

## Some feedback to the Care Quality Commission and to a Ministerial Oversight Group about DNACPR Decisions

Forenote: I will be e-mailing this to the Ministerial group and to those of its members for whom I can find e-mail addresses, but I want to also point members whose Twitter/X addresses I can find at it – so I've decided to post this piece online.

A couple of months ago, I became aware of various bits of 'work' which were about Do Not Attempt Cardiopulmonary Resuscitation (CPR) and it took me a while (I should have realised this more quickly) to realise that this work/research stems from a Care Quality Commission (CQC) recommendation, and the implementation of that recommendation. See the CQC webpage at:

<https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19>

As it happens, although I have some considered views about EoL/MCA/CPR (End of Life/Mental Capacity Act/Cardiopulmonary Resuscitation) because I have been thinking and writing about those things for over a decade, there isn't [so far as I'm aware] any formal invitation or mechanism by which I could contribute feedback to this process. The PHSO recently held an online survey for doctors, which was open to all doctors who cared to complete the survey (at least one of the questions in the survey, was very dodgy if you viewed it 'with an MCA eye'). But the PHSO did not post online an open-to-all survey for carers: it has instead commissioned some work by third-party organisations, and in essence these seem to involve interviews or focus groups of/with carers who are already known to the organisations. I'm also unaware, of any work to establish the views of nurses and 999 paramedics around CPR.

However, I have never been shy of providing unsolicited feedback: and, as it happens I sent a few comments to the CQC early in 2021, and I received a reply from Dr Benneyworth, on behalf of the CQC, dated 28 April 2021. What Dr Benneyworth said in her reply to me was:

Dear Mr Stone,

Thank you for your email of 3 April 2021 in response to our publication 'Protect, connect, respect - decisions about living and dying well during Covid 19', and also for sharing your publications. As those publications and our report set out, this is complex area.

You will have noted from our report that the review and recommendations were shaped by a range of stakeholders. All of whom reflected to us the importance of an ongoing and well timed compassionate conversation with people, their families or representatives, as to their wishes at the end of their life. Including what they would like to happen in the event their heart stops beating and there is a CPR decision to be made. Our intention was not to promote one approach over another, ReSPECT was cited as one example, amongst other approaches.

What was evident in our review was the need to ensure that people are treated as individuals, are able to make their own decisions where able and are supported sensitively by well trained professionals in the application of DNAR decisions. We identified the need to ensure consistency to enable people, families and workers to share an understanding of positive experiences, and to enable oversight.

I hope this helps with your queries about our report, and may I take the opportunity to thank you once again for reaching out to share your thoughts and links to publications. Yours sincerely,

**Dr Rosie Benneyworth BM BS BMedSci MRCP**  
**Chief Inspector of Primary Medical Services and Integrated Care**

Since that correspondence with the CQC, the CQC has published its final report, and I have been publishing various pieces about DNACPR and Advance Care Planning (ACP). I have decided to provide URLs to some of my pieces at the end of this piece, rather than inserting those URLs within the text.

I think, the way to improve discussions between clinicians and patients or relatives about DNACPR, is to pose three questions – the

patient/relative should be enabled, by virtue of a satisfactory conversation, to understand the answers to these three questions:

- 1) Why are they (the clinicians) talking to us?
- 2) Are they talking to us enough?
- 3) Are they saying the right things?

Actually, if a patient or relative can answer question 1, the relative can also answer questions 2 and 3 – and the answer to question 1 requires an understanding of the law around CPR/DNACPR decision making. Importantly, I believe patients and relatives should be aware of the legal justification for any ‘DNACPR’: in principle there are four justifications, in practice one of those is never used (the justification that the likely aftercare costs of CPR would be so high as to be unfair on other NHS users), so we are left with three:

The patient, while capacitous, is understood to have refused CPR for the situation of the arrest;

There has been a properly-performed MCA best-interests determination, which arrived at ‘DNACPR is in the patient’s best interests’;

If it is certain that attempted CPR could not restart the heart and breathing (and it is ‘not’ - ‘almost certainly wouldn’t’ is arguably insufficient to move away from MCA best interests to this justification) then there is no obligation to offer CPR.

There is a paper by Tomkow et al

<https://academic.oup.com/ageing/article/52/6/afad087/7190220>

which as I understand it is feeding into this work.

Uncritically – and clearly incorrectly [under English and Welsh law] if you ponder what is written above – the paper states ‘Relatives’ role in DNACPR decision-making was a frequent source of misunderstanding. Despite DNACPR being a medical decision, ...’ on its page 4. There is a definite lack of differentiation between decisions based on ‘CPR couldn’t work’ and MCA best-interests determinations in this paper, and I think the crux of it is revealed by the question ‘no 36’ posed:

Several participants described their frustration at feeling they were asked to be involved in decision-making about DNACPR, and then their wishes were overruled (also on page 4):

*‘I explained that I couldn’t overrule my mother’s wishes, and the doctor said . . . ‘we can . . . it’s a clinical decision really’. . . . well why have we had all these phone calls? Why are we here today talking . . . why are you talking to us about it if it’s a clinical decision?’ Participant 36*

**INDEED: why are you talking to us?** This phrase or statement ‘DNACPR is a medical decision’ is utter twaddle, and the first thing to do to improve discussions between clinicians and relatives would be to extirpate that statement from conversations and guidance.

A friend of mine posted a year or two ago on Twitter, about a time when a relative had been in hospital, and the family were not happy with how the clinical team were interacting with them. My friend told the clinical team ‘The family want a Best Interests Meeting’. This had a dramatic and useful effect – from then onwards, the clinicians engaged with the family more cooperatively and more sensibly, and everything went more smoothly, with the result that it turned out that no formal best-interests meetings ever took place. **BUT – that seemed to have happened only because my friend ‘is MCA aware’: it should happen as a matter of course, for ALL relatives.**

A barrister told me that the foundation of the MCA wasn’t, as widely believed, ‘autonomy’ - he said the foundation of the MCA is its legal protections for professionals. I replied by saying that if it wasn’t founded

on patient autonomy and individuality, then it wouldn't have had provision for Advance Decisions and Welfare Attorneys.

But, the barrister has a point: we do, when considering DNACPR, need to consider the legal consequences of actions and inactions. If by 'do' we include both action and inaction, then we could write:

*Clinicians will not do something, if doing it would incur legal or professional liability,*

and

*Family-carers are free to do something, if doing it could not incur legal liability.*

The barrister, of course, tends to think of the MCA in terms of how it would affect a court case. Whereas as a former family-carer during EoL-at-Home, I think of the MCA as something which should guide everyone's behaviour during EoL, with a strong objective of avoiding anything going to court if at all possible: it would be bonkers, to have EoL routinely going to court.

I'm reading a lot about 'consensus' in the context of EoL/MCA/CPR at the moment. And if a consensus can be achieved, then that is great – a consensus reassures everyone involved, and also reduces the stress arising from difficult decision-making. **But ultimately, a family-carer can stand apart from the consensus of the herd, because '*Family-carers are free to do something, if doing it could not incur legal liability*'.** Interestingly, the situation is trickier for clinicians, because of the consequences of MCA section 42: the consequences of MCA s42 are horrendously complex in reality, and I'm not going to explore that here. Suffice it to say, that 'the literature' tends to explore the legal situation of clinicians much more often than it explores the legal situation of relatives – and, clinically-authored material frequently incorrectly describes the legal situation of family-carers and relatives (in fact, some clinically-authored material also incorrectly describes the legal situation of clinicians).

The BMA, RCN and RC(UK) jointly publish some guidance about CPR decision making:

<https://www.bma.org.uk/media/1816/bma-decisions-relating-to-cpr-2016.pdf>

In the 'Main messages' section we can read:

7. For a person in whom CPR may be successful, when a decision about future CPR is being considered there must be a presumption in favour of involvement of the person in the decision-making process. If she or he lacks capacity those close to them must be involved in discussions to explore the person's wishes, feelings, beliefs and values in order to reach a 'best interests' decision. It is important to ensure that they understand that (in the absence of an applicable power of attorney or court-appointed deputy or guardian) they are not the final decision-makers, but they have an important role in helping the healthcare team to make a decision that is in the patient's best interests.

That is misleading, or perhaps simply wrong, for several reasons. If the patient is capacitous, the patient can decide – so 'involved in' is potentially misleading. And, 'those close to the patient' during incapacity, cannot impose their own position about best interests onto the healthcare team – but that doesn't necessarily mean that the family and friends cannot FORM best-interests positions, and there isn't 'a final decision' in this situation (unless the decision has been made by a Judge, we should probably steer clear of the phrase 'final decision' - only when CPR has actually been attempted or withheld during an arrest, can we talk of a 'final' decision having been made). Being really 'MCA nerdy', it turns out that the healthcare team are not making best-interests decisions – they are only making best-interests determinations (only judges, welfare attorneys and court deputies can make best-interests decisions).

Also in 'Main messages' we can, correctly, find:

8. If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable advance decision to refuse treatment (ADRT), specifically refusing CPR, this must be respected.

It seems to me, that if a hospital patient spends 15 minutes explaining to a hospital consultant doctor that the patient is refusing CPR, and the patient then arrests before the doctor has walked away from the bedside, the doctor must not attempt CPR. Similarly, if my dad has made it clear to me that he is refusing CPR, and he arrests before this information has been passed on to the GP and thus 'entered the notes', I should not attempt or in any way promote CPR. I will point out: if at 11pm on a quiet hospital ward a patient makes it crystal clear to a lone hospital nurse that he is refusing CPR, and as the nurse turns to walk away the patient arrests, I am far from confident that the nurse would respect the patient's refusal – I think many nurses would attempt CPR in that situation.

Having spent years failing to persuade ReSPECT to allow the signatures of patients, welfare attorneys, court deputies and even relatives and friends on its main form, it is interesting that ReSPECT is sponsored by the RC(UK), and in section 10.2 of the Joint Guidance we can read (my italics):

It is important to understand that a personal welfare attorney is not empowered to make decisions on behalf of a patient regarding whether or not CPR will be attempted, unless their power of attorney document states specifically that the personal welfare attorney has the power to consent to or refuse life-sustaining treatment (which would include CPR). *It is likely (although this has not been tested by the courts) that in such a case the attorney can make an advance decision that CPR should not be attempted.* Such a decision should be recorded on the CPR decision form or equivalent. *If the welfare attorney makes that decision, it is a binding decision that clinicians must respect, unless:*

- the circumstances of a cardiorespiratory arrest are not those envisaged when the advance decision about CPR was discussed with and made by the welfare attorney, or

- the clinician has good reason to believe that the decision made by the welfare attorney was not made on the basis of the patient's best interests.

The wording is dodgy – the MCA is clear about 'Advance Decision' and it uses that terminology in sections 24-26 – but the idea is sound: the patient wanted the attorney to make the best-interests decisions. And, **it really is** 'a decision' we are talking about here: it isn't 'a recommendation'. So, the attorney's 'advance DNACPR decision' cannot be recorded on a ReSPECT form, and logically it should be recorded on **the attorney's form**. The attorney should sign such a form – the doctors or other clinicians could 'witness' it, but think of a Will: the testator signs a Will, and other people witness it.

I will mention section 4(7) of the MCA at this point. There seems to be confusion about what section 4(7) is stating – although, it is tricky because it seems that *strictly* attorneys only have a moral obligation to make and express best-interests decisions. This is section 4(7):

*(7) He must take into account, if it is practicable and appropriate to consult them, the views of—*

*(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,*

*(b) anyone engaged in caring for the person or interested in his welfare,*

*(c) any donee of a lasting power of attorney granted by the person, and*

*(d) any deputy appointed for the person by the court,*

*as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).*

We can read at the start of MCA section 4:



*(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—*

I get the impression, from many of the things I read, that doctors think section 4(7) says 'the doctor must consult a welfare attorney'. If the attorney possesses MCA s6(6) authority over CPR, then as soon as the attorney has indicated 'I'll make and express a decision about CPR', very obviously the attorney is from that point onwards consulting the doctor. After all, it is absurd to say 'you must consult yourself'. If the attorney doesn't have authority over CPR, then the doctor [or anyone else who wishes to claim to have satisfied s4(9)] would need to consult the attorney. Although, I don't think the word 'consult' is helpful if there isn't an attorney whose authority extends over CPR – in that situation, I think the concept of DISCUSSION is much more useful than the concept of CONSULTATION.

It is interesting, although this seems to be a sort of breach-of-moral-obligation on the part of the patient's attorney, if the attorney tells a doctor 'I don't think I'm going to express a decision about CPR'. We could have a room full of relatives, this 'reluctant attorney' and a doctor, discussing whether attempted CPR or DNACPR would be in the patient's best interests. The doctor might – most current guidance would lead the doctor to think this – consider that she is 'consulting' the other people in the room. I think the conversation, if properly performed, would allow legally-aware family and friends to also arrive at best-interests determinations – so I think there is not 'a consultation' but rather 'a discussion' happening in that room. And, if at the end of the discussion the attorney decides to make and express a best-interests decision about CPR/DNACPR, then 'who if anyone, had been consulting whom?'.

In fact, my 'reluctant attorney' might have a valid reason for initially stating 'I don't think I'm going to make and express a decision'. The nature of the conversations, is I feel likely to be different if everyone believes the attorney will be making the decision. If the attorney 'withdraws' then a more complete thrashing out of what everyone believes would be in the patient's best interests might happen –

something the attorney would want to consider before making a decision.

The other thing about 4(7), is in a situation when a welfare attorney has made it clear that 'I'm consulting people, to make a decision about CPR', where does the doctor appear in sections (a) to (d)? The answer, is in section (b). If a doctor claims to be making a best-interests determination, where do relatives appear? Again – in section (b). The MCA is much more symmetrical, in fact, about the legal situations of doctors and normal family-carers than we are usually told: when I read it, it looks as if the 'rules' for doctors and normal family-carers (i.e. family-carers who are not also welfare attorneys) are in essence identical – it is 'more-junior clinicians within a clinical team' whose situation is different [because of the consequences of section 42]. If we read what clinicians and clinical bodies write about best interests, it looks as if there is a pyramid with doctors at the top, then nurses lower down and with relatives and family-carers at the bottom. But if we simply read the MCA itself (the Act), that pyramid is split into two halves: one half of the pyramid has got doctors at the top and nurses lower down, and the other half has got family-carers and relatives at its top, at the same level as the doctors.

The CQC interim report, November 2020, started its page 4 with:

### ***What is a DNACPR decision?***

*A DNACPR decision is an instruction not to attempt cardiopulmonary resuscitation.*

That immediately rules out – despite the fact that some Trusts seem set on replacing 'DNACPR forms' with the ReSPECT form – the ReSPECT form as 'a DNACPR decision': the ReSPECT form is explicitly a **recommendation**, whereas a 'DNACPR form' should be an instruction.

As it happens, it isn't really possible to have an anticipatory document which is 'a DNACPR instruction'. The thing which is almost an instruction, is a written ADRT refusing CPR. But there is 'wriggle room'

provided by section 25(4)(c), and in practice even an ADRT will not be successful as an instruction to not attempt CPR in the community.

Further down on page 4 (and after we have read the exemplary '*A best interests decision about CPR is unique to each person and is to be guided by the quality of future life that the person themselves would regard as acceptable.*') we can read:

*Only the most senior clinician responsible for a person's care (this could be a consultant, GP or suitably experienced and competent nurse) can make a DNACPR decision.*

That, of course, is incorrect.

Further down the page, we can read:

*A person can state that they do not want CPR to be attempted, as part of their advance care planning. This will be taken into consideration by the clinicians who are making decisions about treatment (see Footnote).*

*Footnote: If a person wants to specify what treatment they do not want and for it to be legally binding, they should complete something called an 'advance decision refusing treatment'.*

That is dodgy as well: only **after** the reader of an ADRT has decided it is **applicable**, does it become 'legally binding' (only an idiot, would say 'I considered the ADRT refusing CPR was valid and applicable – and I attempted CPR despite that') – and, I point the reader back at the 'Main messages' section of the Joint CPR Guidance with its 'If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable advance decision to refuse treatment (ADRT), specifically refusing CPR, this must be respected.'

I will now address something I am deeply-vexed by – the recent determination to put CPR/DNACPR on the same documents as other

treatments. The paper by Tomkow et al, suggested that there was something anomalous about the Tracey and Winspear rulings, because we now have a situation when if the clinicians do not intend to offer CPR on the grounds of clinical ineffectiveness, they must still inform patients or relatives of this. The argument being ‘when other treatments couldn’t work, clinicians are not required to tell patients that those treatments are not on offer’. What Tomkow et al seem to have missed, is that CPR is different from other interventions:

CPR is ‘offered by default’ and many patients will be aware of that – so if at some point the clinicians decide ‘CPR could no longer work’ then patients and relatives need to be told that CPR is no longer being offered;

Many family-carers could perform CPR – whereas we can’t attempt emergency brain surgery, or provide an emergency blood transfusion, etc;

The clinical outcomes of attempted CPR are so uncertain, that almost always no useful information, beyond that which a patient or relative had already understood before an arrest, could be provided by a clinician at the time of an arrest (as that interim CQC report points out: *CPR is an invasive and traumatic medical intervention and most CPR is unsuccessful. In most hospitals the average proportion of people who survive is about 15 to 20%; out of hospital the survival rate is lower, around 5 to 10%. Due to the nature of the treatment, in some circumstances CPR can do more harm than good. In some cases, CPR can cause injuries such as punctured lungs, broken ribs and bruising.*)

I consider the main ReSPECT form to be deeply-flawed, especially from the perspective of family-carers during End-of-Life-at-Home and Welfare Attorneys (‘LPAs’), and to me it is unhelpful to ‘mingle’ CPR and other interventions on the same form – which would be true, even if there were no other issues with the ReSPECT form (and there are many other issues!). I’ll return to the ReSPECT form later, when I present a bit of analysis of ‘DNACPR forms’. Here, I’ll just address the recording of DNACPR on the same document as ‘wanted interventions’.

One of the justifications for putting DNACPR and ‘interventions the patient would want’ on the same form, seems to be that hospital nurses have asked for that: the suggestion being that ‘if a patient has a DNACPR, the patient tends to also not get the appropriate level of support in the context of other interventions’. That might be true, in the hospital environment, and in the context of nurses – but it isn’t, in my opinion, true as a wider point.

Over about a decade, I’ve discussed EoL/MCA/CPR with a variety of people, including the Palliative Care Doctors Bee Wee, Mark Taubert, Kathryn Mannix and Ilora Finlay – and NONE OF THOSE has ever suggested that the presence of a DNACPR decision should impede the provision of other interventions. As a former family-carer, I can’t see that during EoL-at-Home the knowledge that your loved-one doesn’t want CPR, would stop you from pressing the GP and district nurses to provide interventions which you know your loved-one does want.

So, it seems to me that this ‘put CPR and wanted treatments on a single form’ reflects something specific about nurses and perhaps ‘the hospital environment’ – and I would suggest that those things need to be addressed, rather than creating documentation which implies that ‘CPR is just an intervention, like all other interventions’ when it clearly isn’t: CPR is fundamentally different from almost all other interventions.

One factor which might be relevant, from the ‘perspective of’ hospital nurses, is the reason for a DNACPR or an ADRT refusing CPR. Clinicians always seem to think more of ‘CPR could not succeed’ whereas I tend to think of ‘the patient is refusing CPR’. So very often, an in-hospital patient with a DNACPR will be very frail and probably close-to-death. Whereas, it would make pretty-good logical [if ‘unemotional’] sense for almost everyone to forbid CPR if they arrested while out-and-about (shopping, out for a country walk, fishing on a quiet river, etc), HOWEVER HEALTHY YOU ARE – ‘accepting bystander CPR’ is particularly ‘optimistic’, within a spectrum of essentially rather poor outcomes of attempted CPR (it is almost always ‘optimistic’ to accept CPR). This might lead hospital clinicians, especially busy nurses, to conflate ‘DNACPR in place’ with ‘this patient ‘is dying’’. But as I’ve said: hospice doctors know that their patients are dying, and they don’t

conflate 'DNACPR' with 'so [automatically] fewer other interventions as well'. Hospice doctors think-it-all-through-properly and therefore behave correctly – and I suspect that family-carers during EoL-at-Home also will not make any simplistic and inappropriate link between a DNACPR and the non-consideration/provision of other interventions.

It is now appropriate for me to point at some of my online pieces. I will include publication dates, and a description of the themes of the pieces, but I will not reproduce in any depth what you can read by following the URLs.

I have written a recent piece, which suggests a fundamentally different approach to 'CPR documents'. In essence, I argue that the only thing which should be recorded on a document, is what individuals would do if the patient arrested at the time the document was being completed.

Published 12/07/23 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-a-proposal-for-a-different-type-of-DNACPR-document./1142/>

I have also written on the related topic of Advance Care Planning over the years, and my views are influenced by my own experience with the 999 Services after my mother's death

Published 26/03/18 <https://www.dignityincare.org.uk/Discuss-and-debate/download/315/>

A Journal of Medical Ethics paper which I co-authored raises an issue about the applicability of ACP in all situations of cardiopulmonary arrest, and it also touches on the issue of MCA best-interests decision making.

Published 02/10/21 <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/>

My position on ACP, is that currently it is inappropriately 'excluding family-carers', that England should quickly follow Wales and adopt the superior concept of Future Care Planning instead of the incomplete concept of Advance Care Planning, and crucially that the system is over-stressing the utility of 'planning ahead' in the context of CPR/DNACPR: it is USEFUL to try and plan ahead, but it is NOT A PANACEA.

Published 31/03/22 <https://www.dignityincare.org.uk/Discuss-and-debate/download/454/>

Published 18/07/22 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-am-trying-to-persuade-the-Royal-College-of-General-Practitioners-to-change-what-it-writes-about-relatives-when-patients-are-dying/1129/>

See also, published 29/08/23 <https://www.dignityincare.org.uk/Discuss-and-debate/download/476/>

Also, 'formalised/structured' ACP as described in the literature, in my opinion often isn't what will happen within the reality of EoL-at-Home.

Published 28/07/18 <https://www.dignityincare.org.uk/Discuss-and-debate/download/325/>

I suggested a single-sentence description of the objective of a best-interests determination, in a piece published 16/11/17.

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

My suggested sentence was:

*The objective is to make the best-interests decision which would result in the most satisfactory future when considered from the perspective of the incapacitous person as an individual.*

It is interesting to compare the above, to what the CQC wrote in its 2021 interim report:

*A best interests decision about CPR is unique to each person and is to be guided by the quality of future life that the person themselves would regard as acceptable.*

I can hardly over-stress the need for an accessible but legally correct, description of MCA best interests. The best way to check that clinicians are applying best interests correctly, is to enable relatives and friends to see what the clinicians are doing, and to form a judgement as to whether the clinicians are behaving correctly – and for that to happen, everyone, not just a few ‘MCA nerds’, needs to have an understanding of what should be happening. Usually, MCA best interests is described in a circular and non-helpful manner: typically, all that we find is a fragmented, but no clearer, rewriting of the same phrases which are in section 4 of the Act. Sometimes with the worse-than-useless ‘balance sheet approach’ thrown in.

Either of the above sentences, is accessible – Jane and Joe Relative could understand the objective of a best-interests determination for CPR/ DNACPR, if before a discussion they were shown that sentence the CQC published.

And, it DOES make it obvious, that it cannot then be ‘the family informing the clinicians [who then make the best-interests determination]’ and it must be ‘everyone informing each other [and individuals each arriving at best-interests determinations]’. The way things necessarily must work, is for the clinical prognosis/es after CPR to be explained first, and then for the people who understand the patient as an individual to consider ‘is that a *quality of future life that the person themselves would regard as acceptable?*’.

I used to explain this, with the situation of someone who wants to stroke a strange dog. You don’t ask the dog’s owner ‘how does your dog think?’ and then try to work out if the dog would bite you if you tried to stroke it. You ask the dog’s owner ‘If I try to stroke your dog, will he bite me?’.

I have described my understanding of the legal situation for family-carers here

Published 10/09/21 <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/>



why relatives and family-carers are being told incorrect and incoherent things by current 'guidance', and that we should be angry about this, here

Published 30/09/22 <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-dont-believe-family-carers-and-relatives-are-being-told-the-truth-about-how-the-law-applies-to-them./1134/>

and very recently, in the context of why 'DNACPR is a medical decision' should not be said when CPR/DNACPR is being taught, I have suggested a few things which could correctly be said here

Published 08/09/23 <https://www.dignityincare.org.uk/Discuss-and-debate/download/477/>

That 'is a medical decision' either implies 'is a decision which only medics can make' or else it is merely stupidly 'restating' the obvious 'is a decision about a medical intervention'. So, a reader of 'DNACPR is a medical decision' or 'DNACPR is a clinical decision' must interpret that as meaning 'the decision to not attempt CPR can only be made by a medic or clinician'. We know this is absurd: patients and suitably-empowered welfare attorneys can forbid attempted CPR, and most patients and attorneys are not clinically trained.

There is also evidence, that while relatives find the 'burden of' making and expressing MCA best-interests determinations stressful, clinicians have a tendency to apply a concept of 'medical best interests' instead of correctly applying MCA best interests (Mr Justice Charles mentions this in his Briggs ruling, and it is a well-known problem if MCA best interests is left to clinicians).

I checked, by asking the Office of the Public Guardian some years ago, that if LPA paperwork was correctly completed and the donor lost capacity while the application was being processed, the LPA would normally proceed and the attorney would be appointed. And it can take several weeks between the application going in, and the paperwork confirming the attorney's appointment being sent out. So, if I believed what I keep reading, we could have a GP and a relative whose application was still being processed, disagreeing about what would be

in the loved-one's/patient's best interests, the patient having become incapacitous after the LPA application was made. I'm told – by many clinical authors – that the GP's position on best interests is the one which counts. However, clearly with nothing else changing (neither relative nor GP has changed their best-interests position, and the relative has not become any more expert in terms of his understanding of the MCA), if the LPA confirmation documentation drops through the letter-box while the GP and the relative are arguing about best interests, then instantly the relative's best-interests determination is now the one which counts, as he is now also an attorney.

Appointment as an attorney, doesn't change a person's understanding of the MCA and of section 4: the only thing that changes, is that on becoming an attorney the person has section 6(6) authority.

I published a long piece about MCA best-interests on 13/01/22 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/>

And finally, as the CQC has pointed out that a best-interests DNACPR decision *'is unique to each person and is to be guided by the quality of future life that the person themselves would regard as acceptable'* it is blindingly obvious, that this is something which relatives and friends will understand far better than any suddenly-introduced 999 paramedic could. To be frank, if I were to call 999 because my dad had collapsed, an attending paramedic said 'he is in cardiopulmonary arrest', and then the paramedic by statement or action seemed to imply that he/she understood what future quality of life would be acceptable to my dad better than I did, I would find that unacceptable.

It is perfectly possible, to construct a set of rules which satisfactorily guide the paramedic's behaviour WITHOUT the paramedic 'making' a best-interests determination – **provided** we 'trust relatives as the default position'. To my great annoyance, that is NOT what 999 paramedics currently do – and in consequence, I am being forced to point out to

family-carers ‘that 999 don’t trust you – so, you cannot in certain situations trust 999’.

Clinicians and family-carers need to be working together during end-of-life if we are to best-support dying patient’s/loved-ones. Telling us (relatives) that as soon as clinicians become involved, best-interests decision-making falls to the clinicians is akin to ‘clinicians being ‘body snatchers’ and we relatives and family-carers should not accept that – we should insist that the MCA best-interests process requires two types of expertise for it to be applied correctly: the expertise of the clinicians in aspects such as possible treatments and prognoses, and the expertise of close family and close friends in ‘the patient as an individual’.

Published 26/02/19 <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/>

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