

An open letter to the BMA: would the BMA prefer cooperation and collaboration between doctors and relatives, or does it wish for increasing division and conflict between relatives and doctors?

Introduction and my background

After a bad personal experience about a decade ago, and my efforts to address the reasons why that happened, I am by now [I think] fairly well-known to be something of a pain-in-the-backside for any clinicians who still believe the legal situation is as it was 50 years ago. My perspective stems from my involvement during End-of-Life-at-Home, although much of this piece will focus on what the BMA has published about clinically assisted nutrition and hydration (CANH).

The fundamental law for the withdrawal of life-sustaining CANH, and the withholding of potentially clinically-successful cardiopulmonary resuscitation (CPR), is identical. However, it is significant that for CANH the patient will usually be within a hospital or similar environment, while for CPR during EoL-at-Home the issue is usually should CPR be attempted when the patient's heart stops. I will return to these differences later, but first I will analyse the current BMA publications around CANH.

What the BMA writes about CANH

I should point out, that I have not read the BMA guidance in detail – doing so is not necessary, because my objection is to something fundamental. When, as a former family-carer who has now read the Mental Capacity Act (MCA), I read the BMA material, it seems to me that the BMA has not accepted that our law no longer implies that when patients are incapacitous, the senior clinician ‘makes the important decisions’. It is as if the BMA is still living in a bygone age, when ‘the doctor owns the patient’ - as opposed to my view, within which the doctor is helping my loved-one.

Before I start to critique the BMA's material, I should point something out. Clearly, if a patient in hospital is receiving CANH, the hospital and its clinicians must be subject to the MCA's provisions: when viewed as a legal defence against ‘intervention without consent’ the MCA raises some interesting questions which I suspect the BMA will not have clearly addressed (notably, what is the legal defence available for someone such as a nurse or ‘stand-in’ doctor, who was not personally involved in best-interests decision-making {in other words, a clinician who could not stand in front of a judge and say ‘I personally believe that I have satisfied MCA 4(9) [and therefore can claim the legal protections in section 5]} and I will not examine that issue

here. Also, withdrawal of CANH, will indeed be performed by clinicians. This is different from EoL-at-Home, when a family will often be alone with the patient when the patient's heart stops, and when many relatives would be able to attempt CPR having been trained in it as first aid. However – the law around decision-making, is essentially identical in both situations [with a complication, in that a relative might argue 'I was not legally required to either intervene, or to seek medical assistance for the patient'].

I will start by looking at part of the BMA's guidance for doctors. This is what the BMA has written, if there is not a welfare attorney empowered to make the best-interests decision.

Who is responsible for making decisions?

For significant decisions, such as those to provide or withdraw CANH, decisions should ideally be made and agreed by the whole of the treating team and those close to the patient. Nevertheless, it should be established clearly, at all times, who has formal decision-making responsibility and this information should be shared with those close to the patient. Seeking clarity about who the decision-maker is at an early stage ensures that CANH is provided, or withdrawn, as appropriate for the individual patient and is not continued, 'by default', because nobody sees it as their responsibility to carry out a best interests assessment.

The MCA does not identify a particular individual as having legal responsibility for decision-making, focusing instead on collaborative decision-making. Nevertheless, in practice, this will fall to the individual with overall clinical responsibility for the patient's care, as part of their duty of care to ensure that the care being delivered to the patient is in their best interests. This will usually be:

— *In hospital* – the named consultant. Where consultants rotate on a regular basis, it is the responsibility of the Trust or hospital management to have a protocol that identifies at any given time the individual with overall responsibility for the patient, and to ensure that decisions are not delayed because of regular staff changes.

— *In a hospice/palliative care unit* – the named consultant or senior doctor with overall clinical responsibility for the patient's care.

— *In the community (in a nursing or care home or living at home)* – the patient's general practice, which will be responsible for determining which of their GPs has the most direct involvement in the patient's care. In some cases, there will be no named GP and GP practices will provide care on a rotational basis. The GP who prescribes it is ultimately responsible for ensuring that CANH is in the best interests of the patient. Where the patient is under the care of a secondary care team, however, the decision should be made with support from the relevant secondary care clinician. If the patient is in a nursing or care home with NHS continuing care funding, the general practitioner should be supported by a named individual (usually the case manager) identified by the Clinical Commissioning Group (CCG) or Health Board to

take on this responsibility. In these circumstances, the CCG/Health Board must satisfy itself that the package of care the patient receives is appropriate.

The above is a mixture of what the MCA actually says:

The MCA does not identify a particular individual as having legal responsibility for decision-making,

what would clearly be most convenient for clinicians:

Nevertheless, in practice, this will fall to the individual with overall clinical responsibility for the patient's care, as part of their duty of care to ensure that the care being delivered to the patient is in their best interests.

and what is not actually stated in the MCA, but must be logically true:

The MCA does not identify a particular individual as having legal responsibility for decision-making, **focusing instead on collaborative decision-making.**

As it happens, I think that the historical concept of 'duty of care' no longer exists legally: I cannot see how the situation is not, post-MCA, a 'duty of clinical competence' and a requirement to comply with the MCA.

But – why does the BMA, think that close family and friends, do not have a personal 'duty' to ensure that the clinicians do not do something which is not in their loved-one's best interests? If when the clinicians are not 'the decision-maker' (because an attorney is) the clinicians can still form a view of best interests, why do you believe that even if [incorrectly!] the senior clinician is regarded as 'the decision-maker' (when there is not a suitably-empowered attorney), the family and friends cannot form a view as to best interests – and, if they disagree with the senior clinician, seek a view from the court?

Before the Supreme Court elaboration of the withdrawal of PD9E, back in Aintree Lady Hale had written in paragraph 47:

Third, if the clinical team are unable to reach agreement with the family or others about whether particular treatments will be in the best interests of the patient, they may of course bring the question to court in advance of those treatments being needed.

When I read that, Lady Hale is saying 'if **the best-interests opinions** of BOTH the laypeople and professionals involved ARE IN CONSENSUS' then ...

To me, it is exactly what I wrote in a BMJ piece:

<http://www.bmj.com/content/352/bmj.i222/rr-0>

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).

Between Aintree and the Supreme Court's piece about the withdrawal of PD9E, we had Briggs, and the very clear elaboration by Mr Justice Charles that for a life-sustaining treatment Best Interests is, in effect, now Substituted Judgement (paragraph 62 in 'REASONING'):

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:

- i) the decision maker and so a judge must be wary of giving weight to what he thinks is prudent or what he would want for himself or his family, or what he thinks most people would or should want, and
- 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.

That can be translated away from legalise, into 'if the patient had been capacitous in the situation, and would have refused continued CANH, then CANH should be withdrawn' - **and surely logically it is the family and friends, and not the senior clinician, who are better-equipped to answer that question!**

In situations when a patient has rapidly become a CANH patient, having previously been mentally capable, it is not contentious what 'if the patient had been capacitous' means. It would be trickier – very much trickier – if someone who had been living with severe dementia was then receiving CANH, because the MCA's concept of 'the capacitous mind' is then much more challenging (do we, by the capacitous mind, mean the mind prior to dementia developing, or if dementia reduces 'analytical ability' but also causes a 'personality change' is the concept for a mind with the new personality but normal levels of 'reasoning ability'?). But, in situations such as Briggs, the best-interests decision does effectively become 'if we can work out what he would have decided, then we do that'.

And, that is surely not only the best-interests decision, but it is something which the close family and close friends are equipped to answer, and the clinicians are not equipped to answer – and not only that, but as Mr Justice Hayden has effectively pointed out, 'the family and friends can know the answer, without being able to explain exactly why they know the answer':

<http://www.bailii.org/ew/cases/EWCOP/2014/4.html>

The patient was in a minimally conscious state and the section of real interest is this one:

53. *If ever a court heard a holistic account of a man's character, life, talents and priorities it s this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. 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.** I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.*

How, as someone who knows the patient, can I possibly explain [as opposed to **using within my own considerations**] ‘the many oblique and tangential ways over many years by which I understand this’?

It surely cannot have been the intention of the Supreme Court, to encourage ‘taking to court’ the withdrawal of CANH if everyone close to the patient and the clinical team agree it would be in the patient’s best interests for CANH to be withdrawn, and ‘estranged uncle Bill, who had not seen the patient during the previous 30 years, suddenly turns up and shouts ‘I object!’’. Logically, the court must have been saying ‘facilitate the discussions, equip a group of people comprising those close to the patients and some clinicians with the ability to individually form best-interests decisions which satisfy 4(9), and if everyone within that group agrees about what is in the patient’s best interests do not come to court’.

So – why does the BMA not say that? Why does it assert that ‘the senior clinician makes the best-interests decision’?! Instead of stating what I have written, with ‘the senior clinician has a responsibility to facilitate the discussions of best interests’?

Two Hypothetical Conversations

I invite the reader, to ponder two variations on a similar theme.

We will consider a woman in her fifties, who is not in a relationship (so no partner), childless, who is involved in a road accident and very rapidly is in the situation of being hospitalised and receiving CANH. The woman has two sisters and two brothers, and 'the siblings are all very close'. The situation in both scenarios, is that best interests re continued CANH is being considered.

Scenario 1

There is not a welfare attorney. The named consultant, tells the siblings that a best-interests decision has to be made, and the consultant tells the siblings what your leaflet for family and friends states: *'family and friends have a formal role to play in decision-making by providing information about their loved one to help the medical staff make a judgement about their loved one's best interests.'*

The siblings respond with:

'That is partly true, partly wrong, and overall misleading. The legal situation in our view, is that you, the consultant treating our sister June, and we, all have 'a formal role' within the best-interests process – but we don't consider that we help you to make a judgement about June's best interests, any more than that you help us to make judgements about June's best interests'.

The consultant might object, and there might be a discussion about the pieces of law I have already mentioned earlier in this piece, but where I want us to get to is this:

One of the siblings says to the consultant:

'Well, as you say, there needs to be a best interests decision made here. We are all agreed – if you explain to us the clinical situation, options and prognoses, we will each then tell you what we consider to be in our sister's best interests. If you persist in asserting that you 'make the best-interests decision' as opposed to we are all forming best-interests decisions here, then we are not going to co-operate with you at all – we are going to make a complaint instead. And we are all fascinated to understand, how if we do not co-operate with you, you will form a decision which is based on our sister's individuality, as required by the MCA, when you know nothing about our sister as an individual'.

Scenario 2

The same situation, but one of the siblings is a welfare attorney with authority over life-sustaining treatments, and the attorney turns up at the hospital with the LPA documentation, tracks down the consultant, and says 'Tell me the clinical situation, the options and the prognoses'. Having been told those, the attorney says 'Right – I will discuss the situation with my brothers and sisters, and I'll come back and tell you my best-interests decision'.

In passing, I will point out that I consider the attorney in 2 is not doing anything which technically departs from the MCA, but it isn't exactly 'collaborative'. It also raises a really interesting question in the context of your flow-chart about CANH, which correctly points out that if the clinicians believe an attorney's decision is not in the patient's best interests, the clinicians can apply to the court: the interesting question, is in scenario 2 how do the clinicians form an opinion as to what would be in the patient's best interests?

The above is **NOT** 'collaborative'.

Collaborative, is what I wrote [in the context of CPR] in my piece here:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/283/>

*It is surely logically the case, that **in the absence of an attorney or deputy with authority** over best-interests decision-making conferred by 6(6), after the discussions between the various parties involved in the ongoing care of an already incapacitous person, **there will often be a group of people** – loosely, I'll here write 'a group composed of family and clinicians' - **who can each individually say** 'my decision would be 'whatever' - and I think I can claim to have made that decision in compliance with section 4(9)'*

That situation is only clear, if all of that group believe the same recommendation would be in the patient's best interests: but in such a situation, logically the most 'compelling and legally defensible' thing on the form, which would then be read by someone such as a 999 paramedic, would be along the lines of:

'We the undersigned, have discussed whether it is likely to be in this patient's best-interests for CPR to be attempted, and we hereby sign to confirm that we all believe that DNACPR is in the patient's best interests – we also confirm that to the best of our knowledge, no sufficiently well-informed person has expressed the opinion that attempted CPR would be in the patient's best interests'

SIGNED BY EVERYONE – family and clinicians.

There is for me, a huge difference between saying that when a patient is in hospital it is a requirement that the senior clinician FACILITATES best-interests decision-making, and claiming that the senior clinician MAKES the best-interests decision: stepping over that line, is logically peculiar (because it is obvious that whatever best-interests involves, normal lay people can perform the process) and hugely offensive (it implies either that you distrust family and friends, or else that 'the clinicians make decisions which are non-clinical').

On the limited basis of some Twitter Polls I performed, it seems most people agree with me on the above issues [even if they don't have awareness of the MCA]:

https://twitter.com/MikeStone2_EoL/status/931819196207509504

A mentally-capable adult is 'dying' ['end-of-life' = 'sometime within predicted final year of life'] at home. Who should the family-carers living with their dying loved-one be taking instructions from? Please retweet - an analysis of answers would be 'interesting'.

From the dying patient 92%
From the GP and nurses 2%
From nobody 6%

Total votes cast 60

https://twitter.com/MikeStone2_EoL/status/919195401898680321

An 82 years old man is diagnosed as terminal. He and his 79 years old wife 'invite clinicians to help while he dies'. Does that invitation of itself, imply that if he loses the ability to make his own decisions, he wants the clinicians, and not his wife, to make them?

Yes it does 8%
No it does not 92%

Total votes cast 79

My Conclusion re CANH

What should be happening re CANH, which will inevitably involve patients who are in hospital or a similar environment, should be that group discussions

are facilitated, everyone should attempt to be as open as is possible, and it should be accepted that the discussions will often result in a number of individuals who become sufficiently well-informed as to make and express defensible best-interests decisions. Whereas an attorney can then 'impose a decision' if there is not unanimous agreement, nobody else can do that (so not the senior clinician, not one or more 'normal relatives – without an attorney, a disagreement is a disagreement!). And, more to the point, provided everyone is in agreement, we should not make claims about there having been 'A decision-maker' - we should simply say 'it was discussed, and everyone agreed about what should happen'.

We really should, by now, be in the 21st century:

<http://www.bmj.com/content/352/bmj.i26/rr-5>

The recent ruling by Mr Justice MacDonald (see ref 3) has made it clear that mentally-capable patients make their own decisions, which are not then to be questioned by others, and I have pointed out above that sometimes it is legally clear that a welfare attorney [or, but never for CPR, a court deputy] is the decision maker. The Winspear ruling starts its point 4 with 'Although the precise terms of that conversation are a matter of dispute,' and exactly who said what during Tracey, is very uncertain indeed. The ECTP prototype does mention conversations between clinicians, patients and relatives - but it does not suggest that such records of conversations, should be 'signed off' by 'all sides': the ECTP wants only clinicians to sign. Similarly, the ECTP does not seem to want attorneys and deputies to sign to confirm their decisions - again, it wants the clinicians to do the 'signing off'.

This is both legally dubious - people should sign for whatever they are responsible for, so a clinician signs for a clinical prediction, a welfare attorney signs to 'authenticate' his/her own best-interests decision, etc - and anachronistic. This type of 'clinical control' of 'patient records' reinforces inappropriate distinctions between clinicians and involved laymen, it potentially introduces 'bias', and it definitely does not promote the necessary cooperation and integration between the clinicians, family, friends, and if they are present attorneys and deputies, which decent 'joined-up' care requires.

Once, husbands 'owned their wives' - but no longer: and clinicians do not 'own their patients'. Until patient records contain within them the 'right' signatures (at the very least, the possibility of the right signatures being present: I accept that it might be difficult for patients and family members to sign such documents, but they should definitely not be prohibited from signing them) - signatures based on authority, responsibility and involvement,

and not simply on whoever happens to be 'the senior clinician' - there will in my opinion never be satisfactory integration between the many people who are typically involved in supporting, and caring for, patients.

How the above relates to EoL-at-Home

As I mentioned earlier, my interest is not really in CANH – my interest is more in CPR.

There is a particular issue, which arises from a combination of the attitude the BMA has for CANH best-interests decision-making, when it is transferred to patients who are at home, and it is asserted that 'once involved an attending 999 paramedic [who knows nothing about the patient as an individual] 'makes the best-interests decision about CPR' with the level of information dissemination made possible by modern social media.

This is the problem: if relatives are aware that the attitude of 999 is 'the relatives inform the paramedic, and then the paramedic makes the CPR decision' instead of what I consider we need (which is 'together the relative/s and paramedics/s try to arrive at the best best-interests decision'), then some relatives who feel sure that their collapsed loved-one would not want CPR, might feel unable to involve 999. This is deeply unsatisfactory: a relative can be as certain as it would ever be possible to be, that their loved-one would not want CPR, while being unsure if their loved-one is in cardiopulmonary arrest – perhaps the collapse is due to a stroke, which if untreated would not be fatal but would be life-damaging, and if treated the stroke would be less life-damaging. The problem of 'I need to call 999, to find out if my husband's heart has stopped or not – but I can't risk involving the 999 paramedic who could confirm that, because I can't trust the paramedic to not attempt CPR' is not a happy one to be faced with. Nor is it a happy one for the patient, who might indeed be having a stroke as opposed to a CPA.

Some years ago, a paramedic sent something to me in an e-mail, which I have since used here:

<http://www.bmj.com/content/355/bmj.i5705/rr-15>

'We are a long way from doing this (although I would!!) But at least we are beginning to agree .. Resus in my opinion is just a clinical intervention like any other skill and should not be seen as a mandated right by health care professionals .. After all if we were not called it would not have been done!! The simple answer is to ask why were we called and how can we help!'

About a decade ago, someone (probably a nurse) posted the following during a discussion on Nursing Times [online] – for me, as a relative, the family acted completely correctly here, because you do what your loved-one wants:

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.

OVERALL

Stop 'claiming control' when it clearly is not legally yours to claim, become genuinely collaborative [despite the problems that involves for a hierarchical and records-based NHS <http://www.bmj.com/content/358/bmj.j3257/rr-4>] and genuinely involve 'those close to the patient'. Otherwise, I fear that the future will become increasingly one of confrontation, instead of co-operation, and that is not really the future any of us should be aiming for.

Written by Mike Stone, July 2020

MikeStone2_EoL