

## Perhaps evidence of change

Recently, after I tweeted a question about something a doctor had written about the Archie Battersbee court cases, some really 'illustrative' tweeting about 'best interests' followed. These tweets point to the current problems with the Mental Capacity Act.

I (@MikeStone2\_EoL) tweeted, about something @doctor\_oxford had written about the Archie Battersbee court case/s, the following on 10 August 2022:

**NOTE: I have added comments to the tweets in this coloured text.**

I am – genuinely – interested in this. I feel sure I typically see doctors implying that they are presenting a best-interests position, while relatives are presenting 'what we want to happen'. So – why don't doctors write 'there is disagreement between the family and the clinical team about what would be in the patient's best interests'? Are doctors implying that clinicians understand best interests, but relatives don't? I would love to discuss that one! @katemasters67 @KitzingerCelia @ProfMarkTaubert

Kate Masters then tweeted:

I am very interested in BI because I don't think it exists. I think it's a concept to tick a box that 'family was involved' and 'patient wishes end believes (and beliefs) were respected' but actually in the majority of cases medicine wins. And as it isn't an exact science that is dangerous.

I replied with:

BI (for adults) is the right concept in my opinion – and you to have to 'think from' section 6(6) of the MCA (that the patient can chose a friend or relative to 'take control of' best-interests-decision-making).

Mark Taubert chipped in with:

I have come out of a few Best Interests meetings where I, as the doctor, have had to remind myself that my opinion does not matter. That was always quite a step, and I know other doctors/HCPs increasingly 'note this'. Perhaps evidence of change?

Replies to Mark's tweet, were:

Kate Masters:

I'm guessing you mean the non-medical opinion which of course does matter immensely because what you're asking is what the sick person would do/say/feel/believe.

Celia Kitzinger came in with:

But I think your opinion DOES matter – I need to know your opinion on diagnosis, prognosis, treatment options etc to arrive at my own decision about what someone would want (or their best interests).

Mark Taubert replied to Celia with:

I know what you mean, but for me those are a 'given', but it is the final best interests decision on what X would have then decided given all the info received. That is the bit where my views don't matter an inch. It is something doctors find hard.

I replied to Mark with:

It isn't best thought of in terms of 'my opinion doesn't matter'. It is better thought of – by both doctors and relatives – in terms of 'do I understand enough, to justify me giving an opinion on this 'question'?'. If you ask yourself that question, and your answer is 'no – others understand this bit/aspect much better than I do' then you should not give an opinion. I usually use the situation of a parent in CPA, two children and a 999 paramedic: the question is 'would dad want CPR to be attempted?'. If I were one of the children, and my sibling's answer was different from mine, 'it would be 'fraught' but both of us would be expressing an 'informed view'. If the paramedic suddenly announced 'I know what your dad would want better than you' then I hope both children would immediately confront the paramedic with 'How the hell do you know that?!!! – you've never met or spoken to our dad!!!'.

Kate Masters:

I think it's at this point, maybe first or second conversation where there is no consensus, this is where intervention is needed. Early and independent. **I feel sure that Kate was thinking of situations – such as the Archie Battersbee one – when 'trust is lost' between the clinicians and the family.**

I also asked a question:

I would be interested in answers from any other doctors, as well as Mark, as to how you describe the purpose of a best-interests meeting to family and friends? How would you describe the purpose/objective of a best-interests meeting, to a relative who asked 'what is the meeting for?'. Please don't tell me '... the family never ask me that' – I would 'be depressed' if nobody ever asks you that question.

Kate Masters has more recently added:

In theory maybe, but in reality, how often do people appoint someone? And when they do the hurdles they encounter in having their decisions respected are high and broad! I think it needs a rethink.

Kate also tweeted:

Hospitals don't even abide by GDPR. We should all be asked to appoint a deputy/contact person but it rarely happens. Is there a place on ReSpect to do this? Honest question.

Everyone in this Twitter conversation, has got a decent grasp of the Mental Capacity Act (MCA) – which, as it happens, does not apply to children, so doesn't in fact apply to the Archie Battersbee case.

I'll start with the obvious. We can only 'make decisions' about what will happen now, or 'in the future'. We can't alter the past. If you have literally 'painted yourself into a corner', you can either wait until the paint has dried or you can walk across wet paint. Of course, if we were birds, we could fly out of the corner.

And, we usually gather the options together, and then apply our minds to the decision: we research options for a holiday, travel arrangements, etc, and then decide where and when (and indeed if) we will go somewhere on holiday. MCA best interests works in the same way – **we need to understand the available treatment options and their outcomes, after which 'we work out what would be in the patient's best interests'**.

As Celia and Mark said: (Celia) 'But I think your opinion DOES matter – I need to know your opinion on diagnosis, prognosis, treatment options etc to arrive at my own decision about what someone would want (or their best interests)' and then Mark 'I know what you mean, but for me those are a 'given', but it is the final best interests decision on what X would have then decided given all the info received. That is the bit where my views don't matter an inch. It is something doctors find hard.'

We now get to the first problem with best interests as explained in the Mental Capacity Act - '... it is the final best interests decision on what X would have then decided given all the info received.'. The MCA does **not** say that the best-interests decision 'is what X would have decided'. X here means the incapacitous patient – lawyers would tend to use 'P' instead of X, and we should probably be using 'the incapacitous person' to make it easier for most readers. In general, we can say that whenever possible, anyone making a best-interests determination **must try to work out** 'what the incapacitous person would have decided' - **but the Act doesn't say that 'the best-interests decision should be what the person would have decided** [if the incapacitous person 'could somehow decide in the situation']'. There is, now that we have the Briggs ruling, some clarity that if a patient goes from capacitous to incapacitous (for example to coma) very quickly, and the treatment being considered is of a life-sustaining nature, then we should withhold or withdraw the treatment if we feel sufficiently certain that the patient would have refused the treatment. See my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/A-Comment-about-something-in-the-Draft-MCA-Code-of-Practice-regarding-the-Briggs-ruling-and-Best-Interests/1124/>

This is, I think, what Mark was getting at (and I have been pointing this out for about a decade, by the way!) when he wrote ‘That is the bit where my views don’t matter an inch’. Although, as I pointed out in the tweets, it is not so much that the doctor’s views on what the patient would have decided don’t matter – it is more that because the doctor doesn’t (usually) know the patient as a person, the doctor simply doesn’t know what the particular patient would have decided. As I commented: ‘It isn’t best thought of in terms of ‘my opinion doesn’t matter’. **It is better thought of – by both doctors and relatives – in terms of ‘do I understand enough, to justify me giving an opinion on this ‘question’?’**. If you ask yourself that question, and your answer is ‘no – others understand this bit/aspect much better than I do’ then you should not give an opinion.’.

As I wrote in a Journal of Medical Ethics paper, **‘Put simply, the clinicians are the experts in the clinical aspects, and the family and friends are the experts in ‘the patient as an individual’**’.

I think (I’m not certain) this is what Kate was pointing at, when she wrote ‘I am very interested in BI because I don’t think it exists ... as it isn’t an exact science that is dangerous.’.

Kate also, in the same tweet, pointed to a problem: ‘I think it’s a concept to tick a box that ‘family was involved’ and ‘patient wishes end believes (and beliefs) were respected’ but actually in the majority of cases medicine wins.’. **This is very bad indeed – if clinicians ‘get the best-interests process wrong’ then often the relatives will feel ‘ignored, misled, duped and resentful’**. Kate also said, in the context of Welfare Attorneys – who exist in order to make the best-interests decisions - ‘In theory maybe, but in reality, how often do people appoint someone? And when they do the hurdles they encounter in having their decisions respected are high and broad!’.

It is easy to see – after all, doctors witness the consequences of ‘bad decisions made by capacious patients’ - why, as Mark wrote, ‘It is something doctors find hard.’.

I have been ‘banging on about’ the MCA’s best interests, and misrepresentation of it, for many years. What the MCA actually says, is a little tricky to decipher – and, having done that, it is sometimes very challenging to apply if you are a front-line clinician. See a recent piece I wrote about the MCA:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-think-we-need-a-different-way-of-explaining-and-teaching-the-Mental-Capacity-Act-MCA/1114/>

There is 'a hole' at the heart of MCA best interests: we don't really know how to explain how we get from what we need to consider, to an actual best-interests decision. I see this as really problematic: if nobody can explain 'what we are trying to do' then how can everyone involved, lay and clinical, 'see if we are all rowing in the same direction'? I have suggested a description of the objective of best-interests decision-making in my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/MCA-Best-Interests-compressed-to-a-single-sentence-an-ansatz/972/>

What I suggested, is:

**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.**

It is striking, that nobody has so far answered a really-important question that I've asked a few times, such as in the series of tweets:

'I would be interested in answers from any other doctors, as well as Mark, as to how you describe the purpose of a best-interests meeting to family and friends? How would you describe the purpose/objective of a best-interests meeting, to a relative who asked 'what is the meeting for?'.'

**If we could have clarity on the answer to that, then family and friends would be able to see if 'best interests' was being 'done properly': we would then, I hope, have fewer issues with 'the relatives will feel 'ignored, misled, duped and resentful'".** As the author Dr Kathryn Mannix said, commenting on my one-sentence description of the objective of a best-interests determination: **'I like your sentence because it helps decision-makers and those participating in a decision-making process to be clear about the task'.**

We also need to understand why treatments are being offered or not offered, and for adults there is an obvious [and in my experience, not often mentioned] way of working out when a decision is NOT a best-interests decision/determination. I recently explained this, in a BMJ rapid response:

<https://www.bmj.com/content/378/bmj.o1980/rr-1>

'Section 4(6) of the MCA, says that if it is known, what I shall term 'the patient's individuality' must be considered when coming to a best-interests determination. Logically, that leads to 'If the patient's individuality could never affect the determination, then the decision being made is NOT a best-interests decision'. It would be a very silly law, that required a decision-maker to consider something which could not affect the decision (and MCA 4(6) says 'must consider').'

*4(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 so.*

I am also acutely aware, that often 'uncertainty of knowledge' is not correctly-analysed when people write about the MCA. The best-achievable certainty, in most situations will NOT amount to 'absolute certainty': and any guidance or protocol which 'requires more certainty than is logically possible' is unreasonable. So – **'the best real-word certainty' is what we are forced to work with**. As I wrote in one of the pieces I have referenced:

'The Mental Capacity Act is applied with all-manner of 'uncertainty'. And it is unreasonable to seek '100% uncertainty' in most real-world situations. If a 'dying' loved-one has made 'decisions about future interventions' clear to a family-carer who is living in the same home, then the family-carer will of course assume 'if dad decides to change his mind, and no longer absolutely doesn't want CPR to be attempted, then he will tell me'. That is IN THE REAL WORLD as certain as it is ever possible to be, 'that dad doesn't want CPR'. It is much more certain, than a person who is reading an ADRT refusing CPR but who doesn't live with the patient could be: there, the 'doubt' is 'has he retracted this ADRT'. The family-carer would of course have almost no doubt regarding any possible retraction of an ADRT – 'the first thing dad will do if he decides to change his ADRT, is to tell me he has done that'.'

Clinicians and 'the system', seem to move from one logically-dubious assertion about the MCA to another, as soon as the previous assertion has been shown to 'have no legs to stand on'. A recent one I've come across, has invented something weird around the 'outcome of' discussions about future care:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/454/>

And, General Practitioners seem currently to be 'regarded as being responsible for' things which are clearly not their responsibility, and are logically outside of their control:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-am-trying-to-persuade-the-Royal-College-of-General-Practitioners-to-change-what-it-writes-about-relatives-when-patients-are-dying/1129/>

At the heart of this, seems to be a 'desire' for the senior clinician to 'be in charge of' records and the like: which often [especially for End-of-Life-at-Home, or when a welfare attorney or court deputy is involved] doesn't make logical sense (although it is more reasonable to place a 'co-ordinating role' onto the senior clinician: if I'm in hospital and make it clear to my consultant that I would never want attempted CPR, then the consultant should make sure a duty-doctor who runs to my bedside at 2am three days later is aware of my refusal of CPR).

It is time to return to tweets by Mark Taubert, a doctor, and Kate Masters, a 'relative':

**I have come out of a few Best Interests meetings where I, as the doctor, have had to remind myself that my opinion does not matter. That was always quite a step, and I know other doctors/HCPs increasingly 'note this'. Perhaps evidence of change?**

**I am very interested in BI because I don't think it exists. I think it's a concept to tick a box that 'family was involved' and 'patient wishes end believes (and beliefs) were respected' but actually in the majority of cases medicine wins. And as it isn't an exact science that is dangerous.**

I don't know, how strong the evidence for change is. Nor do I know, if the change is going far enough (although ReSPECT certainly isn't truly empowering and respectful of patients, welfare attorneys, and relatives: if it were, it would allow those individuals to sign its main form, which it stubbornly does not allow [at least in any meaningful way]). To resolve the concerns of people such as Kate – that, to use my phrase, 'only lip-service is being paid to the involvement of family and friends during best-interests decision-making' - we need doctors to truly respect that family and friends 'are the experts in the patient as an individual'. We need family and friends to accept that the clinicians are the experts in treatments and prognoses. We need it to be clear why a particular treatment is, or is not, being offered: usually this will be either because the treatment has no clinical benefit, or because it isn't being funded by the NHS. It is important to understand that a treatment can NEVER **not be offered** 'because it isn't in the patient's best interests'. And crucially, we need to be clear that if three relatives and a doctor all agree about a best-interests decision, then 'no particular individual 'made THE decision''.

It would be really helpful, if there was a good and easy-to-understand answer to that question of ‘what does best interests mean?’. If people object to my sentence – which seems to have been well-liked by the people I’ve asked – then we need to find and agree about an alternative description, if at all possible. We need doctors and medical organisations to stop making assertions that do not necessarily follow from the MCA – notably, the claim that if there is not a welfare attorney or court deputy with authority over best-interests decision-making, then the senior clinician has authority over best-interests decision-making. Everyone needs to appreciate, that what sections 4 to 6 of the MCA do, is to provide a legal defence.

If we can do these things, then what is going on will be more transparent and better-understood by family and friends – fewer misunderstandings should arise, and things should move more smoothly with less stress all round. People such as Kate Masters and I cannot achieve this – we need doctors, paramedics, etc to pick up this ball and run with it. But what Kate and I can do, is to try and make other patients and relatives better-informed: they will then be able to ‘fight their corner’ more effectively, if doctors do not move into the 2020s and modify their behaviour to fit with what the MCA actually says.

Written by Mike Stone August 2022

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PS Since I wrote the above, Daniel Sokol has provided an answer to my question about how should a doctor describe the objective of a best-interests meeting. I hope more people will answer that question, and if I get more answers, then I will post them on Dignity in Care.