

Two Hypothetical Conversations about the Mental Capacity Act

What follows is something I first published on Twitter, as a series of 'image-tweets'. I have collected them – about twenty tweets – into a single PDF here, and if I spot any minor typos I'll try to correct them, but I am not going to alter the text beyond correcting things such as 'are are' which were typos.

The first conversation is with a hypothetical student nurse, and the second is with a family carer who is also a welfare attorney.

Mark Taubert has suggested that my usual style of writing about end-of-life, the Mental Capacity Act, etc, is often difficult to follow. Mark is the 'expert teacher' so I've decided to have a go at doing it differently. I've decided that I'll write something about 'advance planning' as a PDF, and to create this series of tweets which is about the Mental Capacity Act (MCA).

Before I start, I will point out that the 'style' I am going to adopt in this set of tweets, is definitely the style I would adopt if I were discussing the MCA with a person, or a group of people, face-to-face: but it isn't 'the style' that I myself would prefer to be reading, if I were 'learning by reading'.

I am going to adopt a pseudo-conversational style: I will embark on an imagined conversation, between another person (*text in italics*) and me (plain text) – I'm a little nervous about this approach, because I have a vague recollection that it didn't turn out at all well when an Italian chap adopted this 'style' a few hundred years ago.

I also need to have in mind, an identity for my imaginary partner in conversation: this will change during the tweets, but I am going to start with the idea of the person I'm talking to, being a student nurse.

The topic is the MCA but **excluding Deprivation of Liberty**: I could claim to be avoiding DoLS because it is in the process of being changed, but mainly I'm avoiding DoLS because thinking about DoLS in depth almost always 'makes my brain hurt'. So I try to steer clear of DoLS!

This is the conversation with the student nurse – she talks in italics:

The MCA is all about about the care of mentally-incapable people, isn't it?

No – it isn't.

No to which bit?

No to the entire sentence, basically. If the MCA is 'all about' anything, it is all about 'consent' - and, the MCA is about people who are mentally-capable as well as being about

people who are not mentally-capable. In fact, the MCA is clearest when it is about people who **are** mentally capable.

All right – but, the MCA includes the rules about how the professionals who are responsible for people who cannot make their own decisions, should make the decisions which affect the lives of those people: mainly that is what the MCA is about, isn't it.

No – it isn't. It is about how anyone who is involved with a person who doesn't have the capacity to make his or her own decisions, should behave – it isn't about how professionals must make decisions which affect incapacitous people, it is about how anyone making decisions which affect incapacitous people must make those decisions.

But the MCA says that the professionals are the people who make those decisions, unless there is a welfare attorney or court deputy who the professionals must consult.

No – it absolutely doesn't say that!

You are wrong – I know you are wrong, because I can remember reading the part of the MCA that says that the doctor or nurse making the decision must consult with any welfare attorney or court deputy. It is in section 4 of the MCA.

Indeed it is – you are talking about section 4(7). But section 4(7) – which takes a bit of deciphering, by the way – states that **the person making the decision** must consult attorneys and deputies. It obviously cannot mean attorneys and deputies whose authority extends over the best-interests decision being made, because if it did, that would require a welfare attorney who was the decision-maker to consult himself – which would be an absurd idea! It can only mean, that attorneys or deputies whose authority doesn't extend over the decision must be consulted by the person making the decision – which, is both true and also deeply problematic.

Right – you've got me thinking – it doesn't make sense that you would 'consult yourself', so I'll accept that you are right that the attorneys and deputies mentioned in that section, must be attorneys and deputies who are not empowered to make the best-interests decision. But, why do you claim it is problematic – that section is clearly telling us, that if there isn't an attorney or deputy who has been given legal powers to make the decision, the clinician making the decision must consult any attorney or deputy who isn't empowered to make the decision. That is surely right.

It would be right – except for one significant detail: where do you get 'the clinician making the decision must consult' from?

My lecturer told me that, I feel sure: you are supposed to consult people, such as the close family, when you are making best-interests decisions.

Yes – the problem is why do you think the clinician, is the decision-maker?

Well, it's obvious, surely. And anyway – doesn't it say that somewhere in the Code of Practice!

Oh, the Code definitely implies that in section 5.8 – for example, it says in 5.8 'Where the decision involves the provision of medical treatment, the doctor or other member of

healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker.'

There you go then – I'm right, you've just said so!

No, you are not right, and I haven't said that you are right: I've said the Code implies that you are right, but the Code is wrong to imply that, because that isn't what the Act says.

Oh come on! We are told to do what the Code says – I keep being told that!

Yes, I'm not surprised that you are told to do what the Code says – but I write as a family-carer, and why do you think I'm supposed to pay attention to what the Code says, when what the Code says is obviously wrong?

Well – they wouldn't go to the trouble of writing a long Code of Practice which doctors and nurses are required to obey, and to not expect family-carers to obey it, would they!

It seems they would, because they have: if you read the Code, it states that normal family-carers are not required to have regard to the Code, although the Code then makes the peculiar claim that '*They should follow the guidance in the Code as far as they are aware of it.*'. I prefer to stick with what the Code has already pointed out – although in fact I prefer to just read section 42 of the Act – which is '*the Act applies more generally to everyone who looks after, or cares for, someone who lacks capacity to make particular decisions for themselves.*'

Hmnn – so what are saying about people obeying the Code?

To start with, nobody has to 'obey' the Code – people have to 'obey' the Act, but the Code is a case of 'must have regard to' if you are a nurse, doctor or whatever. If you are a nurse and you simply ignore the Code, then the NMC might bring that into something like a disciplinary hearing, or a judge might bring it into a court case against you. But as a normal family-carer I don't have an equivalent to the NMC – and if I were being accused of something in court, and it was suggested that I had 'breached the Code' I would point out that I can't really be accused of breaching a Code which section 42 of the Act specifically says does not apply to me.

This isn't what I can remember being taught about the MCA – but I'm also not quite sure why what you are claiming is wrong.

Partly good, partly bad: I'm pleased that you can't figure out why I'm wrong – because I think I'm right – but I'm not so happy that what I'm saying doesn't fit with what you've been taught, although I'm not surprised by that.

My brain is starting to hurt now – are you saying that the law doesn't say that the doctor or nurse providing the treatment, is the best-interests decision-maker: that seems stupid!

I'm saying, the MCA isn't framed that way. The MCA doesn't actually say who can make what decisions – all it does, is to impose a legal duty on the people involved with mentally-incapable patients to make decisions in the patient's best interests, and it provides a legal defence against a charge of 'intervention without consent'. And, it gives authority over best-interests decision-making to two classes of people: attorneys and deputies. It simply doesn't give any true legal authority to doctors, nurses, etc.

But – we need to know who the best-interests decision-maker is, surely.

I get that from clinicians – but you cannot expect to know, something which it isn't possible to know. The MCA imposes a duty to make decisions – both decisions which lead to an intervention, and decisions which lead to 'doing nothing' - on everyone who could be held culpable for not obeying the Act. It is fairly easy to see when an intervention has occurred, so if someone intervened, the decision to intervene should be defensible according to the 'test of' MCA 4(9) – less easy to see when someone should have considered intervening and decided that it was the correct best-interests decision to not intervene, but the same concept. In fact, the Act never makes it clear, who can make best-interests decisions.

Hang on – didn't you say that sometimes the MCA makes it clear that an attorney or deputy is the decision-maker?

It is difficult to talk about the MCA – if I did say that, I was wrong. What the Act says, is that if an attorney or deputy has expressed a best-interests decision, nobody else can go against the decision: see sections 6(6) and 6(7) of the Act, or section 7.29 of the Code – and in this instance, the Code does describe the situation correctly.

So that I've got this clear – you are saying that sometimes the Code is wrong?

Yeah – section 9.13 of the Code is clearly wrong – that simply doesn't fit with the Act's description of Advance Decisions, and 9.13 seems to be some sort of 'hangover belief' from a time before the MCA.

Well – surely doctors and nurses, who have got lots of experience, are better at making best-interests decisions about medical interventions than relatives are: that surely has to be true.

Well – no, it isn't necessarily true – it might be true, or it might be the case that relatives usually make better best-interests decisions than doctors and nurses. Arguably, relatives should be better-equipped to make better best-interests decisions than doctors and nurses, but we can't prove it one way or the other. Do you remember that bit of the Code you referenced earlier – section 5.8?

Yes – sort of – the bit that says 'Where the decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker.'

Yes, that bit. It also says in a different part of 5.8 'If a Lasting Power of Attorney (or Enduring Power of Attorney) has been made and registered, or a deputy has been appointed under a court order, the attorney or deputy will be the decision-maker, for decisions within the scope of their authority.'

Right – where is this going?

Suppose that my wife is developing dementia, and she decides to get me appointed as her Welfare Attorney. The paperwork is sent off to the OPG, and during the month or so while we are waiting for the OPG to confirm my appointment, my wife sharply deteriorates and loses her mental capacity for some decisions about treatment. It is usually claimed that the doctor – her GP – would be the best-interests decision-maker for decisions about treatment.

Er – yes.

Well, although it wouldn't be my main concern if my wife was living with dementia – helping my wife would be my main concern – I would have looked at the MCA and the Code if I knew I was going to be my wife's attorney. Most clinicians are taught that before my appointment is confirmed, the GP would make the best-interests decisions – admittedly that the GP would have to consult me, but that the GP would then make the decision. Is that what you've been taught?

Yes, I think so – by now you've made me rather confused as to what I have been taught! So are you about to prove that the husband makes the decision, even before his appointment as an attorney is confirmed?

Of course not – that isn't true, so it cannot be proved. I'm about to prove something different. In fact, you can prove it yourself: what changes between the paperwork being sent off to the OPG, and the paperwork coming back from the OPG confirming the husband's appointment, in respect of the husband's understanding of the Act and the Code, if we assume that he had read and thought about them before the paperwork was sent off?

Er – nothing?

Right – carry on. So, you've been taught that until the paperwork comes back, the GP's best-interests decision is the right one – and as soon as the paperwork confirming the husband's appointment as an attorney reaches the house, the husband's best-interests decision 'is the right one'. So – what does that tell us?

Er – that I'm getting confused, mainly!

Well – put simply, it tells us that we can't work out whose best-interests decision is better. The MCA never lets us work out whose best-interests decision is better – it sometimes tells us whose decision has to be followed, but it never proves whose decision 'is best'.

Suppose that before the paperwork comes back, the GP and the husband are in disagreement about whether or not CPR should be attempted if the wife has a cardiopulmonary arrest. One says 'yes' and the other says 'no'. Provided each of them can reasonably claim to have made their decision in line with the requirements of section 4, there is nothing in the Act which would allow the GP to prevent the husband from attempting CPR, and ditto nothing in the Act which would allow the husband to prevent the GP from attempting CPR.

I think you should probably be discussing his stuff with my lecturer, instead of with me.

Well – let's press on: you are here, your lecturer isn't, and besides that as you are my mental construct, you don't really get much of a say. Let's move on to the issue of 'what does best-interests mean?' - enough of the easy stuff, let's get to some of the harder stuff now.

Some of the harder stuff now – you mean, that was the easy stuff!

Yes, of course it was. But there is no need to panic about the harder stuff – nobody really

understands the harder stuff, which makes it considerably easier.

It seems to me – that you have a very weird brain!

Interesting – I don't usually get that from nurses. I've had 'we thought you were a doctor - you write like a doctor' and I've also had 'You are an idiot who understands nothing' from nurses. I'm probably 'a bit Aspergerish' but the main thing about my brain is that my memory is hopeless – I have to work with 'concepts' because I struggle to remember 'facts'. So I probably do have 'a weird brain'.

Think back to when you were learning about best-interests decision-making – what were you told about how you actually make a best-interests decision: about how you decide that 'this decision is better than that decision'?

I never really understood that bit of the lecture.

Good – that suggests you were paying attention. Nobody 'really understands' that bit.

Do you remember the things that seemed to be relevant?

Well – there was a bit about not – what was the phrase? - 'being motivated by a desire to bring about his death'.

Yeah – section 4(5). And what else?

There was a piece about what the patient had said, written and about trying to work out what the patient's wishes would have been – we students were talking about that bit, and we couldn't make complete sense of it, I seem to remember.

Nobody – and I'm including Judges – can make 'complete sense of' that section: it is the only real hint in the MCA about how you are supposed to actually make a best-interests decision. It is section 4(6). Tell me, were you told what the best-interests decision was trying to achieve?

I think so – but I can't remember the exact words of what we were told.

Was it something like 'the aim is to make the least-restrictive decision, while maximising the person's freedoms but also keeping the person safe'?

Er – that sounds about right. That makes sense – surely that is what we are supposed to be doing, isn't it?

'What we are supposed to be doing' is a bit too philosophical for me – but that isn't a satisfactory description of the objective of a best-interests decision-maker.

Why not?

There is a court ruling, where Mr Justice Peter Jackson ruled that a mentally-incapable patient with a gangrenous foot, who was strongly resistant to its amputation, must not have the operation unless he changed his mind and stopped objecting to the amputation. Without the operation, the patient would inevitably die quite quickly. Mr Justice Jackson ruled that the operation would not be in the patient's best interests – he argued that 'it was

better for the patient to be allowed to die, rather than to force him to have his foot amputated, and for the patient to then face an uncertain future which the patient strongly objected to'.

Ah – not easy to reconcile that ruling with 'while keeping the person safe'. So have you got an alternative description of the objective of the best-interests decision-maker?

Yes – my suggestion 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.

Well – I can see how that fits with the judge's ruling much better. But isn't it only judges who are supposed to make decisions like that one?

That type of decision often seems to end up in court, being made by a judge. But the MCA in its section 4(9) uses the words '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.' and judges have been telling us that they also apply section 4 of the MCA when they arrive at their best-interests rulings – so, in theory the rules are the same whoever is making the decision. It looks as if a doctor or normal family carer should be able to make those decisions without involving a judge – and certainly a welfare attorney isn't required to involve a judge – but in the real world, I think that doctors tend to be nervous about making such decisions and as a result 'send it to court'.

Go back to my attempt to explain best interests – who do you think understands enough to have an informed opinion about that 'the most satisfactory future when considered from the perspective of the incapacitous person as an individual.'?

Well – if you are stressing 'as an individual' - then, that would be the people who are close family or close friends of the person: they are the only people who understand people 'as individuals'.

Indeed – so why does the clinically-authored guidance I keep coming across, suggest that the doctors and nurses are the people who make those best-interests decisions? It isn't the doctors and nurses who understand the patient as an individual – it is the family and friends, who know the patient as an individual.

Because the MCA says the doctors and ... oh, hold on – we've already been over this haven't we: you claimed that the MCA doesn't say that, didn't you. You reckon the MCA only explains how a decision-maker can defend having made a decision, don't you!

So – suppose a wife calls 999 because her terminally-ill husband has just collapsed, and is unconscious or worse. In such a 'clinical emergency', if we believe that the most important aspect of best-interests decision-making is that 'understanding the patient as an individual' thing – the ability to work out what the collapsed person would decide in the situation, if the collapsed person could decide – then who might be able to make a best-interests decision. The wife, or the 999 paramedics who turn up?

Well – I can't keep track of half of what you've been telling me, but it is very clear that from your arguments, the wife might be able to make a best-interests decision – the paramedics definitely can't, because they don't know anything about the husband as an individual, and there is no time for them to acquire an understanding of the patient's personality in an emergency.

And – you are not being fair to me!

I'm a nurse – I thought I had a vague understanding of the MCA, but if your arguments are right – and I can't figure out why you are wrong – then my lecturers have been telling me things that are clearly wrong. That isn't fair – what you are doing to me, is somewhere between unfair and downright cruel!

I'm not known for being naturally empathic – I agree that I'm being a bit unfair on you, although as you are my mental construct, you are immune from damage. I would try to be kinder, if I was talking to a real student nurse.

I'm real – and the way I was treated by the 999 services when my mum died, was 'unfair and downright cruel': the start of some 'professional behaviour' which contributed to me being very depressed for a couple of years. **And your senior clinical colleagues are still writing guidance, which promotes such 'unfairness' to relatives.**

I now change the person I am talking to, to a hypothetical family carer who is also a welfare attorney – as before the hypothetical welfare attorney is in italics, but for practical purposes it now hardly matters, because I've given my welfare attorney exactly the same views as my own: the significance of this 'conversation', is in what we are saying about the beliefs of the professionals.

I am now talking to a Welfare Attorney, as opposed to the student nurse.

So – you are your dad's welfare attorney under the LPA, then.

Yes. Dad was diagnosed with dementia, and he asked me and my sister if we would be willing to be his welfare attorneys – mum died a couple of years ago – and I am now his attorney. My sister didn't want to do it.

Right – I've been discussing the MCA with a student nurse, which was relatively tricky: I'm guessing that it will be a much 'easier conversation' when we talk about the MCA.

Probably – we are coming from very much the same place, I'm guessing. You start.

Okay. My first question, is why did your sister not want to be a welfare attorney for your dad?

She didn't want to be the person making the decisions – she saw the 'burden issue' as being too overwhelming for her to handle.

Ah - 'the burden issue. I'm now assuming that you have looked at both the MCA, and also at some of the things clinicians write about the MCA and end-of-life care?

Yes I have – and I'm now assuming that you have as well.

So, although your sister wouldn't become an attorney because of that 'burden of being responsible for the decisions' issue, you weren't put off by that. Why not?

Because the more I looked at the stuff written by the doctors, and at clinical guidance, the more it became obvious that unless at least one of us was a welfare attorney, we wouldn't be able to stop them – the doctors and nurses – from doing things to dad, which my sister and I were convinced my dad would not have wanted to happen. That – the realisation that unless at least one of us was an attorney, we had no way of stopping things which we knew dad wouldn't have wanted from being done to him – overcame my strong wish to avoid having to make decisions which affect my dad's life.

Interesting – from my 'informed family-carer' position, I see that exactly the same as you do: I'd sum it up as 'I really don't want to make best-interests decisions – but the only thing worse than me being responsible for best-interests decisions, is being powerless to stop other people from making best-interests decisions which I know my loved-one would not have agreed with'.

EXACTLY – I had to become a welfare attorney, not because I want to make the decisions, but because it was clear to me that the clinicians think they should be making the decisions – the only way to stop them from doing things I know my dad wouldn't have wanted to happen, was to become his attorney.

I'm a bit 'nerdy' - when you said 'things I know' ...

Yes – point understood – are we going to discuss the MCA, or are we going to discuss how difficult it is to describe the MCA with the words we have available: let's carry on and set that aside, because your question makes it obvious we both understand the point.

Have you noticed all of these 'assertions' that unless a family carer is an attorney, best-interests decisions about medical treatments are made by the clinical team – those statements such as 'CPR is a medical decision'?

Of course I have – utter twaddle, isn't it! My sister and I both understand those things in section 4 of the MCA as well as each other – I can't make best-interests decisions any better than my sister can. The only difference between us, is that people have to accept my decision if I express it – the authority given to me by the MCA/LPA, is not the same thing as the understanding needed to make best-interests decisions as explained in section 4. My sister and I both have a similar understanding of those things in section 4 – and particularly of the things in 4(6), which it seems to me is the important bit of best-interests decision-making: the doctors and nurses don't understand those things like we do.

I knew I'd enjoy this conversation? Have you looked at something called 'ReSPECT' by any chance?

Yes – and I'm assuming you don't like it any more than I do, or else you wouldn't have asked! Why is ReSPECT promoting best-interests decision-making, instead of stressing that it is much better to avoid anyone having to make best-interests decisions by getting the decisions from the patient? I am empowered to make those best-interests decisions – and I hate the idea of having to do that, so I spent a lot of time making sure that I understood what dad would have wanted to happen.

Your dad has now lost capacity?

He is now living with quite significant dementia, so 'yes' - 'loosely speaking', of course.

How do you interpret that 'the person's past and present wishes' in 4(6). My parents basically died 'from being capacitous' so for me, it amounted to projecting what they had wanted forwards into a very short period of 'incapacity' while they were dying. But you can't use that approach as easily with dementia, can you – surely 'present wishes' is very tricky, during dementia?

Bothers me as well – my dad told me things before he started to become significantly demented, but as well as his – what shall I say here - 'analytical thinking' - changing, his 'personality' has changed as well since he has become more demented. He never used to listen to pop music – now he hums along to it. It seems to me that if a racing driver says 'if I'm ever involved in a crash, then I absolutely do not want CANH', then the car crash cannot somehow create 'a new personality'. But dementia can do that – dementia can at the same time remove capacity, and also change the person's 'personality'. And the MCA's best-interests test, seems to involve the person's 'personality': but which personality? The personality the person had before becoming demented; the personality of the person during the dementia – and, if it is that one, does that make Advance Decisions inapplicable?; or some sort of 'if somehow I could remove the dementia, then what would my dad's 'personality' be now?' hypothetical personality?

I haven't figured that one out either – that is why I tend to analyse end-of-life at home situations, which involve a terminal-but-capacitous loved-one having a cardiopulmonary arrest. My main issue, is that the professionals seem to think that if my dad makes it clear to me at 9 pm one evening that he no longer wants CPR, then somehow that doesn't count until a GP has embedded it in the records. I had a conversation with my mum when she was dying – I don't care whether anyone else was there, if a dying parent makes something clear to you, then you know, full stop!

Absolutely! Why do professionals think they can legitimately 'blame us' for the simple fact that we were there, and they weren't – HOW IS THAT OUR FAULT!

We seem to have uncannily similar views about things – perhaps we can speed this up because we seem to be able to

finish each other's sentences – yes, let's give it a go.

The potential conflict between providing information to people who could contribute to the making of a better best-interests decision, and

'patient confidentiality' - yes, I agree that clinical guidance defers to confidentiality, whereas I would defer to disclosure when that would lead to a better best-interests decision being made.

Your views on a related issue – what would you tell people who were asking you 'why did you make the best-interests decision you made?'

Depends – what is the situation. If the decision is 'anticipatory' or in general is in the process of being made, then if the GP, my sister, etc asked me to 'explain my thinking' then 100% I would do that. But if I had made and acted on a best-interests decision and afterwards I was being asked by 999 people – paramedics, police – then

you would say 'none of your business – making best-interests decisions is my responsibility, and all you are allowed to ask me is how had I put myself in a position to defensibly make that best-interests decision'.

Agreed. But wouldn't that annoy the 999 people?

I think it probably would annoy the 999 people – but if they were asking me those questions, then the 999 people would probably already be annoying me. There is nothing unreasonable in pointing out to people that the MCA doesn't require a decision-maker to explain 'why I decided 'A' was a better decision than 'B' - and anyway, if a friend or relative asks a doctor or nurse questions about patients, they frequently introduce 'confidentiality': so our introduction of confidentiality, when people are asking questions we are not legally required to answer, is surely fair!

I've got one final question – this was posted in a Nursing Times discussion some years ago, probably by a nurse.

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounded by his family.

The family are right to do what the father tells them to do – he says 'don't call anyone if you think I'm dying' and that is his decision, his instruction and they have to follow it. They might have to do something different if he collapses and doesn't in fact quite quickly die – then they would have to involve 999. But if he collapses, it turns out that he is dying so within a short time it becomes clear that he is dead, when the family then phone someone after he has died, nobody should try to suggest the family have done something wrong!

Well – I completely agree with you, but

*'the system' seems not to: yes, and 'the system's' view on that one, is completely unacceptable! **'Our father told us – we listened, we did what he told us to do' is all there is to it, if you are one of the family.***

I commented on Twitter that if anyone said 'quite a lot of points in there – if you could only make one point, what would it be?', that it would be the point in the final tweet – that the 999 Services must accept that family carers are supposed to do what their loved-one tells them do, so if the family only called someone after the father had died, once the family have said '... we didn't call anyone, because he told us to not call anyone' **then 999 paramedics and police officers must accept that.**