# Where to start when thinking about the MCA

There is a text-only version of this on the Dignity in Care discussion forum, but without the hyperlinks: the version on DIC is posted under the same title, but this PDF is a better, and easier, read.

I will start with some 'obvious and fundamental truths' which are clearly inside the Mental Capacity Act (MCA): then I'll move on to some 'logically-sensible 'assertions' which we can add-in to our thinking; and then to some 'obvious issues with the MCA'. I will conclude, with the statement of something which 'rather gives me hope' - because there is something inside the MCA, which offers the opportunity for the laymen to assert the control which currently professionals think belongs to them. The MCA can be found here.

## Obvious and Fundamental Truths inside the MCA

1 The MCA starts by clearly describing patient autonomy for mentallycapable patients

The Act describes patient autonomy for mentally-capable patients, and it states that capacity must be assumed present.

So the law in England is now 'Genuine Informed Consent' and the role of a clinician during a consultation is that of Supported Decision-Making (NOT 'shared decision-making' – whatever that phrase supposedly means!). See the court rulings <a href="here">here</a> (by Mr Justice MacDonald – 'woman C'), and <a href="here">here</a> (the Montgomery ruling) for proof.

2 The MCA intends that mentally-capable patients can project their autonomy forwards into periods of anticipated mental incapacity

The provision within the MCA for Advance Decisions, although potentially confusing in some aspects (notably the validity or otherwise of verbal refusals of life-sustaining treatment), makes it clear that patient autonomy should legally apply during future incapacity, if the patient had clearly considered the situation, and had clearly expressed a refusal of a possible treatment. The term 'Considered Refusal' might be used here – section 25(4)(c) of the MCA, links to the concept that 'a considered refusal must be respected'.

3 The MCA allows 'patient control' to be strengthened by the appointment of an Attorney

People can, while they are mentally capable, appoint another person (an attorney: you can appoint 'financial attorneys' or 'welfare attorneys', and you can appoint several attorneys if you decide to) to make decisions if you (the 'donor') become mentally incapable in the future. I'm interested in decisions about medical treatments, and the point is that your Welfare Attorney makes

any necessary best-interests decisions (if you have given the attorney power over the decision in question – you decide which decisions your attorney would be able to make when you appoint the attorney).

There is a VERY IMPORTANT CONCLUSION which follows from the power given to welfare attorneys, bearing in mind that most attorneys are normal people [and are NOT experts in clinical things, nor experts in the law]:

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Whatever the best-interests decision-making required by the MCA involves, normal people must be able to make best-interests decisions perfectly satisfactorily {this must be true, because normal people can be appointed as welfare attorneys} – and, we must be able to work out what best-interests decision-making requires simply by reading the MCA itself {because normal people are not experts in case law}.

It also follows, that because normal people are capable of making bestinterests decisions, that decisions about whether a treatment should be applied or withheld, are NOT 'clinical decisions' (and it logically follows, that certain decisions, such as how to best proceed with a treatment {for example, the decisions a surgeon has to make during an operation} are presumably NOT 'best-interests decisions').

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4 The MCA's best-interests decision-making is very complex indeed

The description of patient autonomy for mentally-capable patients, is, to use my choice of phrase, 'conceptually clear'. The principle is that unless the patient has been shown to lack mental capacity, the patient is informed of things such as clinical consequences and then the patient makes his/her own decisions.

The MCA is nothing like as 'conceptually clear' in its description of 'the rules during mental incapacity'. The requirement is that if any other person makes a decision which the patient cannot make [because the patient is not mentally capable], then the decision-maker must comply with section 4 of the MCA – and compliance with section 4, which means satisfying section 4(9), provides the decision-maker with legal protection against what would otherwise be 'intervention without consent'.

If you read the MCA (the Act, not the Code of Practice) it is clear that:

\* the Act does not restrict decision-making, beyond imposing the requirement that to satisfy 4(9) a decision-maker needs to 'be well-enough informed to defensibly make the decision': so, if you were adequately informed, then you

could make ANY decision, irrespective of 'who you are' - what matters is the 'are you adequately-informed to consider the decision?' issue

- \* the Act doesn't explain how you balance the factors you need to consider, to reach the decision: put bluntly, the Act implies that you must consider as many relevant factors as it is possible for you to consider, but it isn't at all clear how you put those factors together
- \* in particular, the wishes of the mentally-incapable person are mentioned in the crucial section of part 4 of the MCA if the patient went from capacity to comatose in one step, clearly 'wishes' must mean the wishes the patient had when the patient was mentally capable: but, if the patient is mentally incapable but still 'engaged with living', for example significantly demented, 'wishes' could be a combination of 'legacy wishes from a former mentally-capable time' and 'current wishes while mentally incapable'. This is just one of several 'complications' which arise when you think about section 4(6) and because section 4(6) is 'the core of best-interests' I will show it here, along with the rest of section 4 of the Act:

#### 4 Best interests

- (1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—
- (a) the person's age or appearance, or
- (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.
- (2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
- (3) He must consider—
- (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and
- (b) if it appears likely that he will, when that is likely to be.
- (4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
- (5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.
- (6) He 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

- (7) He 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).
- (8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—
- (a) are exercisable under a lasting power of attorney, or
- (b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.
- (9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.
- (10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.
- (11) "Relevant circumstances" are those—
- (a) of which the person making the determination is aware, and
- (b) which it would be reasonable to regard as relevant.
- \* the Act apparently allows anyone to make a best-interests decision, but the legal protection offered to a decision-maker is not only restricted by the requirement to satisfy 4(9) it is also restricted by sections 6(6) and 6(7):
- 6(6) Section 5 does not authorise a person to do an act which conflicts with a decision made, within the scope of his authority and in accordance with this Part, by—
- (a) a donee of a lasting power of attorney granted by P, or
- (b) a deputy appointed for P by the court.
- 6(7) But nothing in subsection (6) stops a person—
- (a) providing life-sustaining treatment, or
- (b) doing any act which he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.

We also need to keep in mind these sections of the Act:

5(4) Nothing in this section affects the operation of sections 24 to 26 (advance decisions to refuse treatment).

20(4) A deputy may not be given power to make a decision on behalf of P which is inconsistent with a decision made, within the scope of his authority and in accordance with this Act, by the donee of a lasting power of attorney granted by P (or, if there is more than one donee, by any of them).

# Logically-sensible 'assertions'

# 5 Best-Interests should NOT depend on the decision-maker

Whatever the making of a section-4 best-interests decisions does involve, it seems clear that the Act isn't 'a free for all': there must be an implication that some best-interests decisions are 'better' than others. So, for any particular patient, in a particular situation, there must be the 'concept' of 'the best best-interests decision' (technically, there might be several equally good decisions – it doesn't affect this argument).

We know that 'understanding and considering the 'individuality of the patient' is a strong feature of the best-interests decision-making required by the MCA. The external and objective factors – the clinical situation, other aspects of the situation – can in principle all be described separately from the patient's individuality.

So we can make this VERY IMPORTANT CONCLUSION/ASSERTION

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Provided all potential decision-makers are fully-informed, then all potential decision-makers should make the same best-interests decision.

So, if in the same situation doctors and relatives tend to make different bestinterests decisions (I mean the doctors tend towards one decision, and the relatives tend towards a different decision) then 'something isn't right'.

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Inevitably there will be situations when there is disagreement within relatives about the 'right' decision, or within a group of doctors: there is no way of deciding on 'who is right'. BUT if doctors and relatives consistently 'reach different conclusions about best-interests', then something is wrong, because such differences are not supported by the structure of the MCA.

There are such differences, and they stem from 'where people are standing', and from 'training', to a large extent. <u>I wrote</u> in one of my pieces:

'Without CPR, 'alignment of mindsets' between relatives [who, I believe, tend to see 'my dad doesn't want you to attempt CPR' as the justification for DNACPR] and clinicians [who, it seems to me, are much more concerned with 'could CPR be successful'] would not be a problem for CPR decision-making. When I constructed a 'DNACPR Justification Hierarchy' (ref 3) I placed 'the patient is understood to have refused CPR' at the top, and 'successful CPR seems clinically very unlikely' much lower: but doctors seem to be more concerned with 'we predict that CPR would fail'

During the comments to an <u>article</u> in Nursing Times, about clinicians needing more training in the MCA, I included in one of my comments:

'You cannot in fact fit 'soft medical paternalism' to the MCA (something doctors are very reluctant to accept), and the self-determination of the MCA runs directly opposite to any idea that 'safeguarding' can apply to mentally-capable patients'.'

Someone called Mike Hostick mentioned the above in his subsequent comment:

'I would extend the comment on 'soft medical paternalism' to a wider spectrum and that the majority of staff would choose to protect the person first and their right to self determination second despite what the law says.'

I had originally made a very concise comment, and one of Mike Hostick's comments gets to the core of many problems with MCA implementation – so, I'll reproduce those two comments here:

#### MICHAEL STONE 8 NOVEMBER, 2016 2:42 PM

DoLS is one of the harder parts of the MCA to grasp, but even the simpler parts of the Act pose problems: the biggest problem, is that, and pardon my language here, 'accepting the MCA as it is written poses huge challenges to any staff who are also having 'safeguarding responsibilities' imposed on them: to be frank, the MCA is 'a sod to apply' if you are a clinician'.

I endlessly point this problem out, on the BMJ - there needs to be a lot of work done on improving understanding of the MCA, and in my view some recent developments are going in the wrong direction (such as some work led by the RC(UK) - very flawed if you think in terms of the MCA).

#### MIKE HOSTICK 10 NOVEMBER, 2016 11:21 PM

I agree with the above post and would add that I think the MCA is a great piece of legislation and the associated code is accessible. It is accepted that health and social care staff still experience significant difficulty in understanding the act and putting it into practice.

I would extend the comment on 'soft medical paternalism' to a wider spectrum and that the majority of staff would choose to protect the person first and their right to self determination second despite what the law says.

I have a great deal of sympathy for front line health and social care staff who are having to battle with the ethos of large state organisations who require compliance with eth MCA but who have not embraced the principles of the act into their organisational practices.

I know if you asked most staff what would they want for themselves or their loved ones when they lacked capacity they would favour much of what the MCA stands for but there seems to be a disconnect when these same people get to work and I can't help feeling that this must be due to the work environment in which they find themselves.

I recall going to a safeguarding conference at which there was a call for staff to be trained to be compassionate. I was astounded - we know how to be compassionate at home with our friends and families don't we? So surely we can translate this to the work place? Of course we can unless there is something there that prevents us or that we aren't "rewarded" for this fundamental trait.

At Desuto we have decided that we need to lower the bar a little for staff to begin with and to give them a helping hand. Our tools set a fundamental standard for compliance and reporting meaning there is no excuse for failing to apply the basic principles of the act and to explain how these were applied in writing.

We believe that if everyone used our tools, the understanding and reporting standards would rise for over 90% of the workforce which will be a great step forward and one that the House of Lords would feel is well overdue.

6 Some legitimate decisions made during incapacity cannot logically be 'best-interests decisions'

I have <u>a piece</u> on Dignity in Care and you can download a file from it, and in the PDF file I describe a 'DNACPR Justification Hierarchy'. In essence, it is a hierarchy of decision justification, based on the MCA. It goes, a little simplified here, with the 'strength of the justification' from strongest to weakest':

The patient arrests while you have been talking to him about CPR, and during the conversation he made it clear to you that he was refusing CPR and that he was aware of the consequences of refusing or accepting CPR;

The patient is found in arrest, when you were not previously with him, and he has made an apparently valid and applicable Advance Decision which forbids CPR;

Someone who has previously been 'deeply involved with' the patient, and who possesses sufficient understanding of the overall situation to be able to defensibly make a best-interests decision, decides that DNACPR is the best decision:

None of the above apply, and it appears that CPR might be clinically successful – in this situation, CPR should be attempted.

The final decision, does NOT seem to be an MCA best-interests decision: it surely cannot be a section-4 decision, because the person embarking on this 'default CPR' could not sensibly claim to have complied with section 4(9).

In general we can assert:

Any decision which can be made without an understanding of 'the patient as an individual' CANNOT BE A 'GENUINE' BEST-INTERESTS DECISION.

7 Best Interests is more complex than keeping people 'safe and healthy'.

There is a <u>court ruling</u> in which the judge makes a decision that a mentally-incapable patient, who was resistant to the amputation of his gangrenous foot, could not legally have the operation forced on him against his wishes: in effect, the ruling was that 'it is in his best interests for him to die, rather than to be kept alive and to face a future he would probably be deeply distressed by'.

Baroness Ilora Finlay, writing about the MCA, has written that:

'Any care decisions must be taken with a view to preserving their dignity, safety and liberty as much as individual circumstances allow. And even if that person is deemed unable to make their own decisions, they must still be an active participant, as far as possible, in processes intended to keep them safe and healthy.'

This clearly isn't legally correct – it is a misleading over-simplification of section 4 of the MCA, and experts such as Baroness Finlay really should stop writing such things: then, we might have some debate about what can correctly be written about best-interests decision-making.

And, it is problematic – as Mike Hostick wrote (see earlier):

'I know if you asked most staff what would they want for themselves or their loved ones when they lacked capacity they would favour much of what the MCA stands for but there seems to be a disconnect when these same people

get to work and I can't help feeling that this must be due to the work environment in which they find themselves. '

Put simply, when Judges make best-interests decisions, they 'resort to keeping the patient alive' much less often than when clinicians and social-care staff, who have 'safeguarding agendas thrown at them', make best-interests decisions. That is probably inevitable, but the judges are applying the MCA when they rule – so, you CANNOT claim that the objective of best-interests decision-making is to 'keep the patient safe and healthy'.

A London GP wrote in an e-mail to me, autumn 2014:

'I recently had MCA training and it was made clear that the hope of the act was that it would be empowering of the patient and perhaps the development of the IMCA role demonstrates that aspiration.

We also have the whole 'safeguarding' agenda pushing in the opposite direction.'

8 Best Interests decision-making involves understanding the patient as an individual, beyond the clinical situation, and that requires a level of both time and commitment which GPs do not have

There is a <u>recent report</u> on the Marie Curie website, of a survey of GPs. The piece starts with:

'GPs say a lack of time to spend with patients is a key challenge they face when caring for people with a terminal illness, according to a survey published today.'

The GP Dr Susannah Hill tells readers:

"As GPs, we're a familiar point of contact for our patients, from the point of the diagnosis of their terminal illness right until the end. That's why caring for someone at the end of their life is such a fundamental part of our role as GPs. In my practice, I've known a number of my patients as long as 20 to 30 years, so giving the very best care that you possibly can is something you want to do for them and their families. But this vital relationship we have with our patients is getting squeezed. It's enormously sad to hear from colleagues in primary care that we all struggle to give patients who are terminally ill and their families the time and support they need from us ... I know from my experience that it takes knowledge and resources, especially time, to deliver good end of life care... Ideally, when one of my patients is approaching the end of their life, I'd like to visit them in their home every day. But in the past few years, I've found it more difficult to do regular home visits to see patients who are terminally ill. There's the constant compromise between doing what's best for our patients and the limited resources we have, including time and nurses working in the community."

A comment: many family carers DO HAVE that time – time to listen to and understand the decisions their dying loved-one makes and expresses, time to develop an already existing understanding of their loved-one as a person into an understanding of 'the loved-one as a dying individual'. And certainly when my parents were dying, my objective was to try and make sure that they died as they wanted to – not that they died to 'suit a GP, or to suit a district nurse', but that they died as they wanted to. That has to be correct – patient control is at the very heart of the MCA.

And I DEFINITELY would not have supported the suggestion that my dying parents should be required to die in a way that fitted 'some tick-box protocol'!

If only the professionals, and 'the system', would accept this, and ACCEPT THAT FAMILY CARERS ARE FULL MEMBERS OF THE PATIENT'S SUPPORT TEAM, innumerable problems would be resolvable!

We need to move to, and adopt, the concept or approach I describe as 'The Core Care Team' – see the PDF which can be downloaded from 'poser no 8' in my <u>poser series</u>.

This does of course, involve trusting family and friends as the default position – which doesn't seem to be the case at the moment: I find that 'distrust by default' as both unwarranted and also deeply offensive. I have written about this, frequently:

Why should relatives accept being treated as suspects if nurses are not?

Also in a piece on the BMJ here

And only a few days ago, a contact included this comment in an e-mail to me:

'I dislike the apparent 'rebuttable presumption' that social workers (for example) sometimes appear to have, that all family members are out for their own best interests.'

9 There is much confusion still to be sorted out about the difference between patient autonomy and best interests, etc

I struggle to understand, why many people seem to find the MCA (the Act itself) so hard to grasp. A few months ago, I came across an MCA online Learning Tool on the SCIE website. One issue which arose, is explained in my piece:

The SCIE Robyn and Anne scenario compared to my Alan and Liz scenario: the essential difference between 'informed consent' and 'best interests'

Another issue which needs to be sorted out, is analysed in my piece:

My reasons are my own - it is entirely up to me, whether or not I decide to share them

And yet another, absolutely fundamental issue is discussed in my piece:

I believe that Advance Decisions should be encouraged but that 'advance statements' should be discouraged

I find that I am increasingly writing about the paradox between the MCA and 'safeguarding', and about whether or not 'medical soft paternalism' can be reconciled with the MCA:

Is 'Soft Paternalism' an arcane process?: or 'don't tell us its our decision, until you don't agree with our decision!

#### Obvious issues with the MCA

As I've pointed out, anyone who tells you 'the MCA explains how to make best-interests decisions' is being misleading – in fact the MCA tells you what you must consider in order to claim the protection offered by the Act.

There is an issue, which hinges on the logical answer to 'how should best-interests decision-making work?'.

Clinicians and other professionals will probably tell you, that they consult with family, friends, etc, and that the professionals then make the best-interests decision. This strikes me as flawed, on the grounds that 'understanding how the patient thinks, is very difficult indeed to explain – but the description of things such as clinical prognoses is much easier'.

Logically, it should be the people who are 'close to the patient' - the patient's close family and close friends, who 'understand how the patient thinks', who are best-placed to consider best-interests: as <a href="I've written">I've written</a>:

If there is not an attorney – and it is unusual for there to be an attorney – the Act does not define who can be a decision maker, it merely requires anyone who makes a best interests decision, to be able to have legitimately made it (section 4(9)). So, instead of assuming 'the doctor is the decision maker', let us simply assume 'there is a decision to be made' and look at the mechanism.

The mechanism should be, that the clinicians describe the clinical outcomes with and without any offered treatments to 'everyone who could validly have an opinion (the family and friends) about what the patient would say, if the patient could answer for himself: then, all of the 'family and friends' individually answer. The question put to family and friends is 'What would the patient want to happen' – it is not 'What do you want to happen'. If they all say 'Fred would accept the treatment', or they all say 'Fred would refuse the treatment', it seems simple – in such a unanimous situation, behave as if the (incapable) patient has answered directly, record who was involved in the discussions and who said what, record the best interests decision which emerged, but do not claim who 'made the decision'.

We should be thinking about the MCA, from the <u>patient's perspective</u>: we should be trying to arrive at the best-achievable best-interests decision, and concentrating on that objective, and NOT concentrating on 'who makes decisions'. We need to get doctors to write clearly and correctly about decision-making during EoL, and <u>to stop describing</u> decisions as wishes, expert opinions as decisions, etc. We need to <u>sort out the conflict</u> between section 4(6) and 'patient confidentiality'. Etc!

And professionals must accept the authority of welfare attorneys.

# Something which 'rather gives me hope'

I'll finish off now – I could go on (and on, and on, and ...) but by now anybody who isn't already very familiar with the MCA will probably have lost interest, and the people who are deeply interested in the MCA and who are reading this will be few, I suspect.

This is 'the ray of hope'.

The problem, for most family carers, is a combination of two things: one is that the MCA is very difficult to apply if you are a working professional, and the second is that the professionals [incorrectly in my opinion] assert that THEY 'make the decisions'.

If many more people appoint Welfare Attorneys, then this unsatisfactory situation – which amounts to 'we professionals are the experts, and our views are the ones which count' - will be swept away: because it is 100% clear that welfare attorneys are the people 'whose decisions/views count'.

And those welfare attorneys will almost certainly be largely laymen – if I were my father's welfare attorney, why would I 'downplay or disregard' the opinions of my brothers and sisters, etc, and why would I prefer the views of doctors and nurses?

Written by Mike Stone, November 2016 <u>mhsatstokelib@yahoo.co.uk</u>