted a severe chest infection. Without treatment she is expected to die. With IV antibiotics she will almost certainly be cured of the chest infection.

Mrs K had been a university lecturer and had always valued intellectual pursuits. She had said to her daughter that she would rather die than be like her mother.
will depend crucially on what aspects of life are included on the ‘objective list’ of the elements of best interests.

2.4 Applying the MCA checklist to the case of Mrs K
The MCA identifies seven considerations in its checklist of best interests (see box 1)

Box 2  MCA considerations for assessing best interests
1. The person’s past wishes.
2. The person’s past feelings.
3. The person’s present wishes.
4. The person’s present feelings.
5. The beliefs that would be likely to influence his decision if he had capacity
6. The values that would be likely to influence his decision if he had capacity
7. Other factors that he would be likely to consider if he were able to do so.

How are the MCA criteria for best interests to be applied to a particular case such as that of Mrs K? There is, it would seem, considerable room for health professionals or members of clinical ethics committees to use their own conception of best interests based on ethical considerations. This is for three reasons: the MCA gives no general account of best interests; the checklist covers a wide range of issues so that the decision made may vary depending on what weight is given to each consideration; and the Code of Practice states that further (unspecified) considerations can be taken into account. It is important to remember however that the considerations to be taken into account are relevant only if they help in the assessment of a patient’s present best interests and do not carry weight independently of this.

Factors 1 and 2 (past wishes and feelings) require health professionals to take the prior views of Mrs K into account. Factor 4 (present feelings) could be used to justify giving weight to the (presumed) fact that Mrs K is generally enjoying life, that is to adopt aspects of the mental state theory of well-being. Indeed the Code of Practice (5.40) says that ‘Expressions of pleasure or distress and emotional responses will also be relevant in working out what is in their best interests’. In addition one might argue that Mrs K’s present wishes include the wish to watch TV, and to walk round the garden. Although Mrs K lacks capacity to decide about IV treatment she nevertheless has such wishes and these provide grounds for saying that her best interests involve her continuing to live.

Factors 5, 6, and 7 raise the thorny issue of what is sometimes called ‘substituted judgment’: the judgment about which beliefs and values Mrs K would take into account ‘if she (magically) regained capacity’ but otherwise remained in her current state. The answer, however, depends crucially on the assumptions made in this magical state. Would Mrs K, in this magical state, have the intellectual ability to understand and weigh up the issues about antibiotic treatment but lack her previously held values concerning the importance of intellectual pursuits, or would she also regain her old values and despise the watching of TV soaps? Would she judge the pleasure of walking round the garden in the light of her old values, or through the lens of her current more...
restricted intellectual abilities? It would seem that we must first decide our position on balancing her old values against her current experience, and then interpret the application of factors 5, 6, and 7 from the MCA checklist accordingly.

In short the decision about best interests must be made by professionals, proxy decision-makers and clinical ethics committees on the basis of ethical considerations: the MCA requires only that the items on the checklist are taken into account.

2.5 The case of Mrs K and advance decisions

Suppose Mrs K (see box 1 section 2.3) has written an advance decision, at the time when she had capacity, to the effect that if she, at any time in the future had Alzheimer’s disease and lived in a nursing home, then she refuses treatment for any chest infection including antibiotic treatment. Suppose she had explained, in her written advance decision, that she would prefer to die than to live with Alzheimer’s disease and that this is because of the great value that she puts on intellectual pursuits. Suppose further that she realises that a person with Alzheimer’s might enjoy her life, indeed she believes that this was the case with her mother. She stated in her advance decision that even if she appeared to enjoy herself she refuses life-extending treatments. In this imagined case it would seem difficult to argue that the advance decision was not ‘valid and applicable’. If that is the case then it would seem that under the MCA, life-saving antibiotics should not be given: Mrs K would have to be made comfortable and allowed to die. Opinions differ over whether this is ethically right. This is an example of where the MCA appears to take a specific position that is, ethically, contentious.

3: Exceptions to giving best interests full weight

As we have seen, if the person can validly make the decision himself (either because he has capacity or because of a valid and applicable advance decision) then best interests are irrelevant. But there are also several circumstances, according to the MCA, in which factors in addition to best interests need to be taken into account by carers and professionals even when the person lacks capacity and there is no valid and applicable advance decision.

3.1 Restraint and restriction of liberty

Box 3: Some examples of restraint in health care

- Holding a patient’s arm against her will to take a blood sample
- The use of mittens or bandaging to prevent patients pulling out nasogastric or endotracheal tubes.
- The use of bed rails to prevent patients falling out of bed
- Preventing patients leaving a hospital or nursing home
- Electronic tagging of patients
- Physical restraint of a violent patient
- Chemical sedation in cases of extreme agitation (e.g. postoperatively)
- Rapid tranquilisation in acutely disturbed patients to reduce the risk of violence or injury

The sixth principle set out in section 1 of the MCA states that:
Before the act is done or the decision made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action (MCA section 1).

In section 1(6) the MCA sets out two further conditions that must be satisfied (over and above the conditions of lack of capacity and best interests) before a person can be restrained. These are:

1. That the restraint is necessary in order to prevent harm to the person.
2. That the restraint is proportionate to:
   a) the likelihood of the person suffering harm if not restrained, and
   b) the seriousness of that harm.

This introduces two further ethical principles into the Act, that of liberty (as expressed by freedom of movement) and avoidance of harm or non-maleficence. The MCA places a special emphasis on the importance of liberty over and above the weight it would be given in an assessment of the person’s best interests. At first sight this emphasis on minimising restraint and avoiding harm might be seen as simply ensuring that health professionals and others give due regard to these factors in assessing best interests. A proper assessment, however, of best interests, including consultation with family and other carers, should take the harm of restraints into account. The MCA appears to go further than this by specifically linking restraint to the prevention of harm rather than to the promotion of best interests. Thus the MCA appears to forbid restraint if such restraint is not necessary to prevent harm even if, overall, it is in the person’s best interests. The case example in box 4 describes a situation when restraint may be in the person’s best interests but is not needed to prevent harm. Whether, in passing the MCA, Parliament intended that carers should not use some restraint in order to promote patient’s best interests (even though it is not necessary to prevent harm) is unclear.

**Box 3  Case example: Mr Gibbs**

Mr Gibbs is 50 years old and recently suffered a stroke following surgery to clip a cerebral aneurysm following a sub-arachnoid haemorrhage. He has moderate weakness down his right side and has difficulty swallowing. He is currently getting his nutrition via a nasogastric tube. He is intermittently confused and unable to communicate. He pulls out his nasogastric tube at least every other day and staff are concerned that he is not getting adequate nutrition and also that the repeated dislodging of the tube is causing damage to his nose. They would like to use mittens to prevent Mr Gibbs from pulling out his nasogastric tube.

Mr Gibbs is assessed not to have capacity to make this decision and an assessment of his best interests is made including discussion with his family. The harm he is likely to suffer if he is not adequately fed is balanced against the harm of restraining him from pulling out his tube, particularly the distress that he is likely to experience if restrained in this way. On balance it is thought to be in his best interests to use mittens. Section 6 of the MCA then requires the clinicians caring for Mr Gibbs to consider whether it is necessary to restrain Mr Gibbs to prevent harm (yes, because he will suffer harm if he is not adequately fed) and whether the restraint is proportionate to that harm (in this case the use of mittens is thought to be proportionate particularly as Mr Gibbs is expected to improve sufficiently so that he will not require nasogastric feeding long term).
Deprivation of liberty

The MCA excludes from the definition of restraint a deprivation of liberty as defined in article 5 of the European Convention on Human Rights. Deprivation of liberty is seen as such a significant harm that separate amendments to the MCA have been made through the Mental Health Act 2007 to restrict deprivation of liberty to cases where there has been approval by a court or under the specific regulation of a new Schedule (Schedule A1: hospital and care home residents: deprivation of liberty). The requirements of this schedule (as with the requirement for restraint) specify that deprivation of liberty must be to prevent harm separately from the general consideration of best interests (see code of practice addendum section 3.45). A further requirement of this Schedule is that the person is suffering from a mental disorder within the meaning of the Mental Health Act (see section on MCA and MHA).

The definition of deprivation of liberty is not clear cut and is addressed in the Code of Practice Addendum Deprivation of Liberty Safeguards section 2.8 states:

Box 4  Case example: Emma Jones

Emma Jones is 25 and has severe learning disabilities as well as congenital heart disease. She lives with her parents and every two months spends one week in a young adult hospice. When at the hospice Emma enjoys herself greatly and interacts well with staff and other residents. Her mood and general well being improve and this improvement lasts for at least a week after she returns home. However Emma finds it distressing and becomes agitated when she is required to get into a car to travel to and from the hospice. She struggles and tries to get back into the house or hospice. In order to get her into the car it is necessary to use some restraint and pressure. Her parents and hospice staff wonder whether this restraint is justified under the MCA.

Emma does not have capacity to make a decision about whether she should go to the hospice. An assessment of her best interests cannot take into account her previously held wishes on this subject as she has never had capacity to make such a decision. Overall the hospice staff and her parents agree that the benefit she gains from her time at the hospice outweighs the distress she suffers in getting there. However when considering the conditions of section 6 of the MCA, and the emphasis on protection from harm, it is not so clear that restraint is legally justified. In order to legally justify the restraint it would have to be argued that Emma was harmed by not going to the hospice and this seems to be a different, and a more stringent, test than whether she benefits from her visits there. The concept of harm is not normally interpreted simply as lack of benefit, and by using the term harm and not simply best interests in the context of restraint, it would seem that under the Act restraint to enable her to benefit from the hospice care would not be legally justified. Even if (contrary to the position for which we have argued) it is considered that Emma is harmed by not going to the hospice, that harm is unlikely to be considered a serious harm and the level of restraint would have to be minimal to be justified as proportionate. Thus the question of whether restraint is justified under the MCA in this case rests both on an assessment of Emma’s best interests and also on an interpretation of harm and degree of restraint.
Based on existing case law, the following factors may be considered by the courts to be relevant when considering whether or not deprivation of liberty is occurring:

- The person is not allowed to leave the facility.
- The person has no, or very limited, choice about their life within the care home or hospital.
- The person is prevented from maintaining contact with the world outside the care home or hospital.

It is possible to deprive a person who lacks capacity of their liberty in an emergency situation to give life sustaining treatment or to prevent a serious deterioration in the person’s condition. Thus the doctrine of necessity still holds for treating someone in an emergency situation (see ethical issues pages on consent).

3.2: Research (MCA section 1(30))

Much medical research is non-therapeutic. That is, the participants (patients) are not being given treatment as part of the research. An example of non-therapeutic research is taking a blood sample to measure a chemical in order to see whether the level of the chemical provides as useful diagnostic test. Such research might help patients in the future but would not help the patients who took part in the research. Such participants might face some discomfort and some risks of harm as a result of taking part in the research. International guidelines limit the harm as a result of taking part in medical research even for participants who have the capacity to consent to take part, and who have been fully informed of the risks. But guidelines do allow fully informed participants with capacity to be placed at some discomfort and some risk of harm (often termed ‘minimal harm’).

One major issue arises with regard to non-therapeutic research with patients who lack capacity. Such research may be valuable for people in the future. If the research places the participant at any discomfort or risk of harm then it can be argued that, since the research has no benefit for the participant (because it is non-therapeutic) it will always be in the person’s best interests not to be a participant. In common law and prior to the MCA, since no one can give consent on behalf of an adult without capacity and since it is arguable that from a legal point of view any researcher must act in the patient’s best interests, the question arises as to whether non-therapeutic research (even involving only the slightest risks or discomfort) with adults who lack capacity can be lawful.

The MCA has clarified this issue. According to the MCA (non-therapeutic) research can be carried out on people who lack capacity to consent to research under certain restricted circumstances. These circumstances include the provision that: “the risk to P from taking part in the project is “likely to be negligible”. It is noteworthy that although the risk must be likely to be negligible, the risk is not zero. It would seem here that the MCA does allow research to be carried out on people who lack capacity that is not in the best interests of the person (since there is some, albeit negligible risk). There is good ethical justification for this position in terms of the benefit to people in the future as a result of the research but it does seem to be an exception to the best interests principle. Against this, the MCA also requires researchers to consult carers and to ask carers what in their opinion ‘P’s wishes and feelings about taking part in the project would be likely to be if P had capacity in relation to the matter’. It could be argued that the overall judgment is still whether taking part in the research is in the person’s best interests if in assessing best interests one is weighing up both the risks of harm and the person’s likely (or prior) views.
As we have seen, consideration of the person’s prior (capacitous) views are part of the best interests assessment. Some risk of harm may be seen as in the person’s best interests if that person would in all likelihood (given her prior views) have given consent to the research had she had capacity. But if that were the justification then it is not clear that the restriction on risk (as likely to be negligible) is appropriate since some people might have given consent to taking part even if the risk were greater than ‘negligible’.

The most straightforward reading of the ethical position taken by the MCA is that the benefit that research may bring to people in the future provides grounds for acting against a person’s best interests – although only when the risks of harm are ‘negligible’.

4: Interests of others and conflicts of interests

We have seen that the position that the MCA takes with regard to research gives weight to the interests of those who might benefit in the future from the research. In this section we will examine to what extent the MCA gives weight to the interests of specific people in addition to the person who lacks capacity.

4.1 Carers’ interests have no independent weight

In deciding the care and medical treatment of a person who lacks capacity the position in common law prior to the MCA was that the person should be treated in his or her best interests and that no independent weight should be given to the interests of any carers including family carers. Thus, for example, suppose that the wife of a person with dementia is willing to carry on caring for her husband at home but that this is very wearing for her. Suppose further that there is a good care home available but overall the husband would get better care from his wife in his own home. It might be the case that it is best for the husband that he remains in his own home but best for his wife that he go to a care home. Of course it may be that in the long run it is better for the husband that he goes into a care home now because if he stays in his own home his wife may become so exhausted that she can no longer properly care for him. But suppose that this is not the case. The doctor, who wants to do what is overall best, might believe that although it is in the husband’s best interests to remain in his own home overall it is better for him to go to the care home: his care would be only a little less good but his wife’s quality of life would be a great deal better.

The MCA does not change the position in common law. The doctor, or other carer, must act in the patient’s best interests and should not weigh these against the interests of others, not even of family carers. From an ethical point of view this position can be criticised since according to many ethical positions the interests of others, in addition to the patient, have moral weight.

There is a possible exception under the MCA to the view that the wife’s interests (in the example given above) should not be taken into account. That exception is if the husband, when he had the capacity to consider the matter, would have wanted his wife’s interests to be taken into account and would have wanted to go into the care home. Under those circumstances it might be argued that it is in the husband’s overall best interests to go into the care home (see best interests checklist, box 1 section 2.4). Even if this is persuasive it remains the case that if the husband is not likely to have taken his wife’s interests into account, then health professionals cannot do so either.

4.2 Lasting power of attorney (potential conflicts of interest)

A person with capacity who is over the age of 18 can appoint one or more people as attorneys to make decisions on their behalf should they lack capacity in the future. Attorneys will usually,
we imagine, be members of the person’s family or close friends, particularly if they are being given power to make welfare decisions, including giving or refusing consent for health care decisions on behalf of the person who lacks capacity. There is a potential for conflicts of interest to arise for the attorney. Imagine, for example, a daughter who has lasting power of attorney to make welfare decisions for her mother and is also the sole beneficiary of her mother’s will. A decision to provide home nursing care privately might be in her mother’s best interests and affordable but would reduce the financial capital that will be left to the daughter when her mother dies. The MCA and the Code of Practice (sections 7.54 and 7.6) make it clear that an attorney must act in accordance with the statutory principles and in the best interests of the person who lacks capacity. The Code of Practice also states that the attorney has a fiduciary duty such that they should not take advantage of their position ‘(n)or should they put themselves in a position where their personal interests conflict with their duties’ (7.6). A person who confers a lasting power of attorney must be able to trust the attorney to act solely in their interests when making decisions on their behalf. Ethical principles of beneficence, protection of the vulnerable and trustworthiness are reinforced by a legal duty of care enshrined in the MCA. Concerns that an attorney is not acting in a person’s best interests can be referred to the Court of Protection.

It is not clear what the legal position is in the following situation. Suppose that a person validly appoints his daughter as Lasting Power of Attorney (LPA). Suppose further that the person makes it clear (perhaps in writing) that he does not want his savings spent on paying for him to live in a private care home, if at all possible: he wants to maximise the value of what he can pass on to his daughter after his death. He is willing for his future (incapacitous) self to live less comfortably or safely in his own home rather than to live more comfortably, and more expensively, in a care home. What, in these circumstances, is in his best interests, according the MCA? The answer depends on how much weight one gives, in assessing best interests, to his previous values and wishes and how much one gives to his current experiences. It would seem consistent with the general position of the MCA for the LPA (e.g. the daughter) to give some weight to his wishes that his daughter’s inheritance be maximised.

4.3 Conscientious objection
People may make advance refusals of life sustaining treatment or may appoint attorneys to make decisions to refuse life sustaining treatment on their behalf. Some clinicians might feel that their own deeply held beliefs or values require them to treat patients who lack capacity in order to prevent death. For such clinicians, or indeed other carers, the sanctity of life principle might outweigh other ethical principles. The MCA is clear that respect for valid choice means that a valid and applicable advance refusal of life sustaining treatment must be followed. The Code of Practice, however, allows for conscientious objection to advance refusals of treatment. Clinicians cannot be required to act against their own beliefs but they are required to make arrangements for their patients’ care to be transferred to other clinicians willing to comply with patients’ wishes. A clinician’s beliefs or moral values cannot override a patient’s valid choice.

5. Exceptions to respecting valid choice and right to liberty

5.1 Advance refusal of treatment for mental illness.
Respect for valid choice is not absolute under the MCA. An advance refusal of treatment (and an attorney’s refusal of treatment) for a mental disorder can be overruled if the person is at the time that the treatment is required admitted under an appropriate section of the Mental Health Act (MHA) (see resource materials on the relationship between the MCA and MHA). The provisions under the MHA for compulsory detention and treatment of people with mental disorder trump the MCA even when the detention or treatment is solely for the health or safety of
the patient. The principle of protecting from harm outweighs the principle of respect for valid choice in the setting of mental disorder.

5.2 Refusal of basic care.
Under section 9.28 of the code of practice a person cannot make an advance refusal of basic care (i.e. provision of warmth, shelter and food by mouth). In this instance the principle of best interests overrides the principle of respect for valid choice. From an ethical perspective this is an interesting exception. It suggests that the provision of basic care has more ethical weight than treatment, including provision of artificial hydration and nutrition. The Act appears to view the provision of warmth, shelter and food, as values over and above their contribution to the interests or wishes of the person.

Further reading/notes/references

The case of Mrs K is based on that of Margo [Firlik A. Margo’s Logo. JAMA. 1991: 265: 201]


Advance directives have been criticised by many authors [see for example Fagerlin A, Schnieder C. Enough: the failure of the living will. Hastings Center Report. 2004; 34: 30-42.]. Other authors sees them as potentially valuable but not determinative [for example: Widdershoven G, Berghmans R. Advance directives in dementia care: from instructions to instruments. Patient education and counselling. 2001; 44: 179-186.]
