

I want to send a letter to the Royal College of General Practitioners: after some consideration, I've decided it will be too tricky as e-mail text. And having decided that I need to present my argument in PDF form, I've decided to publish my argument online, so that anyone who cares to can read my piece and decide if it makes sense or not. But, 'think of' this piece, as if it were an e-mail from me to the RCGP.

## What I want to happen

I would like the RCGP, to lead 'a charge into 2022 and genuine collaboration with family-carers for End-of-Life-at-Home': by changing what it publishes about decision-making during EoL.

Kate Masters became an 'NHS campaigner' at about the same time that I became an NHS campaigner, and a few years ago Kate wrote a truly magnificent BMJ rapid response:

<https://www.bmj.com/content/358/bmj.j3831/rr-10>

Kate said this in her piece:

*In addition, a note to all doctors; if you want patients to be part of the solution to the issues you face (not just this CPR debate) you may have to reach into their (our) world a bit more, rather than expecting us to adapt to yours.*

As patients approach death, it seems to me that increasingly the interactions between patients [and/or family-carers] will take place inside the patient's home – so physically GPs are already visiting 'our world'. What I want, is for the guidance written by the RCGP, to correctly reflect the differences between 'our world' (our homes – with clinicians as invited visitors) and hospitals ('a clinicians' world' – with family and friends as visitors).

So I want the RCGP to publish 'guidance' which correctly reflects some obvious real-world points – such as 'family-carers are present to listen to their dying loved-one much more often than the GP, or district nurses, will be present to listen' - and **which also describes the Mental Capacity Act correctly**. To be frank, since I read the MCA in 2009 and subsequently read how clinicians and clinical bodies describe the MCA, I have been astounded: I still don't know if for some reason many clinicians seem unable to read the Act, or if they can see what the Act states but are unable to accept it. I can

definitely state, that what I often see clinicians writing is **NOT** what the MCA says. I recently wrote a piece about the MCA (**ref 1**), at:

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

In the 2007 edition of the BMA/RCN/RC(UK) 'Joint CPR Guidance' (I don't think the 2007 version can still be found online – searches always seem to go to more recent versions) we were told, in the context of incapacitous patients:

*Clinicians should ensure that those close to the patient, who have no legal authority, understand that their role is to help inform the decision-making process, rather than being the final decision-makers.*

Clinicians would have problems 'ensuring that I understood that' - because it is legally incorrect for England and Wales.

More recently, after the judges changed the rules for the withdrawal of CANH, the RCP and BMA published some guidance 'Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent - Guidance for decision-making in England and Wales'. The CANH guidance, tells us this (on page 23):

### ***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.*

This is also flawed – like the Curate's Egg 'it is good in parts'. The problem resides in these two sentences, which are then followed by legally and logically unsupportable statements/assumptions:

*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.*

The CANH guidance starts with an impressive list of organisations and individuals who were involved in its creation – which, when I read the above, becomes 'a disturbing list'.

The first sentence starts correctly - *The MCA does not identify a particular individual as having legal responsibility for decision making* – and ends with a reasonable statement - *focusing instead on collaborative decision-making*. But the second sentence is flawed: while clinicians are obliged to apply the MCA's best-interests requirements, that is not part of a 'duty of care'. In fact, so far as I can see, what was historically 'a duty of care' expected of clinicians, is now an obsolete concept: now in essence clinicians are required to be clinically-competent (when performing surgery, or whatever, they must be competent) and they must obey the law around 'consent' (which usually means they must apply the MCA).

Perhaps more significantly, this sentence while true is deeply misleading:

*The MCA does not identify a particular individual as having legal responsibility for decision making.*

The MCA **never gives anyone** ‘responsibility’ for best-interests decision-making. It gives Welfare Attorneys and Court Deputies an ‘authority over’ best-interests decisions, and it is clear that attorneys and deputies have accepted an appointment when there is an expectation that they will exercise that authority. But what the MCA actually does is to provide a legal defence to anyone – doctor, family-carer, paramedic, relative, nurse and anyone else – who can defensibly claim to have ‘satisfied’ section 4(9) of the Act

*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.*

without breaching section 6(6)

*6(6) Section 5 does not authorise a person to do an act which conflicts with a decision made, within the scope of his authority and in accordance with this Part, by—*

- (a) a donee of a lasting power of attorney granted by P, or*
- (b) a deputy appointed for P by the court.*

*6(7) But nothing in subsection (6) stops a person—*

- (a) providing life-sustaining treatment, or*
- (b) doing any act which he reasonably believes to be necessary to prevent a serious deterioration in P’s condition,*

*while a decision as respects any relevant issue is sought from the court.*

The ‘authority’ of an attorney or deputy, stems from the fact that once such a person has expressed a decision which is within the scope of their authority, section 6(6) [and 6(7)] then applies. In reference 1 I show some tweets by Kate Masters (page 3 of ref 1):

Often, as Kate Masters @katemasters67 has pointed out in tweets on 22 September 2021, relatives will not understand the legal situation while they are in discussion with clinicians:

*The playing field is much more even when the spread of knowledge is more even.*

*When [a] relative was in ICU sedated I found myself in the conversations I'd had about mum. [but] This time I knew what should happen. They [the clinicians] were shocked when I asked for a BI [MCA Best Interests] meeting with legal rep. It never got that far and we worked quite well together after that.*

Jumping ahead somewhat – to my ‘conclusion’ - I would like the RCGP to move not only ‘into our world’ but also into 2022. We are not living in 1942 – because of the internet and social media, patients, relatives and friends can now find and read the material written by clinicians: then, we can decide if it seems ‘right’. Cox and Fritz have recently published a piece in the BMJ ‘Presenting complaint: use of language that disempowers patients’ in which they ‘argue that outdated medical language that casts doubt, belittles, or blames patients jeopardises the therapeutic relationship and is overdue for change’ (BMJ 2022;377:e066720 <http://dx.doi.org/10.1136/bmj-2021-066720> Published: 27 April 2022).

I think Cox and Fritz are arguing that often the issue around the language being used to describe patients is ‘inadvertent’. But, what I read about the situation of family-carers in the context of best-interests decision-making is both **deliberate** and also ‘disempowering’: at least, it is disempowering of family-carers if we believe it. But **we should not believe it** – what we are being ‘told’ is simply not a correct description of the MCA.

There are ‘mysteries’ within the MCA – most obviously, how we get from what we need to consider when making a best-interests determination, to the actual ‘decision’ itself. But there is nothing unclear, about the implications of section 6(6): almost any relative might [conceptually] be appointed as a welfare attorney, and it is obvious that ‘the Act assumes that attorneys can make satisfactory/competent best-interests decisions’ - so, it is obvious ‘that ‘the woman off the street’, if familiar with the MCA and if equipped with an understanding of the things described by section 4(6), can arrive at a perfectly satisfactory best-interests ‘conclusion’. If your best-interests ‘decision’ (see the bottom of page 4 in ref 1) is compliant with section 4, then if you act on it you can claim the protections of section 5. That is true whoever you are. **What you cannot do**, is to ‘impose your best-interests decision on other people’.

The problem with this, from those 2007 CPR guidelines - *Clinicians should ensure that those close to the patient, who have no legal authority, understand that their role is to help inform the decision-making process, rather than being the final decision-makers.* - is obvious: nobody, is 'the final decision-maker' for best interests according to the MCA. Attorneys and deputies are very close to being 'the final decision-maker' - see sections 6(6) and 6(7) on page 4, or see section 7.29 of the original version of the MCA Code of Practice:

**7.29** *Attorneys must always follow the Act's principles and make decisions in the donor's best interests. If healthcare staff disagree with the attorney's assessment of best interests, they should discuss the case with other medical experts and/or get a formal second opinion. Then they should discuss the matter further with the attorney. If they cannot settle the disagreement, they can apply to the Court of Protection (see paragraphs 7.45–7.49 below). While the court is coming to a decision, healthcare staff can give life-sustaining treatment to prolong the donor's life or stop their condition getting worse.*

So what the BMA/RCN/RC(UK) wrote was deeply misleading:

*Clinicians should ensure that those close to the patient, who have no legal authority, understand that their role is to help inform the decision-making process, rather than being the final decision-makers*

Neither those close to the patient [unless they are welfare attorneys with authority over CPR – court deputies cannot be given authority over CPR] nor clinicians 'have legal authority', and the idea of 'final decision-makers' is an unhelpful one.

## Why, How and If

When I was discussing a JME paper which I wrote with a Paramedic, a Doctor and a Barrister – see the link (**ref 2**):

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>

- I commented that in situations similar to the scenario in our paper, the paramedic often would be the person making an MCA best-interests decision. Alex Ruck-Keene, the barrister, misunderstood the point I was making. Alex thought I was agreeing that the 999 paramedic was in some sort of privileged

position in the context of best-interests decision-making because of the paramedic's clinical status. What I was actually saying, is that to claim to have made a best-interests decision (technically a best-interests 'determination') and to have satisfied section 4(9), you must claim to have an adequate understanding of the MCA: as most relatives will not be familiar with the MCA, while clinicians are expected to be familiar with it, only the paramedic would be able to 'reasonably believe' to have satisfied section 4(9):

*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.*

However – many of us, are trying to explain the MCA to patients and relatives. **And if increasing numbers of laymen understand the MCA then I cannot see how what clinicians and their organisations currently write, can survive challenge.**

GP to Family-Carer: 'I am responsible for any necessary best-interests decisions – such as a best-interests decision about CPR'.

Family-Carer to GP: 'Why do you think that? Which part of the MCA gives you some sort of authority over me in the best-interests context? And, how can you impose your decision onto me, if I'm here when my dad arrests and you are not here?'.

The relative could also analyse the claim made in the RCP/BMA CANH guidance (see page 2) that the GP has responsibility for CPR decision-making, especially if the GP is in area which uses the ReSPECT form – that form assumes the reader of the form 'has decision-making responsibility'.

As it happens, while the legal principles of CANH withdrawal on best interests grounds are identical to those for the withholding of potentially-successful CPR, the CANH guidance does point to a significant difference – when it says '*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.*'.

I have recently commented on some ACP guidance (**ref 3**):

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Comments-on-some-NHS-Advance-Care-Planning-Guidance-about-the-principles-of-ACP/1120/>



One of the points I make in the piece, is that CPR is different from most treatments and it needs to be considered separately (I have added reds here):

When a patient has thought about 'ACP' and is talking to 'relevant professionals' (usually doctors and nurses in the context of healthcare) the patient will want to know which treatments would be offered. Then the patient might express a view on those interventions – would she want them, would she refuse them, is she uncertain and therefore doesn't want to 'plan ahead' beyond saying 'I would want to decide at the time'. Many of these 'future options' which would be available to a capacitous patient (or would be considered during best-interests decision making) are delivered ONLY BY doctors and nurses: surgery, skilled nursing-care, etc. That is NOT TRUE for CPR – CPR is taught as first-aid, so many friends, relatives and family-carers can attempt CPR. A person could have discussed the future with his family, and indicated that he would always want CPR to be attempted: a relative could agree to always attempt CPR, and/or to always phone 999 and try to get paramedics to attempt CPR. So, a 'patient' and a family-carer capable of performing CPR, could 'agree the outcomes of their advance care planning conversation through a shared decision making process' WITHOUT ANY PROFESSIONALS BEING INVOLVED. It is worth pointing out, that DNACPR is not 'a treatment' – DNACPR is the withholding of a treatment: as such, a relative who could not perform CPR, could 'agree an outcome' with the person (who I often describe as 'the loved-one') of 'trying to prevent CPR from being attempted' if the person made it clear 'I would NEVER want CPR if my heart had stopped beating'.

The relative talking to the GP, could also ask if the GP believed that decision-making should involve up-to-date information – inevitably the GP must say 'Yes' so the family-carer can then say 'I might have been there to listen more recently than you were, which means I'm more up-to-date than you, doesn't it'.

**This is NOT a good situation: we need everyone, whether clinicians or family-carers, relatives, friends, to be WORKING TOGETHER to try and help the dying person.**

A paramedic commented to me in an e-mail (my added reds) "*Unless the paramedic has reason to consider that what the person on the scene is telling them is 'off' in some way then they should proceed on the basis that they are reliable in relaying what the person would have wanted; our starting point*



*should be belief – if we start at any other point we would fail throughout all of this*’ (although the word I use is usually ‘trust’ as opposed to belief).

## What ‘We’ could do instead – a proposal

We need to keep the bits which do not offend informed-laymen, and adopt an attitude of greater trust, less insistence on **unreasonable** certainty, and have genuinely collaborative decision-making. As we said at the end of the JME paper ‘The guidance and the training should emphasise the teamwork which Mike Stone mentions above: the default assumption should be that clinicians and relatives have a shared goal of what is best for the patient, and work together as ‘us and us’ as opposed to ‘us and them’.’.

We should be attempting to arrive at and implement ‘the ‘best-achievable’ best-interests decision’ and we should be encouraging behaviour which helps with that objective: and setting clinicians against relatives, does NOT help. If relatives do become ‘MCA aware’ then they will know that ‘what dad would have wanted to happen’ is fundamental to best-interests determinations – and it will then surely seem both illogical and deeply-offensive if clinicians say what amounts to ‘... we understand what is in your dad’s best interests, better than you’. Assuming a mother were incapacitous, and three adult children and a GP were discussing best interests, personally I think it is usually quite ‘generous’ of the relatives to accept that the GP’s view of ‘mum’s best interests’ is on-a-par-with their views. And it becomes absurd, to assert that a suddenly-introduced 999 Paramedic, who has never met or talked to a patient, could form as informed a view as to best interests as the relatives could. I could imagine that if I were one of several siblings discussing ‘would dad want CPR?’ that it would be ‘fraught’ if there was disagreement – but, I would accept that it was ‘informed disagreement’. If a paramedic suddenly said ‘I know what is your dad’s best interests’ then I think all of the siblings would turn on the paramedic with ‘How on earth do you know what is in dad’s best interests – you don’t know dad!!!’. As an aside, I have analysed this situation:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-reconciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./1031/>

It also seems unacceptable – at least to me, and I suspect to welfare attorneys, court deputies and probably many family-carers and relatives – that documentation such as the ReSPECT form stubbornly excludes the signatures of non-clinicians. I am really not happy, with ReSPECT:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-issue-with-ReSPECT-which-I-will-be-pointing-out-to-the-Public-Guardian/960/>

I am much happier, with the way that Wales is seeking to improve end-of-life. A recent BMJ SPC blog piece

<https://blogs.bmj.com/spcare/2022/07/14/electronicafcp/>

includes this:

*The development of an electronic Advance and Future Care Planning application (AFCP) is widely recognised as a priority for end of life palliative care in Wales. There are two fundamental goals in AFCP:*

- 1. Everyone approaching the end of their life should be given the opportunity to discuss their wishes about future care.*
- 2. Anyone who expresses wishes should have those wishes respected (where feasible).*

I fully support the above – and ‘respecting what my dad told me he wanted to happen’ is in my view what relatives and family-carers should be doing. And I don’t mean ‘assuming things have found their way into dad’s medical notes’ - I mean ‘as soon as dad has told me, then I know – and once I know, then I should respect what dad wanted’.

We need to recognise (see ref 3) that family-carers are involved, do have ‘agency’ and can be faced with decisions to make – and, which **only they can** make because only the family-carer is present to make it. So GPs need to be clear, in telling the BMA, GMC, etc ‘we cannot ‘be responsible for the decisions which family-carers make’ - we can’t control family-carers, we can only try to work together with family-carers’.

It simply isn't true that a GP has some sort of authority over family-carers – although so far as I can see, whereas I have explained this

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/DNACPR-at-Home-and-a-Twitter-thread-what-is-the-legal-situation-for-relatives/1110/>

it is almost never to be found in clinically-authored 'guidance for' relatives.

Reference 1 contains, on its pages 48/49, e-mails between a lawyer and me on the subject of the witness signatures on Advance Decisions. What the lawyer wrote is true – and it points at the issues with whether clinicians trust relatives – but the lawyer doesn't 'instinctively' think like a family carer. It is correct, when the lawyer writes *'So, my view is that you can always stick to the letter of the law and have anyone you want (because the Act says so) but that you should be aware that if you do then you are potentially opening the way to a problem later, at a point where (by definition) you won't be in a position to do anything about it.'* But, as I point out in reference 1:

*I think, if time allows (and sometimes it wouldn't – in my Father and Son scenario\*, even if they knew about ADRTs and the father wanted to create one, who except the son could witness it: are you expected to 'drag a witness in off the street' at 9pm of an evening?!), it would be useful to add subsequent 'witness' signatures to ADRTs anyway. If created by a patient who asked a relative or friend to initially witness it, subsequently as events allowed to add the signature of a GP or District Nurse – and, if an ADRT were created in hospital and witnessed by a clinician, as events allowed the signatures of family-carers could be added.*

\* 'Father and Son' is already sub-referenced, but it can be found directly at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/298/>

I've been trying to resist the temptation to include lengthy extracts from my pieces in this PDF, but I will insert what I wrote in reference 1 following-on from the above, because it is a description of the possible future if clinicians do not properly accept the situation of family-carers:

Unless ‘informed family-carers’ can feel confident that ‘the NHS will believe them’, I don’t think those family-carers can confidently phone 999 with an expectation that decision-making will correctly combine their ‘expert understanding of the patient, and likely-situation ‘of being the most-recent listener [to the patient]’ and the clinical expertise of attending 999 paramedics. Relatives cannot be confident, of the answer to what I wrote on page 42:

*The problem, is in the ‘give and take’ - are clinicians and NHS protocol-writers, willing to move far enough in the direction of trusting relatives and family-carers, such that [to use my phrase here] informed-relatives can trust 999 paramedics?*

*Can the NHS, come to terms with the ‘fuzzy knowledge and disseminated decision-making’ that an undistorted application of the MCA, situational reality and logic, leads to?*

I myself, will not believe this change has happened, until I see different signatures on things such as the ReSPECT form – see ref 26 on page 43. In particular, I will only believe this change has happened when ‘*signatures based on authority, responsibility and involvement, and not simply on whoever happens to be ‘the senior clinician’*’ can be observed on ‘the NHS’s documents’. I admit, this introduces complexity around ‘ownership of’ such a form (different sections of the form, would be ‘owned by’ different individuals – but surely that is a consequence of a genuinely collaborative approach?).

Documents should stress ‘who has been involved, to what degree have individuals been involved, who has been in ongoing conversation with who, etc’ **much more than** ‘who is the senior clinician’. And, partly as there is ‘history of’ clinicians being quite poor at the ‘talking to family and friends’ aspect, we certainly should not have records/descriptions of such conversations being recorded and signed-off by only the clinicians: both parties to a conversation should have the opportunity to read and ‘sign-off’ a record of a conversation, whoever wrote the record.

And it is always ‘unreasonable’ to expect anyone to prove the unprovable: no paramedic should ever expect a family-carer, standing next to a now-collapsed loved-one, to ‘prove’ that a conversation had taken place a few hours previously if the family-carer says it took place.

I think, I have now arrived at my ‘destination’ for this piece – I hope I have pointed out why the current clinically-authored material about the ‘role of’ relatives, and especially of family-carers during EoL-at-Home, will become

unsustainable if [as I fervently hope] relatives and family-carers become 'MCA aware'. And that if the RCGP wants the best outcomes for patients, and less stress for both GPs and family-carers, the RCGP must change its 'guidance' in the direction I have indicated. But before I end this piece, I will return to the issue of does section 4(9) really mean what it says. So I will show an e-mail exchange with a lawyer who specialises in the MCA.

Me to the lawyer:

*In reality, I am not very bothered about how judges view the Act. My main issue, is an acceptance that family carers who claim to have complied with 4(9) can then claim identical s5 legal protections as a clinician who claims to have complied with 4(9).*

The lawyer to me:

*Yes, family members can certainly claim to be able to benefit from the s.5 defence (with s.4(9) as the underpinning) if they have carried out an act in connection with care or treatment in relation to the person.*

Written by Mike Stone

@MikeStone2\_EoL

July 2022

## REFERENCES

- 1) <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-think-we-need-a-different-way-of-explaining-and-teaching-the-Mental-Capacity-Act-MCA/1114/>
- 2) <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>
- 3) <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Comments-on-some-NHS-Advance-Care-Planning-Guidance-about-the-principles-of-ACP/1120/>