

It's the listening, stupid!

Target audience: Welsh CPR/DNACPR/EoL 'group', NHS England EoL Lead, NHS England Dementia Team, ReSPECT Leads, doctors who talked in a recent RCP EoLC podcast.

Introduction

I keep reading clinically-authored material, which, to use my phrase here, 'seems to imply that family-carers during end-of-life are 'passive observers": I also keep coming across a piece of legal absurdity, which I will move on to later, and which is relevant.

EoL at Home is complicated – it can become incredibly complicated, because of problems with communication and rapidly-evolving events (both clinical, and also other events – for example, a capacitous patient might 'decide to now express a new decision, or to now retract an existing decision'). I also keep coming across the wrong categorisation of the people involved in supporting the patient during known EoL at home: I keep seeing an emphasis on 'healthcare professionals distinguished from family carers' when a much more appropriate separation would be 'the people involved long-term with the patient distinguished from people who become suddenly and temporarily involved'.

I have recently written and placed online some pieces which are relevant to this discussion, and these are:

Ref 1 **My Little Book of EoL Thoughts by Mike Stone v2_**

<https://www.dignityincare.org.uk/Discuss-and-debate/download/317/>

Ref 2 **My Own Story by Mike Stone_**

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

Ref 3 **Comments on the RCP EoLC podcast by Mike Stone_**

<https://www.dignityincare.org.uk/Discuss-and-debate/download/314/>

The first of those, is a collation of some of my frequently-referenced (by me) pieces in a single PDF – partly because I find that is one of the better ways for me to keep track of my own material.

The second, describes the events around my own mother's death about a decade ago, and that is how I became involved 'in EoL debate'.

The third, is a comment about a recent, and good [but quite long] RCP broadcast about EoLC: although good, it wasn't at all clear to me, how 'the podcast' believed that relatives and family-carers 'fitted in' during EoL Care.

I will now move on, to that flawed legal assertion which I keep coming across: accepting that this claim is untrue, fundamentally alters what can legitimately be written as end-of-life guidance and protocol.

Sorry – but 'normal family carers' definitely CAN make best-interests about CPR!

It is clear that ReSPECT also believes this piece of obvious nonsense, which can be found on the rear of a Welsh DNACPR form (and the same flawed analysis of MCA best-interests decision-making can be found on page 21 of '**MY FUTURE WISHES: Dementia Advance Care Planning for all care settings**')

<http://www.wales.nhs.uk/documents/VERSION-3-REVISED-DNACPR-Policy-Sharing-and-Involving-Final-July-2017-1.pdf>

4. Summary of discussion with those close to the patient (e.g. spouse/partner, family and trusted friends, carer, or advocate)

If the patient does not have mental capacity those close to the patient must be consulted and may be able to help by indicating the patient's recent wishes. They **cannot** make the decision to withhold cardio-pulmonary resuscitation - this is a medical decision. If the patient has made a Lasting Power of Attorney for Health & Welfare, ensure that it is registered. If the patient has appointed a Health & Welfare Attorney to make decisions on their behalf, that person must be consulted. A Health & Welfare Attorney may be able to refuse life-sustaining treatment on behalf of the patient if this power is included in the original Lasting Power of Attorney.

If the patient has capacity - ensure that discussion with others is with their consent and does not breach confidentiality. State the names and relationships of relatives or friends or other representatives with whom this decision has been discussed. More detailed description of such discussion should be recorded in the clinical notes.

It isn't difficult – if you both read the Mental Capacity Act and also do a little bit of thinking – to work out what the justifications for withholding CPR are. I describe them in ref 1 on page 30. As an aside, many people do not seem to believe that the strongest justification in my list is 'legally correct' – it 'clearly must be legally correct' and you can see the reasoning on pages 28/29 in ref 1.

CPR 'is a medical decision' only if CPR could not be successful in restarting the heart: if CPR might be clinically successful, then the decision to withhold CPR is **absolutely NOT** 'a medical decision'. And certainly nurses, and perhaps 999 paramedics, have been 'sanctioned' when they decided off-their-own-bat that 'CPR wouldn't be clinically successful, so I will not attempt it'. In practice, less-senior clinicians seem to attempt CPR unless they can find a DNACPR form signed by the

senior clinician – in fact, logically it should be ‘look first for an ADRT refusing CPR’ but at present ‘the emergency services ‘dislike’ ADRTs which refuse CPR’ {I am using ‘dislike’ in the sense of ‘distrust to the point of not respecting/following’ and I will return to that shortly}.

I have a little scenario involving a patient, Anne, who is living with dementia, which I created to illustrate the complexity of best-interests decision-making even in simple everyday situations: see ref 1 pages 12 – 14. If I ‘tweak’ my scenario, it is immediately obvious that ‘those close to the patient cannot make the decision to withhold cardio-pulmonary resuscitation’ is ‘legally irrational’ – as I pointed out on pages 13/14:

So far, I have not tempted anyone to explicitly state ‘Dr Jones’ opinion is the correct one, because Dr Jones is the professional’.

If someone had suggested that, I would have thrown in this to ponder. Suppose that Anne had been capacitous, and while capacitous she had sent off an application for David to be made her Welfare Attorney under the LPA. The application can take several weeks to be processed: let us assume that after sending the application off, Anne’s dementia suddenly became much worse, creating the situation in my scenario, *while the result of the application is unknown*.

Suppose that Dr Jones is in Anne and David’s home, that Dr Jones and David are still disagreeing about the best-interests decision, **and it is claimed that** ‘the decision of Dr Jones is the right one, because Dr Jones is the healthcare professional’. Then, while they are still arguing about whose decision is the better, an envelope with the LPA documentation confirming David’s appointment as Anne’s welfare attorney drops through the house’s letter-box: **instantly ‘David’s decision becomes the right one’**.

The point of significance, is that in the few seconds between the paperwork confirming David’s appointment under the LPA being outside in the postman’s hand, and inside on the floor by the letter-box, **nothing about David’s decision-making has altered**: obviously the quality of his decision-making isn’t affected by his appointment as Anne’s welfare attorney. It is often implied, that unless a family-carer or a relative is a legal proxy, the person cannot make legally-satisfactory MCA best-interests decisions: wrong, whether anybody at all can make a legally-satisfactory best-interests decision hinges on the person’s understanding of the factors which section 4 of the MCA requires a best-interests decision-maker to consider - *it is authority over best-interests decision-making which is affected by the appointment as a legal proxy*.

The truth is that anyone who could reasonably claim to have complied with section 4(9) of the MCA, **can MAKE** a best-interests decision about a medical intervention: *make is not the same as impose*.

The three linked-tweets here, cover the situation concisely:

https://twitter.com/MikeStone2_EoL/status/906073527236907009

And – ***we are discussing CPR, which is taught as first-aid.***

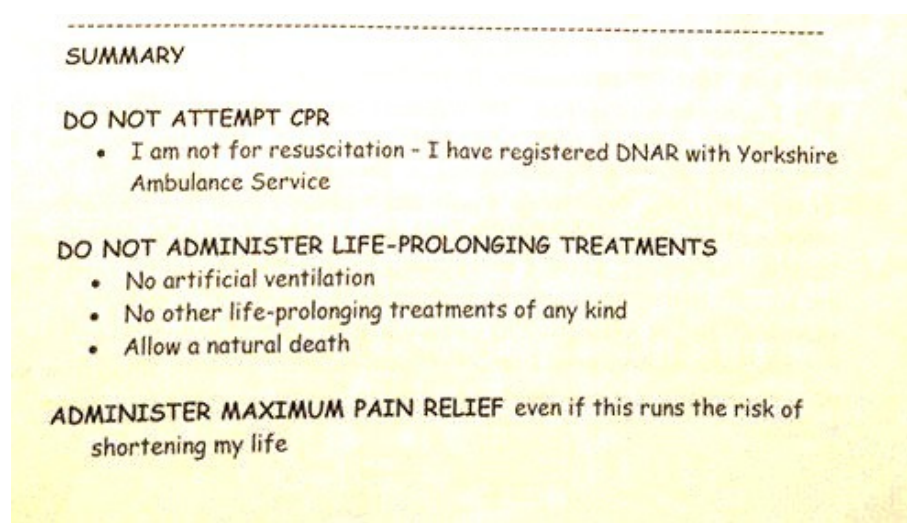
So – a family-carer might be able to perform CPR: how is it not, then, the family-carer's decision, as to whether or not to perform CPR?

I would comment 'that CPR is different from most other medical interventions' and I touched on how, in 'Some Points about CPR', which is one of several short pieces in the composite PDF at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/264/>

The 'Distrust of ADRTs refusing CPR by 999 Paramedics'

There is a Tweeter, who is aged about 60, and who has got an Advance Decision refusing CPR, which is intended to prevent CPR and other life-sustaining interventions: the person is 'healthy'. I know, and so does the person with the ADRT, that 999 paramedics are likely to disregard the ADRT and to attempt CPR: in an attempt to persuade emergency clinicians to respect the ADRT, it contains a lot of explanation which goes well beyond what is required by the Mental Capacity Act. The person has posted some sections of the ADRT and other documents which presumably are bundled with it, in a series of tweets:



DETAILED REFUSAL OF TREATMENTS

If I lack capacity to give (or withhold) my consent to medical treatments then I REFUSE all medical intervention aimed at prolonging or sustaining my life. I understand that this lack of capacity may be sudden and/or that it might be potentially reversible. Nonetheless, my carefully considered and firm decision remains to refuse all life-sustaining treatment.

To avoid any doubt, I confirm that this refusal of treatment is to apply even if my life is at risk or may be shortened by virtue of such refusal. My decision is to refuse all life-prolonging treatments including but not limited to cardio-pulmonary resuscitation, artificial ventilation, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, suctioning for lung infections that might otherwise kill me, and artificial hydration and nutrition. I also refuse all life-sustaining treatments including but not limited to therapies whose purpose is to maintain or replace a vital bodily function and without which death would most likely occur as a result of organ or system failure.

I recognise that the situation in which I may be unable to make decisions for myself may be of a temporary nature, and that recovery from this situation might (with medical intervention) be complete - or virtually so. I have considered this carefully and my decision remains as stated above. I do NOT wish health professionals to attempt to "stabilise" me or to "wait and see" what the nature of my disabilities might be, or to what extent I might recover from them. In particular:

- I do not wish anyone to administer treatment in the hope that I might subsequently regain sufficient capacity to make a decision for myself.
- I do not wish to be offered the opportunity to 'change my mind' about the decision to refuse treatments.
- I do not wish my current decision overruled or ignored on the grounds that there are - or might be in the future - new treatments or medical developments which could improve my chances of recovery.

I have listed these three terms in particular because I know that they are often used as justifications for the judgement that an advance decision is not "valid and applicable". Insofar as is humanly possible I want to ensure that it is not possible to dismiss my advance decision on these grounds. I also specifically refuse fMRI scanning - or anything like it designed to detect possible consciousness - and I do not wish any apparent communication from me while my capacity is in any doubt to be used to justify giving life-prolonging treatment.

LASTING POWER OF ATTORNEY FOR HEALTH AND WELFARE

This Advance Decision is legally binding in relation to any situation to which it is applicable. Nobody has the legal right to over-ride these decisions. I do not intend to confer upon anyone the legal right to over-ride the decisions I have made in this document.

I have appointed my wife, Sue Wilkinson, with Lasting Power of Attorney for Health and Welfare. However I do not intend her to have the right to over-ride my decisions here. There is no need to consult her before implementing any of my decisions as expressed in this document.

However, for any situation to which this Advance Decision is *not* applicable, I wish my wife, Sue Wilkinson, to have full decision-making authority (including in life-and-death situations) and it is for this reason that I have appointed her as my Lasting Power of Attorney for Health and Welfare. (Note: She is also my Lasting Power of Attorney for Finance.) I have full confidence in Sue's ability to make decisions on my behalf. She knows my values and beliefs and I trust her to give expression to them if I cannot.

Here is her contact information:

As I pointed out during the Twitter discussion, I am very confident that the person's documentation - which clearly encompasses an Advance Decision, something that would usually be referred to as 'an advance statement', and also what I can only describe as an attempt to explain our law to readers (which should NOT be the job of the person creating such documentation - that should be 'part of HCP training'!) - 'would be successful during a court case, in persuading a judge' but I doubted that it would prevent 999 paramedics from attempting CPR:

Me:

And I think your ADRT would 'work' in front of a judge, and probably inside a hospital - I'm far from convinced that if you arrested at home, it would stop 999 paramedics from attempting [and certainly 'starting'] CPR.

Reply:

Agree. That's exactly why I have a DNACPR too. And have appointed my wife as LPA(health) and she is willing to interpose her body between mine and the paramedic. Doing everything I can!

This simply cannot be right - **it cannot be sane**, that those laymen who understand both the law and also how the 999 Services behave, conclude '**we simply cannot trust 999 paramedics to support our decision-making autonomy**'.

There is something seriously awry, when Twitter exchanges go like this:

Sue Forsey:

I understand now Mike I didn't understand when mum collapsed I broke the ambulance door trying to stop the paramedics doing cpr the 2nd time It just went on & on Then when she got to hospital it was just terrible don't think I could have stopped them anyway Just what is the law?

Mike Stone:

The law is badly understood, badly applied and the best chance of stopping CPR is to have a Welfare Attorney saying 'don't do it' and waving MCA 6(6) & 6(7) under HCAs noses, in addition to an ADRT refusing CPR.

Celia Kitzinger:

Yep - but not even this will stop someone doing CPR on me. Two different intensivists in 2 different HCP/academic seminars recently said they'd give me CPR despite the law (which I'd explained to them) because it was "the right thing to do" and I'd "thank them for it later".

How can this horrible Situation of Conflict be changed to one of Genuine Working Together to Support Patients?

To start with, it isn't that the doctors and nurses who create MCA/EoL/CPR guidance/protocols cannot see the same issues as I, and other informed layfolk, can see: the thing is, that we suggest different 'solutions', because we prioritise 'the caveats' differently, as well as this mysterious 'for some reason HCPs appear unable to actually see what the MCA says' problem [which I discuss endlessly, and have just been discussing in this piece].

In my view the solution has to be founded on a balanced-consideration of some very-obvious truths, which definitely include:

* whoever is making best-interests decisions, the process is so challenging that when at all possible we should be trying to avoid having to make best-interests decisions: that equates to 'get Advance Decisions from patients if at all possible' but it also requires that HCPs 'accept and follow' ADRTs:

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

The problem, fundamentally, is twofold. The 999 Services – perhaps in contrast to senior hospital doctors – do not default to 'trusting the word of relatives, about the understanding the relatives possess in respect of the arrested-patient's position on CPR'. And secondly, the issue of 'where the risk of following a written Advance Decision forbidding CPR rests': surely, it should rest with the person who decided to create that written ADRT. I have discussed this in a PDF that can be downloaded from ref 3, where I reversed the assumption that 999 paramedics currently make about whether an ADRT forbidding CPR, which is not embedded in the medical records, should be followed if it is *prima facie* valid [and applicable]. When you 'think from the position of the patient who created an ADRT', you (well - I do) arrive at this:

One place where this can easily be seen, is the issue of cardiopulmonary resuscitation (CPR) when a patient is at home, and a cardiopulmonary arrest (CPA) is not considered likely. Clinicians often imply, in their writing, that in this situation the patient cannot refuse CPR by means of a written Advance Decision (ADRT). This is utter rubbish, logically: I am not expecting that a drunken driver will swerve his car onto the pavement

and hit me, but I can certainly think about the likely consequences, if that were to happen.

Similarly, I can consider the consequences of an unexpected CPA.

The only thing which does definitely follow from a home CPA being unexpected, is that the GP could not certify the death – but that is an unrelated issue, to whether I can use an ADRT to forbid attempted CPR for a ‘sudden CPA’.

If I consider such a ‘sudden CPA’ and then I write an ADRT refusing CPR for it, I would be doing that in the knowledge that if I were in CPA when 999 paramedics arrived at my home [after, probably, having been called by another person such as a spouse, who had seen me collapse], I would not be conscious – so, I would have written the ADRT with the intention that it should be followed, in exactly that situation (of an unexpected arrest, and when there was no time to look at my ADRT beyond confirming its Prima Facie validity).

Clinicians seem to think, that in this situation – when there is ‘an emergency’ – my ADRT can be ignored, because there is no time ‘to confirm it’. But to the author of such an ADRT, surely that is exactly the opposite of what you would expect – as I wrote in ‘ReSPECT is incredibly DISRESPECTFUL’:

‘An ADRT which appears prima facie valid should be accepted as being valid, if there is not enough time to check in more depth: it is during a non-emergency that the prima facie apparent validity of a written ADRT should be further examined !’

* If we accept my point that the most fundamental distinction is between the people who are able to talk with and listen to the patient on an ongoing long-term basis – and the NHS England Dementia Team (page 5 of My Future Wishes) seem to agree with me –

III. Approach

It is important to emphasise that ACP is not a ‘one-off’ plan-making session. It is an inclusive, personalised, proactive and transparent process that cuts across health, social and community care settings. It focusses on what matters most to the person; so that they are involved in decisions about their health and wellbeing, and are more in control of living their life with their conditions.

then it becomes necessary to change the mindsets and attitudes of emergency clinicians, and of 999 paramedics in particular, to one accepting of **‘the person who called us, might know much more about everything to do with this situation except for the narrow clinical situation’**.

That mindset/culture change, will never be achieved 'while only senior clinicians sign the forms' - for example, from the ReSPECT Form:

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort	Prioritise comfort, even at the expense of sustaining life
--	---

Considering the above priorities, what is most important to you is (optional):

ReSPECT

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment as per guidance below clinician signature	Focus on symptom control as per guidance below clinician signature
--	--

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

SPECIMEN COPY - NOT FOR USE

CPR attempts recommended Adult or child clinician signature	For modified CPR Child only, as detailed above clinician signature	CPR attempts NOT recommended Adult or child clinician signature
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The patient is allowed by ReSPECT to complete box 3 - **but not to sign** box 3.

Ditto box 4 - **only the signatures of clinicians**.

That simply cannot be correct - and personally, as either a patient or as a welfare attorney, I myself would not stand for it - even setting aside the fact that the ReSPECT form is promoting best-interests decision-making, during 'clinical emergencies', and by the wrong people (if you need to read the ReSPECT form, then you were not involved in its creation - and if anybody should be making best-interests decisions during 'emergencies', it should be someone who was involved in

the creation of the form, not a reader of the form). I intensely dislike ReSPECT, and I point the reader at:

<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/>

<http://www.bmj.com/content/356/bmj.j876/rr-7>

* I used 'listening' in the title of this piece, but listening is a part of conversations, and it is the 'ongoing conversation' involving the patient and those closely-surrounding the patient - during end-of-life the family-carers, GP, close friends and relatives, and frequently-involved district nurses - *who can listen, ask and crucially 'be informed by' those ongoing conversations.*

Those are the people who should be listening to and understanding the patient's own decisions, and who should be **jointly** creating any documentation intended to guide emergency clinicians - and, 'jointly implies multiple signatures on such documents'.

I cobbled together some rough drafts of 'DNACPR Forms' which do comply with the logic of the MCA a few years ago, and you can find the piece (which could well be imperfectly proof-read) at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/265/>

But - the resulting forms, are lengthy.

An Alternative Approach to 'DNACPR Forms'

The Tweeter's forms intended to prevent CPR (among other interventions) surely illustrate a crucial problem, with any form intended to prevent a 999 paramedic from attempting CPR: even if you do not object to conflating the legal justifications for withholding CPR (and to be clear - I do strongly object to such conflation!) **it simply isn't possible, to 'read and digest' that amount of information, before starting CPR.**

It isn't possible, to create a legally-sensible DNACPR Form and also to restrict the form to only one or two A4 pages - to 'make sense legally' you would need sections such as the one on the following page.

I included a lot of 'the legal theory/background' in the construction of my draft DNACPR Forms - because I suspect that it is from such forms, that many front-line clinicians 'pick up their legal understanding'. But, the forms while correct, would only be useful for CPR at Home if the attending 999 paramedics understood both the law, and also [therefore] which sections of the form to concentrate on.

In light of these problems, I would support an entirely different type of DNACPR Form, and I will 'give a rough description of concept' towards the end of this piece. I will point out here, that **ReSPECT is flawed because it is both too ambitious and too over-simplified at the same time** - and that while DNACPR Forms are apparently falling out of favour, they were never correctly designed in my opinion.

SECTION 5 DNACPR Decision NOT made by a Welfare Attorney but made when CPR might be clinically successful

The senior clinician should sign below, along with [ideally] all of those 'close to the patient' ('family and friends') who it was possible to involve (and who indicated that they felt sufficiently-connected to the patient to legitimately be involved in best interests decision-making) in best interests decision-making about CPR. If a less senior clinician signs, then the senior clinician should also sign later. If at least one of the 'family and friends' who was involved in best interests decision making has not signed, the clinicians should explain the reason for this in the box provided.

We the undersigned hereby confirm that after discussions between the Multi-Disciplinary Team and the patient's Family, Friends and others who could legitimately contribute to the decision, there is unanimous agreement that DNACPR is, in our opinion, in the patient's best interests. In particular, we confirm that to the best of our knowledge, none of the patient's family/friends are objecting to the DNACPR decision.

The Best Interests DNACPR decision applies:

1) Whatever caused the CPA, and however likely or unlikely an arrest was considered to be Tick to confirm this is the case ☐

2) (TO BE COMPLETED ONLY IF THE REFUSAL OF CPR IS CONDITIONAL):

The refusal of CPR applies if ...

...

...

...

Name	Role or relationship	Signature	Date
.....			
.....			
.....			
.....			
.....			

MUST BE COMPLETED IF NO FAMILY/FRIEND HAS SIGNED ABOVE: The reason no family/friend has signed is

Name and signature of clinician who explained this: NAME SIGNATURE

All of the signatories above hope that less-involved clinicians, such as 999 Paramedics, will be guided by our [more-holistically-informed] decision as described here.

An Alternative Approach to CPR/EoL forms

I would stress - **this also requires** *adequate and correct training of all healthcare professionals, about decision-making law.*

It would be possible to include within 'a DNACPR document' all of the justifications for withholding CPR: patients, attorneys, GPs etc could all sign appropriate sections, and then while not conflating decision-making authority provided the various sections contained the legally-appropriate signatures, a single document would cover everything. But, that probably isn't a good idea - to start with, different sections of the document 'would have different owners', and I'm sure that would result in arguments over 'who owns the document'. So, I am inclined towards only two types of document: Advance Decisions (signed by the patient) and a semi-composite document, of variable-and-uncertain 'ownership' but 'with-the-patient-residence', which covers both 'CPR could not be clinically successful' AND ALSO 'CPR is being withheld on [MCA] best-interests grounds'.

It isn't legally possible, to prescribe the details of an Advance Decision refusing CPR, because the MCA has done that in sections 24-26 - so, what follows is a discussion of the principles-of-design of the second document.

The Second 'Combined' DNACPR Document - Principles of Design

1) It **must stress** that any Advance Decision refusing CPR should be considered **first**, and it must if a paper document incorporate the principle that 'any ADRT refusing CPR should be attached to the front of this document if at all possible'.

2) People should:

a) sign for things they personally are responsible for, **but also**

b) sign to indicate 'awareness and involvement' if appropriate, for things they are not responsible for.

So, 2(a) means that where 'responsibility is clear' a specific individual signs the form: thus 'CPR could not be clinically successful' would be signed by the clinician who is making that assertion, but 2(b) means the section could be signed by the patient and or family-carers, relatives, etc, 'to confirm their knowledge of the section'.

Similarly, 2(a) means that if a welfare attorney whose authority extends over life-sustaining treatments records on the form 'CPR would not be in the patient's best-interests' then the attorney would sign that section, but 2(b) means that clinicians and relatives, etc, could sign to confirm their knowledge of the section'.

3) While I object to forms such as the ReSPECT form which at the very least IMPLY THAT 'all decisions are either made by or 'verified by' the senior clinician', I fully support the idea that the form should include helpful statements signed by the senior clinician - such as 'I have seen the relevant documentation (read on DATE) and I confirm that 'A N Other' is the patient's welfare attorney under the LPA, and that the attorney possesses decision-making powers over life-sustaining treatments including CPR'.

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Has-anyone-come-across-any-MCA-section-47a-statement-forms-online/956/>

My Mental Capacity Act section 4(7)(a) statement

A standard section identifying the 'patient' goes here.

The information I have recorded in this statement is for the purpose of improving best-interests decision-making, should I be unable to make my own decisions and if I have not already expressed a refusal of the intervention by means of a valid and applicable Advance Decision.

I am naming the following individuals to assist any person who is considering my 'best interests' - as the MCA puts it:

(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,

The individuals I list below, are being named by me for the purposes of section 4(7)(a)

Name	Contact details	My signature

I am reviewing this statement regularly to ensure that it is up-to-date.

NOTE: I am **not** suggesting that if best-interests decision-making becomes necessary, that **only** these individuals can usefully contribute – I am stating that the listed individuals should be involved unless having been contacted, the individual declines to become involved.

I am not sure if this form should be signed by the person and also witnessed – any ideas about that?

In Conclusion, and a Question arising from the Welsh DNACPR Policy

It doesn't make much sense, I feel, to continue with detailed suggestions, at this point: this is 'an incomplete analysis' as it stands, but my position is sufficiently at odds with the 'mindset of' many doctors, that it requires feedback indicating that doctors are willing to move towards my own position, before looking at these ideas in more detail. I would also add, that so far as I can see, it isn't possible to recommend to emergency clinicians that CPR should not be attempted on MCA best-interests grounds, if there is no decision-maker empowered by MCA 6(6) and if there is a disagreement about whether CPR would be in the patient's best-interests [and an observant reader, will see that I have actually reflected that principle {implicitly} within my DNACPR Justification Hierarchy

But, I would point out, on the basis of a couple of Twitter Polls I have performed, the idea that 'the senior clinician 'is in control" **is not supportable**:

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

I asked this question in my poll, and offered 3 answers: 60 people voted, and I show the results:

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

In an earlier poll on Twitter, I had asked a related question:

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

There was always something perverse (and since the Montgomery ruling made it clear that 'Bolam does not apply to consent', for anyone who had not noticed that the MCA did that about a decade before Montgomery even more perverse) about the position that 'because we consider that CPR could not re-start your heart, we will not attempt CPR' **IF** an informed patient then says '... but I want you to attempt CPR, anyway'. So, I see it as progress that section 8.3 of the Welsh DNACPR Policy starts with (the bolds are in the policy itself):

8.3 A clear request for CPR – when CPR is not clinically in the patient's best-interest

A patient might insist that CPR is provided - even when (for clear clinical reasons) the clinical team feel it to be an intervention which cannot provide clinical benefit. When a patient requests CPR following a discussion that clearly outlines very significant risks and burdens, the senior clinician must record fully the patient's expressed wishes alongside their own clinical views. **When conflict exists and whilst further advice is sought the interim position should normally be to provide CPR.**

It is also perverse [and at the heart of the analysis I am presenting in this piece] that 'traditionally legally-**binding** ADRTs refusing CPR are 'translated into' legally-**advisory** DNACPRs'. It would seem to be rather more 'legally logical' to see if when clinicians believe that CPR could no longer be successful, whether those patients would, if they did not want CPR to be attempted, create a legally-binding ADRT refusing CPR.

So, in connection with another section of the Welsh DNACPR Policy, I await an answer to the question I have recently tweeted:

https://twitter.com/MikeStone2_EoL/status/985135260278165504

Text of my tweet:

I would like the Welsh DNACPR Policy team - whoever they are - to actually answer this question for me. The MCA is very clear about 'the activity of' a written ADRT - it becomes 'active' as soon as it has been witnessed. It doesn't need - LEGALLY - to be 'mirrored by' a DNACPR.

Image attached to the tweet, with the question I asked in it:

5.6 Who should have the DNACPR discussion with the patient?

A senior team member should be nominated for the role. The professional undertaking the discussion should immediately record the discussion on the All Wales DNACPR form and ensure (if they are not the senior responsible clinician) that this is countersigned by the senior responsible clinician at the earliest possible opportunity/next ward round. **When the senior team member is a medically qualified professional the DNACPR will become active when signed, timed, dated and following entry of the GMC number (Section 5 - All Wales form). In all other circumstances sign off (with GMC number) by the senior responsible clinician is necessary for the DNACPR to be active (Section 6 - All Wales form).**

Just imagine – unlikely I know, but suppose – that a District Nurse who visits a terminally-diagnosed patient, finds him and a couple of relatives in his home. He says to her 'I want to discuss CPR with you'. Clinically he is terminally-diagnosed, but not ill-enough to be 'expected death'. He says to the nurse 'I've decided that I'm forbidding attempted CPR, if I arrest for any reason at all'.

Suppose the nurse has got the Welsh DNACPR Form to hand, and produces/completes it.

It also turns out, that he has got a pre-prepared Advance Decision refusing CPR – he was waiting for either a DN or the GP to visit, because he wants several witnesses to it: both of the relatives who are present, and at least one of the clinical team. So he signs his ADRT and gets it witnessed – assume the Welsh DNACPR is also completed but with the restriction on its 'activity' described in 5.6.

How does the nurse answer, when the patient asks:

'Can I be sure that my ADRT will prevent 999 paramedics from attempting CPR, if I collapse, one of my relatives calls 999 and it turns out I am in cardiopulmonary arrest?

And if the answer is 'no' – then if I tell my relatives to not call 999 if they think I've arrested, is that okay 'with the NHS' – because I DON'T WANT CPR ATTEMPTING?'

How does the nurse answer, 'according to the Welsh DNACPR Policy'?

There is a PDF which discusses some scenarios involving 999 paramedics and family carers, and which starts to investigate situations of disagreement within the family carers, at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/263/>

I suggest that readers look at that PDF, a screengrab of which is

Best-Interests Decision-Making when only 'emergency clinicians' and family carers are present: who should decide what, who should contribute what?

My starting point, is that the MCA has moved away from 'the doctor makes the decision' and very clearly to 'informed patients make their own decisions'. This emphasis on the application of what I shall call 'the patient's individuality' to the decision-making, also applies (but with added complexity) to best-interests decision-making when the patient is mentally incapable (which for the purposes of this piece means 'less capacitous until a cardiopulmonary arrest left the patient unconscious'). I would point the reader at:

<http://www.bmj.com/content/357/bmj.g2234n-8>

And also at:

<http://www.bmj.com/content/357/bmj.g2234n-9>

The 'Principles'

- 1) Best-interests decision-making requires two different 'inputs': the clinical prognosis (the outcome with and without treatment) and also an understanding of which clinical outcome the patient 'would have chosen'.
- 2) 'You can only hear a patient's expressed decision, if you are present to listen to it: you can only glean an understanding of the vaguer concept of 'patient preferences' by spending time with the patient (put at its simplest 'by knowing the patient as an individual')'
- 3) Family carers and healthcare professionals should be working together - not fighting each other.

The way a mentally-capable reaches a decision [to consent to or refuse an offered medical intervention] is by 'applying his particular way of thinking' to the information about the clinical factors which has been provided by his clinicians.

The people who 'understand the patient's particular way of thinking' after the patient has lost capacity, are 'those close to the patient': logically we would arrive at 'those close to the patient' work out best-interests after they have been provided with clinical information'.

Scenario: a single family carer calls 999 and the patient turns out to be in CPA

Suppose a single family carer has called 999. Only the family carer is present to input 'any understanding of section 4(6) of the MCA' - the 'understanding the patient as an individual aspect' - and there is not the time to 'involve others' during a CPA. If this sole family carer present tells a 999 paramedic 'I'm sure (and it is definitely the paramedic's role to decide if the patient is in CPA) then I feel sure you should not attempt CPR, then in my view the paramedic should not attempt CPR: doing otherwise 'questions the integrity of the family carer'.

Scenario: 2 or more family carers call 999 and the patient turns out to be in CPA

Suppose 2 or more family carers have called 999. Only the family carers are present to input 'any understanding of section 4(6) of the MCA' - the 'understanding the patient as an individual aspect' - and there is not the time to 'involve others' during a CPA. If every family carer present tells a 999 paramedic 'I'm sure (and it is definitely the paramedic's role to decide if the patient is in CPA) then I feel sure you should not attempt CPR, then in my view the paramedic should not attempt CPR: doing otherwise 'questions the integrity of the family carers'.

Footnote: If there are 3 family carers, and two say 'I'm sure you shouldn't be attempting CPR', while the third 'doesn't know', then this is still 'the paramedic should not attempt CPR'.

Scenario: 2 or more family carers call 999 and the patient turns out to be in CPA

Suppose 2 or more family carers have called 999. Only the family carers are present to input 'any understanding of section 4(6) of the MCA' - the 'understanding the patient as an individual aspect' - and there is not the time to 'involve others' during a CPA. If even one of the family carers present tells a 999 paramedic 'I'm sure (and it is definitely the paramedic's role to decide if the patient is in CPA) then I feel sure you should attempt CPR, then in my view the paramedic should attempt CPR: the reasoning is that there is no way the paramedic can decide whose best-interests decision is 'better', and in this situation the paramedic must default to 'attempting to preserve life'.

Footnote: This does not mean that any of the family carers are 'wrong' - those who are convinced the correct decision is to attempt CPR, and those who are convinced the correct decision is to not attempt CPR, are equally right: the assumption must be that they have considered section 4 of the MCA but have arrived at different conclusions for what is in the patient's best-interests.

The DNACPR Justification Hierarchy

- 1 A face-to-face discussion with a mentally capable patient, which takes place during the clinical events which lead to the CPA, the outcome of which is that the patient issues a DNACPR instruction which those who were involved in the discussion can interpret correctly
- 2 An apparently valid and applicable Advance Decision refusing CPR which has not been discussed with the patient
- 3 A DNACPR decision made and communicated by either a single welfare Attorney (where only one has been appointed), or agreed and communicated by all Welfare Attorneys
- 4 A DNACPR decision made by any person who is sufficiently informed of the patient's clinical situation and likely wishes, to enable that person to defensibly consider section 4 of the MCA.
- 5 A DNACPR action, which is based upon information supporting the reasonable belief that something within categories 1 to 4 makes DNACPR the best available behaviour
- 6 If none of the above apply, but it is clear that attempted CPR would be clinically futile, then DNACPR
- 7 If none of 1 to 6 apply, CPR should be attempted

A face-to-face elaboration of a CPR refusal, directly from the patient, gives the person to whom the refusal is made the best possible understanding of the patient's DNACPR instruction (see also note 1).

If an Advance Decision has been written but not discussed, it must be taken at its face value.

These 2 things are 'true section 4 best interests decisions', and the Welfare Attorney ranks highest because the WA was appointed by the patient to make the decision; then any person who has been sufficiently involved with the patient, to justify making a section 4 best interests decision (see note 2).

This is the situation of someone such as a paramedic, who if called to an arrest cannot have the necessary background and time to genuinely consider a section 4 best interests decision.

This is not a section 4 best interests decision (see note 3).

If a patient is known to be within the 'End-of-Life Care System', then it appears negligent if this default behaviour is resisted.

Note 1
This is not, apparently, a 'genuine' section 4 best interests decision. The reason, is that in this situation there is no plausible reason to doubt the patient's decision - it is the most clearly-understood of all possible refusals from a patient. It isn't relevant if there is a written ADRT, because if the patient is mentally capable until a CPA occurs, his explanation of the meaning of the ADRT defines its meaning: the patient's explanation of what his ADRT means, is superior to anybody else's interpretation of its meaning.

Note 2
A genuine section 4 best interests decision, involves 'working out the patient's likely wishes' - there must be some degree of uncertainty about those wishes (a degree of uncertainty entirely absent for 1). Whoever is considering the best interests test, the fundamental struggle is in persuading oneself that this uncertainty is small enough, to believe that the patient would have refused CPR for the particular CPA in question.

Note 3
If CPR would be clinically futile, it will not normally be offered - this is a 'clinical DNACPR' and it is not a section 4 best interests decision, because it is not dependent on the patient's wishes (and section 4(6) of the best interests test, stresses the importance of discovering the patient's likely wishes).

The first question a person should ask is 'can I defensibly make a section-4 MCA best-interests decision?'

The answer is either yes, or it is 'no - I don't myself understand enough about this patient's 'individuality'.

If it is no then such a person should ask 'is there someone else who could make a better decision than I could?' and if the answer is 'probably' then helping that person by providing information should be your role.

Behaviour should be co-operative with the objective of arriving at the best-achievable decision and the enacting of that decision!

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