

Serious medical decisions regarding people in vegetative or minimally conscious states

The role of family and friends



CDC

Chronic Disorders of Consciousness
Cardiff-York research centre



1. Who is this booklet for?

Family and Friends

This booklet is for family and friends of anyone in a 'vegetative' state (with no awareness) or 'minimally conscious' state (with minimal and intermittent awareness of themselves and their environment).

It is designed to help clarify the law and practice in England and Wales¹ around decision-making in relation to a patient who lacks capacity to make decisions about serious medical treatment on his or her own behalf.

The aim is to support family and friends and help them to ensure the patient's interests are at the centre of any discussions about his or her medical treatment.

Clinicians

This booklet may also be useful for clinicians trying to ensure that families are appropriately involved in decision-making.

2. Why is this booklet needed?

Family and friends are not allowed to make decisions on behalf of their relative/friend in a vegetative or minimally conscious state – unless the patient is a child, or legal action has been taken to give the family member/friend relevant powers. (See page 8).

Nevertheless, family and friends have an important role to play and clinicians need to consult with them. This is because clinicians making decisions about how to treat such patients need to take into account issues such as the patient's prior expressed

wishes. Family and friends are not being asked to make a decision or judgement about what should be done (or what they would want for themselves), but invited to indicate from their knowledge of the patient what the individual might want in this situation.

It is the responsibility of the senior clinician to decide what treatment options are available and what treatments would be futile and therefore not offered, but the information from family and friends can assist the clinicians to choose from the options that are available.

Decisions to be made at different times may include: whether to put 'Do Not Attempt Resuscitation' on the patient's records, how best to respond if the patient develops pneumonia, whether specific investigations and operations should be undertaken, and whether continuation or discontinuation of clinically assisted nutrition and hydration is appropriate.

3. What do families find difficult?

Interviews with families and friends of severely brain-injured patients show that they often find contributing to such decisions very challenging – difficulties include:

- uncertainty about what the patient would want
- even if they know what the patient wanted, friends and relatives may not want to be implicated in decision-making because of their own views and feelings
- there may be ethical challenges related to the options to be considered and there may not seem to be any 'good' outcome - only a 'least worst' option.



Family and friends may also find it difficult if:

- they feel there is uncertainty about diagnosis or prognosis, or that assessment has been inadequate
- they are not being given enough information from clinicians, or not enough time to talk about what their relative/friend would want, or to ask questions
- they do not think that the right level of care and support is being provided, so believe that it is hard to get a true picture of the patient's underlying condition
- they think that decisions are being discussed 'too early' or 'too late'.

Family and friends also often do not understand the rights and responsibilities they have in relation to decision making. For example:

- many people mistakenly believe that 'next of kin' can consent to, or refuse, treatment on a patient's behalf – this is not in fact the correct legal position for adults (see section 4)
- families may feel completely left out of decision-making by clinical teams – this is not legally correct either (see section 4).

Many people mistakenly believe that 'next of kin' can consent to, or refuse, treatment on behalf of their relative – but families do not automatically have any legal rights to do this (except that parents of children under 18 can authorise treatment on their child's behalf).

Clinicians are also sometimes unsure how best to involve families in decision-making. Although every professional working with mentally incapacitated patients in England and Wales should have received training in this area of law and be familiar with the Mental Capacity Act 2005 ('MCA'), there is evidence of continuing poor practices. For example, some clinicians wrongly ask families to 'consent' to treatment of their relative. Alternatively, clinicians may think that the decision is a purely 'clinical' decision, which it is not.

Sometimes clinicians seem to think that a decision is a purely 'clinical' decision – it is not. Family and friends may have information and/or views about what the person themselves would want – and these are legally recognized as being important considerations in any decision-making regarding a mentally incapacitated patient.

4. Who, in law, is responsible for decision-making regarding a person in a vegetative or minimally conscious state?

People in vegetative or minimally conscious states lack the ability to make decisions on their own behalf. They may be completely unaware of themselves or their environment ('vegetative') or only demonstrate some minimal and intermittent evidence of consciousness ('minimally conscious'). Even if a minimally conscious patient can demonstrate reactions at times (eg deliberately pulling away from painful treatment), express preferences or occasionally say some words (eg 'yes' or 'no') she is unlikely to pass the legal test for capacity to consent to, or refuse, medical treatment. This is because the legal test for capacity includes functions such as the ability to *understand*, *retain* and *weigh up* information relevant to the decision about to be made.

When patients are deemed to lack legal capacity to make treatment decisions for themselves then the treating clinician usually becomes responsible for identifying and acting in their best interests.

Exceptions to this would be if:

- a. the individual has previously made a valid and applicable 'advance decision' to refuse treatment (a 'Living Will') – in which case that advance refusal of treatment must be honoured;
- b. legal steps have been taken to appoint someone as the patient's 'attorney' or 'deputy' in relation to healthcare decisions (see Table 1) – in which case that person may make decisions on the patient's behalf (within the remit of their appointment);
- c. the patient is aged under 18, in which case someone with 'parental responsibility' can consent to treatment on their behalf.

Some common questions – and answers

‘She chose me as her ‘next-of-kin’ can I refuse treatment on her behalf?’

No. Next of kin have no legal rights to refuse treatment for their relative. You can, however, argue against a particular treatment being proposed, explaining why you think your relative/friend would not have wanted it (see Table 1).

‘Can I insist on a particular treatment for my son?’

No, nobody can insist on treatment for themselves, or anyone else. Doctors are not bound to provide treatment that they think is futile or harmful. You can, however, argue for the treatment to be given, explaining why you think your son would have wanted it and how you think it will help him.

‘I’ve been asked to sign a consent form for my wife’s surgery. Doesn’t that mean I have the right to consent on her behalf?’

No, although hospitals still sometimes have out-of-date ‘consent’ forms for relatives, or might ask for your ‘consent’, you are not, in fact, able to give or withhold consent on behalf of another adult under the law in the UK. (The relevant statute in England and Wales is called the Mental Capacity Act 2005, discussed later in this leaflet).

‘I have gone through a legal process to be able to make decisions about her finances – so can I also make decisions about her medical treatment?’

No. The right to manage someone’s finances is quite distinct from the right to make medical decisions on their behalf and involves a separate legal process (see Table 1).

5. How do families sometimes experience the decision-making process?

Managing the decision-making process sensitively and appropriately in the difficult circumstances of severe brain damage can be a challenge for clinicians and for families. There is a great deal of research documenting the stresses on families of such patients, and it is clear that a complex set of values and beliefs, hopes and fears come into play for those trying to contribute to decisions about treatment.² The quotations below all come from research specifically exploring how the Mental Capacity Act played out in the UK through interviews with families who had a relative in a vegetative or minimally conscious state.³

This research highlighted that some people may be very distressed about any suggestion that continued treatment might be harmful, futile, or not in the patient’s best interests. Suggestions *not* to pursue some treatments may conflict with family members’ strongly held religious or personal beliefs, or their view about the patient’s own past or current wishes. For some it may also be just too devastating to contemplate. One woman describes her reaction to doctors considering treatment withdrawal: ‘You can’t do that [withdraw treatment]. He’s a man, he’s my partner... he’s my baby’s dad. We were like in tears, me and [his] sister. And we were like, ‘please stop talking about him this way’, it was just really hard to hear him talk about that.’

‘You can’t do that [withdraw treatment]. He’s a man, he’s my partner... he’s my baby’s dad.’

On the other hand, the continued *provision* of treatment may come to be seen as cruel, and be a source of ambivalence or distress. Families may feel that the patient ‘*would not want to be here*’ in his/her current condition, that it is time to ‘*let nature takes its course*’ or they may be concerned by the lack of choice and restricted options available for their relative: ‘*I can remember my Mum being ill and my Mum saying ‘I don’t want this any more, I don’t want any more.’ And she had that choice.*’

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Good information and careful thought is essential to support good decision-making. Although the research showed that some people can have positive experiences of inputting into decision-making, it highlighted some of the challenges.

Families are sometimes left very unclear about their own role. One interviewee told the researcher: *'at first, I thought I had all the decision, and then I felt like we didn't have any decision, like you were just being told'*. Another spoke of feeling unsupported and uninformed: *'I had no blueprint for dealing with it. I felt pretty helpless. I couldn't do anything. We weren't told we had any role. It would be nice if family and friends were accepted into the whole decision-making process.'*

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Families may also feel rushed and want time and space to contemplate and discuss and ask questions. As one woman explained: *'somehow you've got to carve out the tiny little chapel, little space, where you can all talk about what's going to happen, what might happen, the implications of the operation they're about to perform'*.

Many relatives are shocked to discover that 'next-of-kin' cannot make choices on behalf of another adult in the family. They often feel passionately that they should be able to make decisions on behalf of their partner, parent, sibling or adult offspring: *'Who knows him better than us? We know what he would want – we are his voice'*.

Other family members may feel under inappropriate pressure to take responsibility for decisions. For example, one mother commented how hard it was to be asked about whether 'Do Not Attempt Resuscitation' (DNAR) should be placed on her daughter's records: *'You're asking me to make these decisions. How do I make these decisions? I'm fighting for my little girl's life.'* Looking back at how she was approached about DNAR she comments: *'With hindsight I think that that decision should have been (pause) we shouldn't have been asked for a decision. I don't think we should have ever been put in (pause)... It was almost as if the responsibility was being passed over to us.'*

'You're asking me to make these decisions. How do I make these decisions? I'm fighting for my little girl's life [...] We shouldn't have been asked for a decision. [...] it was almost as if the responsibility was being passed over to us.'

Sometimes families are left feeling that they are responsible for decisions, and now regret the decisions that were taken. Sometimes, it helps a family to know they are not 'the decision-maker'. Clinicians should make it clear that they are asking family and friends for information about the patient in order to inform a determination of best interests that has to be made by the *clinical team*. Some families may appreciate clinicians being very clear about the true legal position – as long as this is conveyed with care and compassion: *'I said, 'what if we say no?' And he [the doctor] said, 'well, we probably will still do it.' But it wasn't in such a horrible way. You could tell they care.'*

The following sections give further information about the law framing the decision-making process. It also outlines the circumstances under which different people may become responsible for decisions and the processes they should follow to ensure that patients' interests are protected.



6. The legal framework for decision-making

Decision-making regarding people over 16 in a vegetative or minimally conscious state in England and Wales is governed by the Mental Capacity Act 2005 ('the MCA') and its associated Code of Practice ('the CoP').

The MCA provides a legal framework and was explicitly designed to empower and protect people who may not be able to make their own decisions (as well as guide and protect those caring for them). It has been described as 'ground breaking and on a par in significance with the Human Rights Act'⁴, 'a milestone',⁵ and 'a pivotal moment in our society'.⁶ The MCA came fully into force in 2007.

The MCA and the CoP give clear guidance about the basis on which someone may be judged to lack capacity to make decisions for themselves and how decisions are then made regarding incapable persons. The MCA and CoP also spell out how such decisions about their treatment must be made and who should be consulted. The following sections offer a brief summary of key points from the MCA and the CoP. References in brackets direct readers to the original sources of the information.

Further information about decision-making specifically regarding patients in disordered states of consciousness ('vegetative' and 'minimally conscious') can also be found in the main Royal College of Physicians' guidelines (2013) 'Prolonged Disorders of Consciousness: national clinical guidelines'.

7. Who is the decision-maker?

If a person meets all the criteria listed in sections 2-3 of the MCA for lacking the capacity to make a decision for themselves, and if a decision has to be made, then anyone trying to make decisions on their behalf needs to check two things:

1. Check whether there is a valid and applicable Advance Decision to refuse or guide treatment (a 'Living Will') (ss. 24-26 MCA).
2. Check whether there is an Attorney (s 9 MCA) or Welfare Deputy appointed to make decisions on the patient's behalf in relation to the decision in question (ss. 15-21 MCA). (See Table 1 for explanation of these roles).

In the absence of both (1) and (2) then the treating clinician becomes the decision-maker and she or he must identify and act in the patient's best interests.

8. When do the courts become involved?

Most medical treatment decisions can be taken as a result of discussions between the clinicians and family and friends (and/or official advocates). However, a judge can also determine what is in the patient's best interests in cases of dispute between the parties.

Cases must be referred to the Court of Protection in specified circumstances even if there is no dispute. For example, the courts *must* be involved in any decision to withhold or withdraw clinically assisted nutrition and hydration from a patient in a permanent vegetative (or minimally conscious) state.⁷

9. Who are the key people involved in decision-making (outside the clinical team) – and what are their roles?

It is important to be clear about the legal status of the different people who might be responsible for making medical treatment decisions, or whom the decision-maker might consult.

Lack of clarity about these roles could:

- leave a clinician in danger of treating a patient unlawfully if they do so without valid consent
- leave a clinician in danger of taking decisions that are not in the patient's best interests
- leave family members feeling responsible for decisions which are not theirs to make
- prevent family and friends from contributing to best interest decision-making appropriately
- prevent other key people from contributing appropriately such that the patient is not properly represented.

Key people who should be involved in the decision-making process may include not just 'next of kin' or family/friends but also people with formal roles such as: an Independent Mental Capacity Advocate (IMCA), or a person assigned with Lasting Power of Attorney (LPA) in relation to welfare, or a court-appointed Deputy (health and welfare). Table 1 summarises the legal status of these different categories of person. It outlines whether, and when, they should be consulted and indicates when they are in fact the relevant decision-maker in some cases.

10. What is a 'best interests' decision?

If the decision cannot be made on the basis of the person's consent or by adhering to the decisions the person made by means of an Advance Decision, then the decision-maker (eg treating clinician or welfare deputy) must act in what they reasonably believe to be the 'best interests' of the patient. There is no statutory definition of 'best interests' but rather a checklist of factors that must be considered when working out what is in a person's best interests (s 4 MCA). The decision-maker must be familiar with the best interests checklist and must be clear that best interests is not simply a 'clinical decision'. Assessing 'best interests' requires consideration of a range of social, cultural and psychological factors including taking into account the patient's prior expressed values, wishes and beliefs – eg what the patient would have wanted for themselves.

The MCA states that the decision-maker 'must consider, so far as is reasonably ascertainable –

- a. the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- b. the beliefs and values that would be likely to influence his decision if he had capacity, and
- c. the other factors that he would be likely to consider if he were able to do so.' (s 4(6))

The *Code of Practice* states:

'The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits or recorded in any other way...' (CoP Para 5.41)

Clinicians have a duty to seek information from relevant family/friends, where practicable, and to manage best interests meetings appropriately to ensure that such information is both fully ascertained and then fully incorporated into the determination of the patient's best interests. (See 'further information' section at the end of this booklet for examples of how to manage a best interests meeting).

'All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made.'

Table 1

Key terms for (non-clinical) people who might be involved in decision-making

Term	Legal status in the Mental Capacity Act 2005 (England and Wales)
'Next of Kin'	No such legal concept or status. But those close to the patient (whether family, close friends or carers) must be consulted in order to ascertain the patient's prior values, beliefs etc. as part of the process of identifying best interests.
'The Family'	No legal right to make decisions (unless also appointed as deputy or attorney under MCA – see below). But those close to the patient must be consulted in order to ascertain the patient's prior values, beliefs etc. as part of the process of identifying best interests.
Lasting Power of Attorney (Welfare)	<p>A legal right to make treatment decisions. This is a representative chosen by the patient at a time when they had capacity to make decisions about their personal health and welfare. The correct paperwork must have been submitted to and approved by the Office of the Public Guardian (s.9 MCA). The Attorney can be – but does not need to be – a family member. They are the decision-maker for the patient under the specific terms of their attorney appointment, which may include consenting to, or refusing, life-sustaining treatment on the patient's behalf, if this power is explicitly stated in the LPA.</p> <p>Note, an LPA (welfare) is <i>not</i> the same as an LPA (property and finance) appointed to make decisions in respect of property and financial affairs.</p>
Court Appointed Deputy (Health and Welfare)	<p>A legal right to make specified treatment decisions. A Deputy for health and welfare is someone who has been appointed by the Court of Protection to make specific decisions about the person's personal welfare (eg where to live, medical treatment). The Deputy can be – but does not need to be – a family member. Such appointments are rare, but where the court does appoint a deputy, the extent of the deputy's decision-making powers will be specified by the court order. If a Deputy has been appointed to make a treatment decision then the healthcare professional may not make that treatment decision (Ss.15-17 MCA). However, unlike that of an Attorney (see above), the remit of a court appointed Deputy can never include powers to consent to, or refuse, life sustaining treatment.</p> <p>Note, a Court Appointed Deputy (health and welfare) is <i>not</i> the same as a court appointed deputy, appointed to make decisions in respect of property and financial affairs.</p>
Independent Mental Capacity Advocate	No legal right to make decisions. This is a professional advocate who must be appointed in the absence of appropriate family/friends/deputy/attorney (ss 35-41) and consulted accordingly when best interests are being determined.

11. What do *clinicians* need to know to make a ‘best interests’ decision?

Identification of ‘best interests’ by clinicians is not simply ‘a clinical decision’ based on medical information alone. Clinicians have a duty to consult with those who know the patient in order to inform decisions in the ‘best interests’ of the patient (s. 4 MCA).

The clinician should consult with the family in order to take into account issues such as:

- the patient’s *prior* expressed values, beliefs, wishes and feelings and any other factors the person would have considered if they could
- insights family/friends (and carers) may have about a patient’s *current* state (eg the nature of any experience a minimally conscious patient may have).

Clinicians need to be clear that they are seeking to find out the *patient’s* wishes and feelings, not asking family and friends to talk about what *they* want for the patient nor what they would want in the same situation for themselves.

12. What do *families* need to know about best interests decision-making?

Families and friends need to know that the central concern in a ‘best interests’ consultation is not what they would want for *themselves* in this situation, but what they know about the patient and *the patient’s* wishes.

The central concern in a ‘best interests’ consultation is not what you would want for yourself in this situation, but what you know about the person and *their* wishes.

Often the patient’s previously expressed wishes and the family members’ current wishes are the same. But at other times it can be very hard to separate out what the *patient* might want from what *you* want (as the patient’s parent, sibling, partner or offspring). Some family members feel they cannot

represent what the person would have wanted because it goes against everything they personally feel. As one mother of a son in a permanent vegetative state explained: ‘*I would never agree to that (withholding of treatment). No I could never give up on him. Maybe that’s wrong or maybe it’s right, I don’t know, it’s just who I am*’. She adds that even though her other son has expressed strong wishes to refuse life-sustaining treatment if *he* were ever in a similar state to his brother, she would not feel able to respect his wishes – ‘*No, I wouldn’t give up on any of my children. I can’t think any other way*’. (Clements et al 2013)

If the person has previously expressed strong wishes in writing that can be very helpful for families. One woman referred to a letter her relative had written describing his own wishes in case the surgery he was about to undergo went wrong – which it did. This letter was not a legally binding advance refusal of treatment because it was not witnessed. However, she found it helpful in representing his wishes and clinicians took it very seriously.

13. Who should be consulted to inform the determination of ‘best interests’?

The MCA states that the decision-maker ‘must take into account, if it is practicable and appropriate to consult them, the views of

- a. anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- b. anyone engaged in caring for the person or interested in his welfare,
- c. any donee of a lasting power of attorney granted by the person, and
- d. any deputy appointed for the person by the court, as to what would be in the person’s best interests and, in particular, as to the matters mentioned in subsection (6).’ (ie the person’s values, wishes, feelings, beliefs etc).

The Code of Practice highlights that staff should reflect on *who* to consult and should carefully document cases involving disagreement:

‘Decision-makers must show they have thought carefully about who to speak to ... They must be able to explain why they did not speak to a particular person - it is good practice to have a clear record of their reasons ... It is also good

practice for healthcare and social care staff to record at the end of the process why they think a specific decision is in the person's best interests. This is particularly important if healthcare and social staff go against the views of somebody who has been consulted while working out the person's best interests.' (CoP 5.51- 52)

14. What if the clinical team think that the individual's family and friends are inappropriate people to consult?

Sometimes the clinical team may decide that the patient's family and friends are not appropriate people to consult. This need not be a negative judgment on the family - sometimes a family member may be deemed inappropriate to consult with simply because she or he is too remote or not in a position to know what the patient's previous wishes, feelings or beliefs were. However, family and friends should be deemed *appropriate* to consult unless there are good reasons to dispute this – which should be documented and justified.

It is not lawful for family or friends to be judged inappropriate to consult with simply on the basis that they are thought unlikely to be in agreement with the proposed treatment or because there is some conflict between family or friends and the decision maker.

Family disagreeing with decision makers (or each other) is *not* grounds for clinicians to decide that it is 'inappropriate' to consult with them.

If there are no appropriate friends or family to consult then an Independent Mental Capacity Advocate [IMCA] must be instructed if the decision fits the criteria for instruction. This is in line with the Mental Capacity Act and ensures the person has some form of representation and formal input into decision-making.

Family/friends need to be informed by the responsible body (the NHS or Local Authority) if an IMCA is to be instructed, and provided with the rationale for this decision, and they will still be consulted by the IMCA unless they have requested otherwise.

15. What if family and friends opt out of contributing to the decision-making process?

Sometimes family and friends may want to be kept informed, but choose to opt out of the process of decision-making. This may be because, for example:

- they do not want to be responsible for contributing to a decision
- they feel unable to advocate for what the patient themselves might want
- they think that the patient would not have chosen them to represent his or her views
- they feel they do not understand the medical situation and therefore find it hard to comment on what the person might have wanted under the circumstances.

In addition, sometimes a family may opt out because they feel they are being ignored, so they are, in effect, being side-lined anyway and hope that an IMCA (who knows the system and has skills in advocacy) might be able to represent their relative better and advocate on their behalf.

If family and friends opt out then an IMCA must be appointed.

16. What does an Independent Mental Capacity Advocate do?

An IMCA must be consulted if appropriate family/friends are not available and if serious medical decisions are being made in relation to someone who does not have capacity to make the decision themselves (CoP 10:13).

Advocates usually help people express their views and wishes, secure their rights, access information and help them to be involved in decisions which are being made. Where a person is unable to be supported to express their views (eg because they are in a vegetative state) the IMCA still has a crucial role to play – eg in helping to collect evidence of, and represent, the person's prior expressed values and beliefs.

'The fact that he'd written what he wrote [that he wouldn't want to be kept alive in a severely brain injured state] helped you cope with it in your head. Because otherwise it would feel like it was more your decision'.

IMCAs are statutory advocates, which means their involvement is required for certain decisions. IMCAs are independent of the NHS and Local Authority and are there to support the person when their best interests as to treatment are being identified.

An IMCA will try to find out the views of the person and will talk to other people who know them and look at the patient's health records. They will build up a picture of the person and make sure that what is important to the person is considered when identifying their best interests. They will also make sure the person's rights are being upheld.

The IMCA will write a report which can be very helpful to whoever is responsible for determining best interests. Indeed, the decision-maker *must* take this report into account when determining what is in the person's best interests in respect of that specific decision. (CoP 10.14) However, IMCAs are advocates they cannot and do not make the decision.

17. Is a consensus necessary to make a 'best interests' decision?

No. Decision-makers should do everything they can to consult appropriately in coming to their decision. However, this does not mean that everyone will necessarily agree with the determination of best interests that is then made. The CoP states that the decision-maker will need to find a way of, for example, deciding *between* the concerns raised by those who know the patient well - 'But an agreement in itself might not be in the person's best interests.' The decision-maker cannot side step difficult choices by going along with a majority decision or by waiting for a consensus to emerge.

Where family members express differing views about what the person would have wanted it is the clinician's responsibility to make a decision on the basis of the best evidence available. 'Ultimate responsibility for working out best interests lies with the decision-maker.' (CoP para 5.64)

18. How should 'best interests' be documented?

The CoP includes guidelines on the process of documenting a patient's best interests.

'Any staff involved in the care of a person who lacks capacity should make sure that a record is kept of the process of working out the best interests for that person of each relevant decision setting out:

- how the decision about the person's best interest was reached
- what the reasons for reaching the decision were
- who was consulted to help work out best interests and
- what particular factors were taken into account.

This record should remain on the person's file.' (CoP para 5.15)

Just because everyone is prepared to go along with a particular decision does not mean it is necessarily in the best interests of the patient. It is the responsibility of the decision-maker to ensure that a true 'best interests' decision is made, and that this is not undermined by the search for compromise.

19. How do I *challenge* a determination of best interests?

If you think a decision is being made that is not in the person's best interests then start by raising your concern with the decision-maker. If that does not resolve the issue you can:

- request a second opinion, request mediation, put your concerns in writing
- ask for a formal or informal 'best interests' case conference to review the decision
- contact the local advocacy service and ask to speak to the MCA lead within the hospital
- seek advice from an IMCA in case they can help (see section 15 & 16)
- make a formal complaint through the organisation's formal procedures.

You can also:

- contact the Official Solicitor
- seek legal advice.

20. In conclusion

The Mental Capacity Act 2005 was introduced to 'empower' and 'protect'. Any piece of legislation is only as effective as the organizations and individuals who work with it. Understanding the MCA (and its Code of Practice), and trying to ensure it works on the ground, is the challenge for families, caregivers and policy makers. We hope this leaflet will play its own small part in supporting this.

Further information

The following websites provide additional information:

The Mental Capacity Act 2005 and the associated **Code of Practice** –

www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

www.gov.uk/government/publications/mental-capacity-act-code-of-practice

An easy read version of the Act – www.dca.gov.uk/menincap/mca-act-easyread.pdf

A guide for critical care settings – www.ics.ac.uk/ics-homepage/guidelines-standards (then go to Mental Capacity Act 2005)

Lasting Power of Attorney – www.gov.uk/power-of-attorney/overview

Court Appointed Deputies –

www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act/court-appointed-deputies

Independent Mental Capacity Advocates – www.actionforadvocacy.org.uk

Advance Decisions/'Living Wills' – www.compassionindying.org.uk

Best Interest Meetings –

BPS guidelines (see **Section 3: 'Best interests meetings'**:

www.pmldnetwork.org/resources/bps_best_interests_guide.pdf

See also Medway.gov.uk/pdf/mca_best_interest_meetings.pdf

The Brain Injury Group – 'a support group for people who have loved ones with devastating brain injuries' – www.braininjurygroup.org.uk

Royal College of Physicians (2013) – 'Prolonged Disorders of Consciousness, national clinical guidelines' RCP, London – www.rcplondon.ac.uk/pdoc

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Footnotes

1. This leaflet reflects the Mental Capacity Act 2005 (MCA) - a statute in force in England and Wales which sets out a legal framework for determining mental capacity and making decisions on behalf of those over 16 years old who lack the capacity to decide for themselves. The equivalent legislation in Scotland is the Adults with Incapacity (Scotland) Act 2005. A Mental Capacity Act for Northern Ireland is planned, but currently decisions take place under the common law. This leaflet does not consider Scottish or Northern Irish legislation and readers are recommended to seek advice in those devolved parts of the UK, but some of the general issues discussed in this leaflet will still apply.
2. Kuehlmeier K., Domenico Borasio G., Jox R. (2012) How family caregivers' medical and moral assumptions influence decision making for patients in the vegetative state: a qualitative interview study. *J Med Ethics* 38:332-7
3. Clements, L., Kitzinger, C. and Kitzinger, J (2013) Serious Medical Decisions and The Mental Capacity Act: family accounts of 'best interests' decision-making; see also Kitzinger J and Kitzinger C (2012) The 'window of opportunity' for death after serious brain injury, *Sociology of Health and Illness* - <http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.12020/full>
4. The Public Guardian Board's annual report (2010) In the best interests of us all. [available at www.mentalhealthlaw.co.uk/images/Public_Guardian_Board_Annual_Report_2010.pdf]
5. Boyle, G. (2008) The Mental Capacity Act 2005: Promoting the citizenship of people with dementia, *Health and Social Care in the Community* 16(5): 529-537 p. 529.
6. Alzheimer's Society spokesperson, quoted in Botsford P, 'Mental Capacity Act: A lasting legacy?' (2007) 39, 11 October *Law Society Gazette* 24-28. p.24
7. CoP Practice direction 9E available at – http://webarchive.nationalarchives.gov.uk/20110218200720/http://www.hmcourts-service.gov.uk/cms/files/09E_-_Serious_Medical_Treatment_PD.pdf



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If you have any comments on this leaflet please email
Jenny Kitzing at kitzingerj@cardiff.ac.uk

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