How should an MCA Best Interests meeting 'work'?

I recently published a piece, analysing the question of whether a DNACPR instruction can be documented in advance of a cardiopulmonary arrest under English law – my answer was in essence 'no – only a written Advance Decision is even close' - at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/435/

I had a best-interests meeting as part of that analysis – what I wrote in the piece was:

Imagine a room in a hospital, with an unconscious patient, and the patient's consultant, a junior doctor, the nurse in charge of the ward, the patient's spouse, two brothers of the patient, and three children of the patient all in the room discussing whether or not CPR should be attempted if the patient arrested. After 30 minutes of the people in the room discussing this, 'a passing nurse' enters the room. If the nurse suddenly announced 'You should attempt CPR if he arrests' we would legitimately comment 'On what basis has the nurse concluded that – she hasn't been in this room for the last thirty minutes, trying to work out whether CPR should be attempted?!'.

It is the discussion which makes the opinions about CPR/DNACPR INFORMED – the people in the room possess informed opinions, and the suddenly-intruding nurse is expressing (for reasons which are hard to guess at) an UNINFORMED opinion.

I did not need to elaborate, on **what happens inside the room** in my earlier piece – but, I am going to do that in this piece. It might help, unless people are already familiar with the Mental Capacity Act (MCA), if readers download and read the earlier piece from the link above, before continuing to read this one.

Before I continue, I am going to modify the meeting slightly. It is important, to retain the 'unconscious patient' aspect (it is considerably more difficult, to analyse a situation when the patient lacks mental capacity but is able to talk and express what the MCA describes as 'wishes' - forgive me, but I am going to only consider the simpler situation of an unconscious/comatose patient here) but in reality, the room would not contain the patient. The reason, is that there is a belief that unconscious and comatose patients might still be aware of their surroundings. So, the room to be considered can be described like this, if we consider a wider situation than simply CPR:

Imagine a room, with an unconscious patient, and the patient's consultant, a junior doctor, the nurse in charge of the ward, the patient's spouse, two brothers of the patient, and three children of the patient all in the room.

If the patient were at home, it would probably be a GP and a District Nurse, or whatever. For the group I have described above, the meeting would probably be in the hospital where the patient is, but in principle the meeting could be anywhere.

The location and timing of the meeting, is in reality intertwined with who is going to be present: and there is an issue with 'who is invited to the meeting', but it will be better for me to describe that issue later.

Suppose the meeting is going to be in the hospital, and when they are being invited to attend, the wife, children, etc, ask 'what is the meeting for?'. Two possible answers would be 'to decide what is in dad's best interests' and 'to help the doctors decide what is in dad's best interests': the first of those is okay but complex – and the second one, is in my opinion legally misleading and definitely NOT okay. The answer I would give, is 'to see if everyone agrees what would be in dad's best interests'.

Which leaves this problem: most family and friends, are not likely to know what 'best interests' means in my sentence. Suppose the meeting is for tomorrow evening, I say 'I'll come', and I ask '... and what exactly do you mean, by 'best interests'?'. The strictly correct answer, would be 'as in section 4 of the Mental Capacity Act, and made clearer by various court rulings – read up on them before tomorrow evening's meeting'. That is **NOT** a very satisfactory answer. It surely isn't helpful, to summon people to a meeting, if they arrive not understanding what the purpose of the meeting is – at least, in my opinion. I honestly believe that we need to be able to express the objective of MCA best-interests decision-making in a way which is correct, but which almost anyone could grasp. There are now certain situations (the situations comparable to that of the Briggs ruling by Mr Justice Charles – which involve life-sustaining treatments) for which we can express the objective very clearly. But for MCA Best Interests in general, we need something more accessible than 'go away and read the law, and figure it out'. My own suggestion has been published on Dignity in Care, here, and it is this sentence:

The objective is to make the best-interests decision which would result in the most satisfactory future when considered from the perspective of the incapacitous person as an individual.

That sounds a bit 'cold' if stating it to a wife, child, etc – so in the situation we are discussing I think it should be expressed as [appropriate variations on]

We are trying to work out the decisions which would result in the best future when considered from the perspective of your husband.

It really is very tricky to do better than that – nobody who I have asked, has suggested a better sentence.

In the case of a life-sustaining treatment, when the patient became incapacitous 'directly from capacity', expressed simply and based on the Briggs ruling, we can write:

If we can be sure enough of what your wife would have wanted us to do in this situation, then we do what she would have wanted – and if we are not sure enough of what she would have wanted then we try to keep her alive.

It seems very unsatisfactory, if the organiser of the meeting, fails to inform the people coming to the meeting of its purpose. So, if I was running things, then if there was a room

set aside in a hospital for best-interests meetings, I would have displayed on its wall/s an explanation of the purpose of best-interests meetings. And, if people ask 'what will the meeting be for?' they need an answer which is more useful than 'read up on the law between now and the meeting'.

So, we now consider what happens in that room, during the meeting. The doctors and nurses understand what treatments are available and might help [in the sense of improving the patient's clinical situation] – and the family and friends, have an understanding of the patient, or loved-one, as an individual. I can't really see how it makes sense to try and describe a person's individuality, in this situation: it should be 'the clinicians set out the possible treatments and their consequences, then the relatives and friends feed in 'would dad want that or not?". There has to be to-and-fro – ask, answer, ponder, suggest, ask, answer, think some more, etc – going on in that room. And it is all extremely tricky, and potentially 'fraught', in many situations.

IF a point is reached, when **EVERYONE** agrees 'it will be best to do 'whatever", then we have arrived at what should happen next. We cannot claim to be certain the course of action agreed on 'is the best possible decision'. <u>But it isn't apparent</u>, how a better decision could have been arrived at.

Now, section 4 of the MCA, which is as close as the Act gets to 'explaining' Best Interests, is entirely about (when 'beliefs' are mentioned) the beliefs, or as I would prefer to describe it 'the individuality and 'way of thinking", of the patient, and no mention at all is made of the 'beliefs of' the person making a best-interests determination (assuming that we interpret 4(11)(b) as meaning 'circumstances the patient would consider relevant' - and I do interpret it that way). So if I am a strongly pro-life religious person, making a best-interests determination for a patient who is deeply secular, I must not apply my beliefs: I must apply the patient's beliefs. And the reverse. Etc.

Is 'observation of the many' relevant to 'the individuality of the one'? I'm sure that hospital doctors, have a lot of experience of how patients behave: for example, of how some patients might change their minds, or perhaps a patient 'comes to terms with' a situation when the patient had previously said 'I couldn't live with that'. But, how legitimate is it, to use that understanding in our room, when everyone is at the 'what would dad decide?' stage of the discussion? Should that experience and expertise, be fed-in to the discussion at the earlier stage – at the description of the treatment options, as a 'rider' along the lines of 'in my experience, quite often patients who said they would find living with that outcome intolerable, subsequently change their mind and come to terms with it'. Observations of a 'general nature' from family or friends, such as 'my brother has always been interested in sport – he never seems to read any books' would be fed-in at the earlier stage of the discussion. I myself cannot tolerate acidic fruits – if I eat and orange (which I never do!) then I will feel very ill for a few hours, then I will vomit. If it was observed that the majority of people like to eat oranges, concluding 'so Mike likes to eat oranges' would be incorrect.

The paragraph above, is quite tricky: but personally, I would see the working-experience of clinicians, as something which should be fed-in before the people who 'know mum as a person' consider what mum would have decided, if mum could have decided. That is how Informed Consent works – the doctor describes the clinical options and the prognoses, and then the patient decides which options to accept, or to refuse all of the offered interventions. Best Interests replaces 'the stage when a capacitous patient would decide

which options to accept', so I believe it can be described as 'clinical information first – then either the patients decides, or the best-interests concept 'decides'. I realise that my previous description of the discussion within the room (*There has to be to-and-fro – ask, answer, ponder, suggest, ask, answer, think some more, etc – going on in that room*) does not sound like a 'linear' process, but if you read the GMC's descriptions of Informed Consent and of Best Interests Determinations, you will see them described in terms of stages. I append a piece I recently posted on Dignity in Care, about this. I am aware, that some people will say 'but Best Interests is the term for the entire process' - all I can really say amounts to 'you describe MCA Best Interests your way, I'll describe MCA Best Interests my way, and let us then put the two descriptions to 1000 people picked at random, and ask them which description they find easier to understand'.

I am not going to discuss, here (I have discussed it elsewhere), what happens if there is not complete agreement about 'what should happen next' at the end of the meeting. But, I will point out that there is no logical reason within the MCA to believe '... the doctor's decision then takes precedence'. There is no section 6(6)(c) saying '... the senior clinician'. I will now go back to the question I mentioned earlier - 'who is invited to the meeting?'.

When I read section 4 of the MCA, it 'wants' us to discover what will be best for the incapacitous person, based on the person's individuality (section 4(6)). So, what I see is 'I should try to involve and ask, everyone whose input could contribute to a better decision being reached, so far as possible'. And, based on my description of that room, I need to get those people inside the room – and, to describe the patient's clinical situation to them.

Doctors and nurses, have a concept of Clinical Confidentiality, which stretches back to a time before the MCA was a law. And, unless the guidance has been changed very recently, what they write amounts to this:

You can disclose an incapacitous patient's clinical situation and prognoses to the family and friends who could consider, or contribute to consideration of, the patient's best interests, unless before losing capacity the patient had forbidden such disclosure.

That is placing Clinical Confidentiality above MCA Section 4.

Only if, at the time the patient says 'If I lose capacity, I forbid you from disclosing clinical information', the patient makes and expresses all of the decisions which would subsequently be considered within that room if he had not forbidden disclosure, is the conflict removed.

The doctor, combining both the MCA and confidentiality, should really say to the patient something along the lines of 'If I cannot disclose clinical details to the people I would need to involve in best-interests decision-making, then my only option would be to try and keep you alive, however awful your clinical situation becomes'.

Or, the doctor could arguably say 'I am legally-required to try and determine what is in your best interests if you lose capacity, so unless you have got everything covered with Advance Decisions, I will have no option but to disclose clinical information'.

A more compelling statement, would be 'I am a complete loner – there are not any family and friends who you could ask about my beliefs and the like, even if you wanted to'.

Whatever the solution to this conflict between MCA and Confidentiality is, I am pointing out that the position I have made red above, contains a decision to place Confidentiality above MCA Best Interests – and I don't see why the decision should not be to place MCA Best Interests above Confidentiality.

Written by Mike Stone

19 June 2021

I posted the following as a separate piece on Dignity in Care recently:

MCA Best Interests positioned in the process

I have recently been irritated by terms such as 'clinical decision' and 'futile' in the context of decision-making for medical interventions. Those terms and also some others, in my view fail the test of 'clarity': they obfuscate, rather than shedding light.

In this piece, I will use as the base of my analysis the description within some 2010 General Medical Council guidance, of the process which leads to either Informed Consent or a refusal of an offered treatment. The GMC wrote this:

- **14** If a patient has capacity to make a decision for themselves, this is the decision-making model that applies:
- (a) The doctor and patient make an assessment of the patient's condition, taking into account the patient's medical history, views, experience and knowledge.
- **(b)** The doctor uses specialist knowledge and experience and clinical judgement, and the patient's views and understanding of their condition, to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.
- **(c)** The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.

(d) If the patient asks for a treatment that the doctor considers would not be clinically appropriate for them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after discussion, the doctor still considers that the treatment would not be clinically appropriate to the patient, they do not have to provide the treatment. They should explain their reasons to the patient and explain any other options that are available, including the option to seek a second opinion or access legal representation.

I consider the above to be a correct description of the process if the patient is capacitous, and I will now address the process when the patient lacks capacity, based on the above.

Sections a) and b) need a little modification if the patient lacks capacity, so here I will express the combination of sections a) and b) as meaning this:

The first stage of the process, is to establish what treatments might improve the patient's clinical condition, and the risks and benefits for the treatments are determined and outlined.

So I will now present a variation of what the GMC wrote, as follows:

- a) + b) The first stage of the process, is to establish what treatments might improve the patient's clinical condition, and the risks and benefits for the treatments are determined and outlined.
- **(c)** The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.
- (d) If the patient asks for a treatment that the doctor considers would not be clinically appropriate for them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after discussion, the doctor still considers that the treatment would not be clinically appropriate to the patient, they do not have to provide the treatment. They should explain their reasons to the patient and explain any other options that are available, including the option to seek a second opinion or access legal representation.

We now need to introduce a piece of 'external argument'. Presumably, it should not matter, in terms of what treatments **are offered**, whether or not the patient is mentally capable? Because to do otherwise, would surely be unacceptable: refusing to offer a cure for the pneumonia of a person with severe learning difficulties, because of the person's learning difficulties, for example, simply isn't on in 2021!

So, my modified a) + b) works for both capacitous and incapacitous patients.

It is now easy to see, that the Mental Capacity Act's best-interests process <u>stands in</u> <u>at stage c)</u> – at the point when a capacitous patient would consider the options, and then accept or refuse an offered treatment, we have no option but to use Best Interests instead if the patient lacks capacity.

The above is important, because it makes it obvious that whatever the reasons are why a treatment is offered (so, engaging with the term 'clinically indicated', here), **those reasons are nothing to do with MCA Best Interests**.

There is something else of interest, which this use of the GMC's description of a consultation during capacity, but used as it would have to be logically-modified to apply during incapacity, raises. Readers will note, that in section d) the GMC considers the situation of a capacitous patient asking for a treatment which has not been offered by the doctor.

The GMC's section d), is apparently intended to cover treatments which the doctor did not offer because the doctor considered the treatment would not work: however, treatments which would probably work but which the NHS is not funding will also not be offered. And, it might be pointed out that 'if you pay privately, you can get a different treatment or you can get the treatment sooner'.

We are often told, that Best Interests is only about offered treatments. We are told that a Welfare Attorney can only decide whether an offered treatment is in the patient's best interests. I am not at all sure about that: in the same way that I made it clear that a) and b) must involve different criteria from c), I think a welfare attorney could reasonably say 'I think treatment X would be in the patient's best interests – but as the NHS isn't offering treatment X, she can't have that treatment, can she'. It then gets a little interesting: the welfare attorney, if treatment X is not being funded by the CCG but if the welfare attorney thinks it would be the best option if it were available, can surely argue to the CCG that provision of treatment X would be in the patient's best interests (in the way that a capacitous patient, who wanted a treatment the CCG was not funding, might lobby the CCG to try and persuade the CCG to fund the treatment). Whereas the doctor – who is part of an NHS 'which has to use its resources in a way that is fair to all patients' - has more complex issues to consider, when deciding whether to lobby the CCG to provide the treatment (basically, the NHS has to try and spend its money to help all of its patients – it cannot afford to offer hugely expensive treatments to all NHS patients: however MCA Best Interests is about what would be best for the particular [incapacitous] patient).

Anyway: the take-away from the above, is that whatever Best Interests actually involves, *it stands-in for the stage of 'Informed Consent/Considered Refusal' when a capacitous patient would make his or her decision*. So there is not any 'MCA Best Interests' involved in determining which treatments are [at least initially – i.e. if we only consider a) to c), and set aside any issues arising from d)] offered by a doctor.

I feel sure, that in reality, there is often some 'blurring' of the stages which the GMC has described: in particular I suspect that often aspects of a) and b) will 'flow into each other', which is why when I modified the GMC's description I lumped both a) and b) together.

But we should not 'blur' c) with the earlier stages – we cannot accept what amounts to 'the doctor failing to offer a treatment 'because the doctor thinks it would not be good for the patient".

In the lawyer Ben Troke's recent book (A Practical Guide to the Law of Medical Treatment Decisions), Ben mentions that sometimes doctors will make a DNACPR decision which is ostensibly on the grounds of 'futility', but which is in fact 'a covert best-interests decision'. Ben suggests, on page 23 of his book:

'The best way to tease out the clinician's reasoning is to ask whether, if the patient had capacity to decide and wanted to take all the risks involved for the small chance of benefit, the doctor would be willing to provide the CPR. If they would, then it cannot be said to be 'futile', and any DNACPR being led by the clinicians rather than the patient's own choice is really a best interests decision and ought to be seen as such, following the MCA appropriately.'

I know what Ben is saying – although I suspect the final sentence might be a little confusing: I am confident that Ben is saying 'if the DNACPR decision would be for the patient to make if the patient is capacitous, then in the same clinical situation (re CPR) if the patient lacks capacity the MCA's best-interests process must be applied'. Which might not, as it happens, be any clearer to readers! What Ben is pointing out, but in a different way, is what I have said earlier (We should not 'blur' c) with the earlier stages – we cannot accept what amounts to 'the doctor failing to offer a treatment 'because the doctor thinks it would not be good for the patient").

What we should do, is to completely stop using the word 'futile' - if doctors always stated 'attempted CPR could not restart the heart' then we would not have this problem with the meaning of 'futile'.

I don't think any of the above is 'revelatory', and it seems pretty-much obvious to me and presumably to many other people. But, as the MCA still seems to be surprisingly poorly understood, I felt it worthwhile to point it out, even if explaining it (as opposed to understanding it) is something I might not be doing very well!

If we change my:

We cannot accept what amounts to 'the doctor failing to offer a treatment 'because the doctor thinks it would not be good for the patient"

to

The doctor should always offer CPR if CPR stands a chance, even a very small chance, of keeping the patient alive

then it might be clearer.

Written by Mike Stone

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