

## The Mental Capacity Act, PD9E, fish with feathers and a Scream of Frustration.

This is a longer response than some [tweets](#) I made, about Professor Jenny Kitinger when she was [interviewed](#) about something called 'PD9E': I suggested Jenny had been 'too kind' and 'too deferential', and her sister Celia [tweeted](#) 'Not "kind" or "deferential" but ...'. My position isn't that Jenny wasn't doing her best – my position is that with respect to getting the Mental Capacity Act (MCA) correctly implemented by 'the professionals', those of us 'on the lay side' aren't doing well enough. And I am definitely including myself, in that criticism.

One of the people I discuss the MCA with, has done far more than I have to promote better implementation of the MCA, and my correspondent is also a much better writer than I am – my correspondent hit the nail on the head with the following, when we were discussing something called ReSPECT:

**I have heard 'on the grapevine' that the FAQ guidance is in the process of being amended to highlight the primary decision-making role of these people appointed by the person. A small change but I'll be delighted when I see it. I appreciate this still doesn't do anything to address the position of other people who also know the person far better than the professionals. However the guidance is at least being revisited with a view to balancing the professional/lay rights regarding appointed proxies. It's a start.**

**I do think, incidentally, that the more people know about their rights to make decisions in advance about future care or treatment, and how to do this, the better. This is the tenth birthday year of MCA implementation: maybe we can all tell our local communities about the rights it gives us? In my view, and despite the admittedly slow burn on this one (putting it politely), this will in future be recognised as the greatest change that the MCA has brought about - the change from paternalism 'Nurse knows best' to making it clear we can make our own decisions, and telling us how.**

That is the change in law, which the MCA drew together and 'made clear' back in 2007 – we have changed from 'doctor knows best' to 'doctors provide clinical information, and the patients make their own decisions' for patients who are mentally-capable: and we have moved away from 'if the patient can't make the decision, then preservation of life and 'societal expectations' are what matters most', to 'if the patient can't make the decision, then what matters most is what the patient would have decided, if the patient could have decided'.

It isn't that the change described within the MCA is hard to see, if you read the MCA itself – as another correspondent wrote in an e-mail to me recently:

*It's surprising how such a simple seeming set of principles as the MCA can introduce such complexity*

There seem to be two issues in play. One is that if you have read and digested the MCA, then from the perspective of a front-line clinician, applying the MCA is very challenging, something I have [written about](#) recently. The other issue, is that it is far from clear who has read, or even heard about the MCA. Most of the public, will I suspect have no awareness of the MCA – and many clinicians still use the term 'advance directive' instead of the term used within the MCA, which is 'advance decision': it isn't clear whether that indicates a lack of familiarity with the MCA, or whether these clinicians are discussing the 'wider concept of advance directives'. However – while the 'wider concept of advance directives' existed well before the MCA became our law, in England and Wales [it is the MCA's](#) 'advance decisions' which we must apply.

One of the 'very challenging for clinicians' issues of the MCA, is the simple logic of the MCA because as my correspondent pointed out **'this still doesn't do anything to address the position of other people who also know the person far better than the professionals'**. There is a definite 'internal logic' to the MCA – I devoted a section of [my long PDF](#) to that logic (starting on page 8 of the PDF): and that logic, setting aside any issues of 'motivation and 'panic", and similar issues, implies that family and friends should be able to make better best-interests decisions, than doctors and nurses.

That is not a logic, which much of the 'medical establishment' is keen to accept. For example, despite my response to a consultation pointing out that 'you are describing the law incorrectly', when the ReSPECT material was originally published a couple of years ago, its Frequently Asked Questions were [clearly legally incorrect](#) where they described the role of attorneys and deputies as described in the MCA – the FAQs said:

**If the person has capacity for the relevant decisions, they must be involved fully with the process of shared decision-making. Many people want to have the support of family, friends or carers in the discussion, and some may choose to have a family member or friend advise them on what choices to make.**

**If they don't want their family or other carers to know about their condition or their choices, they should make sure that the healthcare team knows about this so that their wishes for confidentiality can be respected.**

**If a person lacks capacity and has appointed a legal proxy with powers to make decisions about life-sustaining treatments, the clinical team must involve them in making shared decisions on behalf of the person. Where there is no legal proxy, the clinical team must consult family or friends about a person's situation and previously expressed views or wishes, in order to make decisions that are in that person's best interests and for their benefit. However, the responsibility for making those decisions rests with the senior responsible clinician. The family must not be burdened with thinking that they are being asked to make these decisions.**

There is a lot in there which I take issue with, but one part is so obviously not what the MCA states, that after much 'nagging' the FAQs were [finally changed](#) about a year ago – this part

**If a person lacks capacity and has appointed a legal proxy with powers to make decisions about life-sustaining treatments, the clinical team must involve them in making shared decisions on behalf of the person.**

is nothing like what the MCA actually says:

That is clearly very-deeply legally-flawed: if a proxy (either a [Health and] Welfare Attorney or a Court Deputy) possesses legal authority over best-interests decisions (via the LPA and explained in sections 6(6) and 6(7) of the MCA) then the proxy would be making the decision – **the proxy would not be involved in making decisions with the clinical team, the proxy would consult the clinicians and then the proxy would make the decision/s.**

'The Great Mystery' is: how come those FAQs were so deeply legally-incorrect, when they were first published? The FAQs have been changed – but, it is revealing that they were wrong in the first place.

Dr Mark Porter, has been discussing the MCA in the current series of Inside Health – Mark explained the legal situation as 'the attorney's best-interests decision trumps decisions made by anyone else'. I liked the use of the word 'trumps' – I was less keen on a description given by the expert Inside Health is using, of how mental incapacity is established (the expert asserted that you must do that, in exactly the [opposite way](#) to how a judge did it in a court ruling – too 'nerdy' to elaborate here, and also 'off-topic').

I can now return to PD9E, and the interview I watched of Jenny Kitzinger, in the context of my objective of 'achieving correct implementation of the MCA'. The Supreme Court explained what it was tidying up:

*1. The question that arises in this appeal is whether a court order must always be obtained before clinically assisted nutrition and hydration, which is keeping alive a person with a prolonged disorder of consciousness, can be withdrawn, or whether, in some circumstances, this can occur without court involvement.*

There had been, until about a year ago, a 'practice direction' which said that all decisions to withdraw CANH had to be taken to court – that was PD9E and I only came across PD9E several years after I had read the MCA. That 'best-interests decisions about the withdrawal of CANH have to be taken by a court' practice direction, was obviously 'completely at odds with the MCA' – in the context of the MCA, 'PD9E was like adding feathers to a fish'.

There was an obvious 'potential danger' in the Supreme Court ruling: it was possible, that the court might have said 'the doctors can make a best-interests decision to withdraw CANH, without going to court, if the family do not disagree with the decision'.

Fortunately the Supreme Court didn't say that – what [the court said](#), was:

*126. In conclusion, having looked at the issue in its wider context as well as from a narrower legal perspective, I do not consider that it has been established that the common law or the ECHR, in combination or separately, give rise to the mandatory*

*requirement, for which the Official Solicitor contends, to involve the court to decide upon the best interests of every patient with a prolonged disorder of consciousness before CANH can be withdrawn. If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court. ...*

The Supreme Court is rather less questioning than I am, on the issue of 'will the professional guidance be correct?', so I would have gone for:

*If the provisions of the MCA 2005 are followed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court. ...*

There is a provision covering 'professional guidance' in the MCA 2005, so in fact I haven't removed anything – although the interaction between the MCA and 'professional guidance' is deeply complex, and deeply 'problematic in practice'. Again – too 'nerdy' and off-topic, to discuss in detail here.

Now – [to the interview](#) by Clive Myrie, of Jenny Kitzinger. It isn't hard to figure out, the form of those interviews. Obviously the interviewee will have in mind 'points to get across', and the interviewer will be setting the scene: during the interview, the interviewee will get some usually-very-brief opportunities to talk. And, of course, things only get their '15 minutes of fame' – so when the Supreme Court ruling re PD9E was given out, there was a very brief flurry of reporting.

My problem, is that Clive Myrie said things – using terms along the lines of 'diagnostic decision' and 'clinical decision' - which seemed to make it clear, that he did not understand the fundamental change of the MCA: that

**we have moved away from 'if the patient can't make the decision, then preservation of life and 'societal expectations' are what matters most', to 'if the patient can't make the decision, then what matters most is what the patient would have decided, if the patient could have decided'.**

Listening to Jenny, it was perfectly clear that what Jenny was saying was 'all correct' [except perhaps for something I discuss on page 8]: it was also clear that Clive Myrie didn't seem to understand that our law has moved on from 'doctor knows best'; and, when I ask myself 'what would the casual viewer of the broadcast take away from it?', I'm not at all sure that 'a correct understanding of the MCA' would be my conclusion.

This is my transcript of the interview - I have removed a few 'ums and ahs' but I think I've got this right:

Clive: Well Professor Jenny Kitzinger is co-director of the Coma and Disorders of Consciousness Research Centre at Cardiff University, and has been campaigning for today's

changes for many years, she joins me now from our studios in Cardiff. Good afternoon to you, thank you very much indeed for being with us. As I indicated there, you welcome this change, why?

Jenny: I think it's a long overdue clarification of the existing law, and is a huge relief for doctors and families, who'd made best interests decisions, formed by good diagnostic information and a knowledge of the patient, and then weren't allowed to enact them because there was this misconception that they needed to go to court.

Clive: But you'd agree that those diagnostic decisions can be difficult to make, and a number of cases that have ended up at the Court of Protection, they have been overturned.

Jenny: They have, sometimes the judge has agreed with the family when there's been a dispute where clinicians have wanted to continue treatment, and families have said the person wouldn't have wanted it, and judges have really taken the lead in promoting patient-centred care, and saying the person's values and beliefs are key here.

Clive: But doesn't it make sense to have a final backstop, an ultimate backstop, with someone completely impartial not connected with the case, who can look at everything - I'm not saying that doctors wouldn't look at a case dispassionately but, but, is in that kind of position where they can see what is going on from a distance (voice trailing off) is that fair?

Jenny: I think it's very important that the RCP - Royal College of Physicians - and BMA - British Medical Association - guidelines are followed, and they include the request for a second independent opinion from an expert in the field, and I think that's the most compassionate and efficient way of ensuring best interests, whereas what we found with going to court, there have been long, long delays, often months sometimes years before cases are resolved, and during all that time patients are then receiving treatment they wouldn't want, or is futile.

Clive: Some have disagreed with today's decision, saying that how can it be in the best interests of any patient to have their food and water removed, and as a result suffer pain potentially.

Jenny: I think there's a long-established tradition now that we with capacity have the right to refuse some treatments, so there's a point for all of us where the benefits are outweighed by the burdens of a treatment, that may be your sixth or seventh round of where you say you'd rather just spend time alone with your family, and go in peace, and I think people with profound disabilities have those same rights, not to inevitably have treatment imposed on them. But the rest of us can choose to say okay I'll have a feeding tube now, but now I'd like to refuse it, and that's a right that should apply to everybody.

Clive: And the key is that the doctors and the family have to be in agreement on this.

Jenny: Yes - and that there has to be a robust best-interests decision-making process. And that includes looking at what the family [is] saying is it what they want for themselves, is it what they want for their son and daughter, or are they actually speaking for that patient, and trying to represent that patient's voice, and that's the key here.

Clive: I'm interested in your particular - er - case - er - Jenny, because you had personal experience to a degree, it is not exactly the same case but to a degree, of the kind of dilemmas that some families end up going through.

Jenny: Yes, my own sister was severely brain injured in 2009, and she was unconscious for some period and then minimally conscious, and I think I saw from the inside both for my own family, and for the other families I met in the waiting rooms, the huge emotional trauma of that, the desire to cling to hope sometimes, regardless of what you're told by clinicians, and the commitment many families have to trying to represent their loved-one, and do what's right for them, so that certainly has inspired my interest and gave me an insider's view. But since then I've interviewed 85 family members from a wide range of families, and tracked those families over time to see how their ideas and their experience evolve as the patient goes through the pathway.

Clive: But a particular family, if they do disagree with the doctor's clinical decision, they can still get an independent decision made by a judge or a court..

Jenny: Absolutely, and I think that's absolutely essential, courts are very good at managing cases of doubt or dispute, and there might be a case for mediation before then and discussion, but I would actually say yeah go to court. The doctor cannot make a best interests decision about a patient themselves if the family are adamant the patient would have wanted a different course of action, you do need court then, definitely.

Clive then closed the interview with his 'goodbye'.

As I've already mentioned – it has been over 10 years since the Mental Capacity Act became a law, and progress towards implementing the MCA seems to be being made 'at a snail's pace'. Jenny and Celia Kitzinger have been influential in getting rid of PD9E, and despite [our failure to see eye-to-eye](#), even the ReSPECT team admit (in an e-mail to me) that my feedback [or, as I would describe it, withering criticism re ReSPECT's legal mistakes] was a significant factor [in the changes](#) which were made to ReSPECT's FAQs.

But – we are not doing well enough: progress is far too slow.

Perhaps, 'we' need to find a way of 'steering conversations with people unfamiliar with the MCA' towards the points we need to make – I think many of us, are agreed about those points.

It wasn't clear to me, that Clive understood that best interests isn't 'a clinical decision' – if you already understand that, then Jenny was pointing that out. Although I'm still not completely sure, whether Jenny thinks that the doctors 'make best-interests decisions and the relatives don't' – not true, so far I can see. So I would not have said what Jenny said at the end of her talk, for example:

*The doctor cannot make a best interests decision about a patient themselves if the family are adamant the patient would have wanted a different course of action, you do need court then, definitely.*

I would have said:

*If the doctor and the family and friends disagree about what would be in the patient's best interests, you need to go to court then, definitely.*

There is something very similar in [a blog](#) by Julie Latchem-Hastings about the withdrawal of PD9E, when Julie wrote:

*Critically, 'best interests' decisions made by doctors regarding whether or not to continue life-sustaining treatment must draw heavily on the prior expressed wishes, feelings values and beliefs of the patient, as described by family and friends, and any other evidence of their views (e.g. via habits and behaviours, religious observance, etc).*

Instead of that, I would have written:

*Critically, 'best interests' decisions regarding whether or not to continue life-sustaining treatment must draw heavily on the prior expressed wishes, feelings values and beliefs of the patient, as understood by family and friends, and any other evidence of their views (e.g. via habits and behaviours, religious observance, etc).*

We are moving into quite difficult 'MCA territory' here, because nobody can clearly explain 'best interests' – we can easily prove some things, including that normal people such as family carers must be able to make perfectly legally-satisfactory best-interests decisions, but nobody can clearly explain the subtle difference between [the MCA's 'Best Interests'](#) and an alternative which is called 'Substituted Judgement'. Substituted judgement, can be described as 'if you can work out what the patient would have decided, then you do that'. But the MCA has best interests instead of substituted judgement: and best interests is 'substituted judgement but with added caveats – and nobody can clearly explain those caveats'.

However, Mr Justice Charles in the [Briggs ruling](#), used this wording about the withdrawal of CANH:

*'62 But, in my view when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self-determination which an individual with capacity can lawfully resolve and determine by giving or refusing consent to available treatment regimes:*

*ii) if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.'*

About 2 years before Mr Justice Charles said the above in his Briggs ruling, I [had written](#) in the context of a best-interests decision to withhold potentially-successful cardiopulmonary resuscitation (CPR):

*'A genuine section 4 best interests decision, involves 'working out the patient's likely wishes' -*

*there must be some degree of uncertainty about those wishes (a degree of uncertainty entirely absent for 1). Whoever is considering the best interests test, the fundamental struggle is in persuading oneself that this uncertainty is small enough, to believe that the patient would have refused CPR for the particular CPA in question.'*

There are some notable differences between withdrawal of CANH and withholding of potentially-successful CPR – notably there is aftercare involved in the CANH decision but not after a DNACPR decision, and in some situations decisions about CPR will need to be made almost instantly – but each is 'a best-interests decision, the consequences of which will be death'.

We already knew that a best-interests decision could legitimately lead to the withdrawal or withholding of a life-sustaining treatment, because of section 11 of the MCA [section 11 describes that using incorrect wording – it uses 'the giving or refusing of consent' when it is obvious that it should instead have been framed in terms of making a best interests decision to accept or decline an offered intervention], and the problem was how do you justify such a best-interests decision, when section 4(5) of the MCA says:

*4(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.*

I had concluded by 2014, and then somewhat later Mr Justice Charles also concluded, that the 'obvious justification' looks very like 'substituted judgement' – it amounts to 'I am sufficiently certain that the patient would have made this decision, in this situation': it removes issues of 'the decision-maker's motivation' by effectively resorting to 'the patient would have decided, if the patient could have made the decision'.

Jenny – and if you want to see why this is true, then look at section 4(6) of the MCA – alluded to this when she said '... speaking for that patient, and trying to represent that patient's voice, and that's the key here'.

But, Jenny seems – perhaps misled by the RC(UK) et al, or perhaps because Jenny isn't as forthright as I am – to accept that the role of the family and friends, is to contribute to the best-interests decision-making of the clinicians: I think that logically, it should be the other way round – that the clinicians should provide information about diagnosis, treatment options and prognoses, and that the family and friends are better-placed to make the best-interests decisions. I would point [to something from](#) Mr Justice Hayden:

*'He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation.'*

What Mr Justice Hayden so clearly points out, is that **'knowing someone is more than merely listening to them** – you also 'see how they behave". How could a friend of the patient, explain to a clinician those '*many oblique and tangential ways over so many years*' as easily as a clinician could explain to the friend the clinical situation and the prognoses?

And, the way that people make decisions, is to 'collect the evidence relevant to the decision, and THEN think about it'. Well – that is the ordering, if we assume that we make decisions 'rationally', anyway.

It seems to be reversing that process, if you assert that the family and friends who 'understand how the patient thinks' are to somehow explain 'how the patient thinks' to the clinicians, and then the clinicians are to input the clinical situation – 'the clinical situation is 'whatever', you know the patient, what would she have decided?' is the ordering that fits with how decisions are made.

The people given legal authority over best-interests decision-making by section 6(6) of the MCA, attorneys and deputies, are often described as 'legal proxies'. I have in the past used a different term, to distinguish between the people who understand the incapacitous individual [well enough to](#) 'think like the patient' - to be included within the group for which Mr Justice Hayden used the term 'friends'- and other people who cannot do that: the term I use is 'proxy minds'.

Nothing which I am about to write, differs from what I have been writing about the MCA for several years – for example, one of the earliest rapid responses which I submitted to the British Medical Journal ([published](#) 19 July 2013) included this:

*Moving on, David Jolley (this series of rapid responses, 18 July 2013) mentioned the Liverpool Care Pathway. The recent review of the LCP, and its follow-on releases, frequently mention communication and shared decision making, without being very clear about the meaning of either term. To put that simply, why do clinicians and 'relatives' have to talk to each other, is the discussion a legal requirement, and who 'makes the decisions' if the patient cannot make his own decisions ?*

*The trickiest issue with EoL behaviour is the legal aspect, and in practice this means the interpretation of the Mental Capacity Act. Clinicians do not usually agree with me about this, and most believe that 'best interests decisions ultimately devolve to the senior clinician' – but the Act does not state that. If there is a suitably-empowered attorney, who almost certainly will be a layman, the attorney is 'the ranking section 4 decision maker' because of section 6(6) of the Act. So, it is clear that 'making a best interests decision' does not require that one is a trained clinician: this is because the section 4 best interests test can logically only start from the concept of 'if we could somehow ask the patient, what would he decide ?' (see section 4(6) of the Act). As an aside, it is often clearer, to think in terms of 'interventions being accepted or refused' rather than of 'treatments being accepted or refused'.*

*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’.*

*It is more complicated, if all of the ‘proxy minds’ are not unanimous (there is not the space to elaborate, here) – but the current interpretation, by most clinicians, of the Act’s best interests requirement, isn’t logical and isn’t coherent. If anyone wishes to discuss this further, email [mhsatstokelib@yahoo.co.uk](mailto:mhsatstokelib@yahoo.co.uk)*

I did not explicitly state that the answer to the question ‘what would the patient want to happen’ is section 4 best-interests in its full complexity (although I refer back to page 7 and the words of Mr Justice Charles), but neither did the Supreme Court (pages 3&4 – the court said ‘*If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court*’). But despite the impossibility of describing MCA best interests, the court must have accepted that ‘the family’ can form a legitimate view about the patient’s best interests: because the court said ‘agreement upon what is in the best interests of the patient’.

In [a more recent](#) BMJ rapid response, I was more explicit about how a person involved with an incapacitous patient, should be deciding on his or her own role in the best-interests process:

*We need to analyse the word ‘representatives’, and to define the circumstances of the disagreement. The MCA describes two situations: either a patient is mentally capable [with respect to the particular decision], in which case the patient considers clinical information provided by his clinicians, and then the patient makes and expresses a decision; or, the patient is not mentally-capable, and somebody else makes a best-interests decision. In both cases, as is logically obvious from that separation, the question of capacity has to be settled before the process moves on to the consideration of the decision. Danbury mentioned the recent ruling by Mr Justice MacDonald, which pointed out in very clear terms that ‘mediation’ does not apply if the patient is mentally capable, and that the patient alone makes the decision [whether or not to consent to offered treatment]. What ‘so troubles clinicians’*

*is the 'value-free' aspect of that - there is no assessment of whether the decision the patient makes 'is a good one', there is simply the decision that the patient is mentally capable [even if also self-destructive].*

*So, if the patient is mentally-capable, the answer to Danbury's question (above) is 'yes'.*

*What, if the patient lacks capacity, does 'representative' mean in Danbury's sentence above ? If by 'representative' Danbury means a Welfare Attorney or a Court Deputy whose decision-making authority extends over the decision being made, the Act is clear that the attorney or deputy is the decision maker (section 6(6) of the Act) and the decision must be followed unless an application to a court is being made (section 6(7)).*

*If there is not an attorney or deputy with the powers described in section 6(6) of the Act, then in my opinion the Act does not give any person decision-making authority: but, it does impose the duty to comply with section 4(9) on anyone who makes a decision. Section 42 somewhat complicates this, but only by allowing senior clinicians to lead the behaviour of more junior clinicians (actually, section 42 is clearly potentially problematic in application).*

*Compliance with 4(9), requires that the guidance available from section 4 is applied by any decision maker: and, section 4(6) of the Act does not explain exactly 'what best interests means' but it does link the concept to 'the patient's individuality'. The people who understand the patient as an individual, are the patient's close family and friends - this is presumably why the COP 'increasingly prefers the relatives' view of best interests to those of the medical profession'. Danbury's phrasing there is interesting - 'the relatives' view(s) of best interests' - because I have always claimed that the relatives are indeed 'expressing best interests decisions' [which, however, cannot be imposed on others] while traditionally clinical authors have claimed that 'the relatives contribute information which the best-interests decision-maker then considers'.*

*If we adopt my position, that unless somebody is empowered by section 6(6) everyone should be contributing whatever they can to the formation of the best possible best-interests decision (clinicians contribute clinical prognoses, family and friends individually answer the crucial question of 'what would the patient have decided ?'), and with luck a unanimous decision emerges, then that unanimous decision is the one to be adopted by everyone. But, if there isn't unanimity, where does 'mediation' fit in ?*

*An honest consideration of section 4 of the Act, first requires a person to answer the question 'Am I sufficiently well-informed to properly consider section 4, and thereby to defensibly claim compliance with section 4(9) ?'. If the answer is no, you would not be involved in 'mediation' [about 'what is the best best-interests decision']. If the answer is 'yes', then your own best-interests decision is the one you must follow: that is obvious, from the wording of 4(9).*

For 'comatose patients', the Supreme Court decided that if there isn't agreement about the best-interests decision, it should go to court. For the situation I write about, end-of-life and especially EoL at Home, clinical changes can be very rapid and 'taking best-interests to court' should surely be very much something we seek to avoid it at all possible.

The MCA doesn't say that disagreements **must** go to court – it says that disagreements **can** be taken to court (actually, it doesn't even say that – it says that some people need to apply for permission to ask for a court to rule, and others have an automatic right: as it happens 'the senior clinician' does not have an automatic right to ask for a court ruling [nor do 'normal relatives']).

So, usually in cases of disagreement, there seem to be two options: one is 'take the disagreement to court', and the other is 'record the existence of the disagreement, and then let everyone do what they themselves consider to be correct'. I will not discuss this further here, but I will point to two PDFs which do discuss disagreement about best interests:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/261/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/271/>

Moving away from PD9E, many of the people who find themselves in a comatose or minimally-conscious state, will not have anticipated that: but terminally-diagnosed people, have an opportunity to plan ahead, even if in reality many people do not seize that opportunity. That forward planning is deeply-intertwined with the law covering 'who makes the decisions', which for England and Wales is the MCA. The MCA is still poorly understood and even more poorly implemented – for example, many clinicians seem to believe that patients are required to explain 'their reasons for refusing an offered treatment, and as Dr Kathryn Mannix recently tweeted:

<https://twitter.com/drkathrynmannix/status/1026793331735576576>

*Indeed, every right to give no reason, and even a not-thought-sensible reason must be respected. But if circs don't match AD, then it's not applicable. Then, understanding values/preferences helps BI decision-making. I speak from sad, regular experience.*

Now, there has recently been what I can only describe as a deeply-dubious 'push to' persuade patients who might lose mental capacity, to explain their 'likely future wishes': not to persuade the patients to make and express Advance Decisions, but to deliberately create 'advance statements'. I see this, as being quite close to insanity – see my piece [here](#).

One reason, is that it is 'a deep shared life-experience' that allows close family and close friends to become what I have described as 'proxy minds' – reading these 'advance statements' **is a very poor second** compared to 'asking someone [who actually knows](#) me'.

And even more to the point: when my own mother was dying, she refused to take some medications and energy drinks. I was **almost sure** that my mum 'wanted to die' – but I was compelled to actually ask her, because 'almost sure' leaves a deeply-unsettling doubt.

Now, once I had been told, then it was okay: so I completely understand the inherent desire of clinicians 'to understand the patient's motivations' – **what I don't understand, is why on earth clinicians think that they will ever be able to do that as well as the family and friends of the patient can do it!**

I am also **incredibly annoyed** by 'it doesn't count if your loved-one told you – your loved-one must have told us': I simply refuse to accept that, it is grossly offensive and also deeply illogical. I write about this very frequently, for example in:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-the-Mental-Capacity-Act-inevitable-unknowns-and-safeguarding./991/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/319/>

<https://www.bmj.com/content/356/bmj.j813/rr-6>

<https://www.bmj.com/content/356/bmj.j1216/rr-1>

Now, Jenny said this during her interview:

I think there's a long-established tradition now that we with capacity have the right to refuse some treatments, so there's a point for all of us where the benefits are outweighed by the burdens of a treatment, that may be your sixth or seventh round of where you say you'd rather just spend time alone with your family, and go in peace, and I think people with profound disabilities have those same rights, not to inevitably have treatment imposed on them. But the rest of us can choose to say okay I'll have a feeding tube now, but now I'd like to refuse it, and that's a right that should apply to everybody.

There is some complexity in there [and the right to refuse treatments was once 'established tradition' but it is now a clear legal right as contained within the MCA], but in the context of PDOC [and setting aside human rights arguments about whether the MCA's best-interests framework breaches the human rights of people judged to 'lack mental capacity' but who can still clearly express their opinions], Jenny seems to be saying what amounts to:

'Life-sustaining treatment should not inevitably be imposed on everyone who is 'in a comatose state'.

Not only do I agree with Jenny – and so must the Supreme Court – but the MCA makes it clear that a best-interests decision can legitimately be made which would 'remove the 'imposition of' such a life-sustaining treatment'. That is what I have been writing about in this piece, and I'll now make a few final points and draw this piece to a close.

I am convinced, that it would help if we could be clearer – not say 'read the Act' or 'read the Code' – about the objective of best-interests decision-making, and in that context I recently

set [a challenge](#): for people to suggest their own single-sentence descriptions of 'the rule/guide for best-interests decision-making'. The sentence I have suggested is this:

**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.**

Jenny and Celia Kitzinger, are very-much influenced by the 'burden' which relatives feel, if you ask the family 'to make those best-interests decisions' for loved-ones who have suddenly become 'comatose'. But, as I have pointed out [in this PDF](#) if the family do not make the decision, because the clinicians do not understand the patient's 'individuality', the clinical team will often resort to 'preservation of life' (as Jenny said 'sometimes the judge has agreed with the family when there's been a dispute where clinicians have wanted to continue treatment, and families have said the person wouldn't have wanted it').

I did try to resolve this problem, in the PDF – and re 'safeguarding' I strongly point at the CONCLUSION, of this section of my PDF:

*The Kitzinger paper states – and while I disagree with this in legal terms, as is clear from the above I agree about the 'burden' issue:*

*... healthcare teams making best interests decisions not to continue ANH-treatment would need to ensure (as they should do currently<sup>22</sup>) that family members know that the decision is not theirs to make, that the burden of responsibility lies with the clinical team and that everyone involved recognises the immense gravity of the decision to allow death.*

*Because the clinicians will usually not understand 'what the patient would have wanted', if you let the clinicians make best-interests decisions, then inevitably the clinicians tend towards 'preservation of life and 'best clinical outcomes" – but, while the legal concept of 'best interests' is incredibly difficult to express in clear and simple terms, it is much closer to 'doing what the patient would have wanted'.*

*As I pointed out at the end of my PDF:*

*That is the point, and the current analyses of these situations by most authors is almost correct: where it is incorrect, is in its 'effective assertion' that the clinical team 'makes the best-interests decision', after discussion with family and friends. What would be a correct description of the wording of the MCA, is that the clinical team and the patient's close family and close friends need to talk together, in some depth, with an objective that after those discussions some individuals would then be sufficiently well-informed about the things described by section 4 of the MCA, as to be able to individually claim to have arrived at a best-interests decision which can be 'defended' by compliance with section 4(9).*

*Those 'sufficiently-well-informed individuals' are not defined by clinical or lay status – they are solely defined by their ability to defensibly claim compliance with section 4(9) of the MCA: 4(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.*

## CONCLUSION

*Provided that there is no exclusion of anyone who wants to be involved in the discussions – for an example, provided no close family or close friends who it is suspected might 'form a contrary [but defensible] opinion about best interests' are excluded from the discussions – then if everyone agrees about the nature of the best-interests decision (here, for example, that CANH should be withdrawn in the patient's best interests) that is the best-interests decision which should guide subsequent actions. Which is NOT 'the clinicians made the decision'.*

*And, of course, the larger the number of individuals who can each claim compliance with 4(9), the 'stronger' is the best-interests decision which each of those individuals had arrived at.*

There is of course one significant complication – the clinicians not only 'do not know the patient as an individual' but the clinicians also 'do not know who does know the patient as an individual', and I have also pointed that out in [a BMJ response](#).

Written by Mike Stone (Michael H Stone in BMJ rapid responses) August 2018, and I can be found on Twitter at [@MikeStone2\\_EoL](#)

Some of the other people I mentioned are also on Twitter:

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Professor Celia Kitzinger [@KitzingerCelia](#)

Dr Julie Latchem-Hastings [@JulieLatchem](#)

Dr Mark Porter [@drmarkporter](#)

Dr Kathryn Mannix [@drkathrynmannix](#)