

Decisions are made 'in the now': we decide when we need to decide, and we decide using our current understanding of the situation. This matters – and it introduces significant complications into 'advance planning' within healthcare.

During some recent exchanges on Twitter, Kathryn Mannix and I were explaining that the ReSPECT Form is not 'a DNACPR'. I will avoid, for now, discussing what 'a written DNACPR' is, beyond pointing out that many people would like it to be 'a decision made when the document was created, such that future readers of the DNACPR document will not attempt CPR'. Put simply, it is often claimed, or at least 'desired that', DNACPR forms are INSTRUCTIONS [to future readers] that CPR should not be attempted (see Appendix).

Kathryn's tweet was this:



This is in fact, very easy to think about. It comes down to this: you ask people, such as doctors, nurses, family-carers, etc, '***If the patient/person had a cardiopulmonary arrest (CPA) now, would you yourself attempt [or support the attempting of] cardiopulmonary resuscitation (CPR)?***'.

It is not a requirement, that everyone will give the same answer: a GP might say 'if your dad arrests, then I will not attempt CPR' and a daughter might reply 'well, if my dad arrests and you don't attempt CPR then I will attempt CPR myself'. But it is 'a requirement' that everyone individually decides on some sort of 'informed basis' - certainly 'ideally' (when there is time for people to talk to each other before each individual comes to a decision).

Without digging into English law too deeply, the Mental Capacity Act is the 'core law' here [if there is a chance that CPR might work in restarting the patient's heart], and the MCA does not explain whether [A]CPR or DNACPR is the correct decision in any particular situation: what the MCA does is to make an individual's decision legally-defensible

provided the person making the decision has ‘followed the process’ correctly. The process, is set out in section 4 of the MCA (for completeness, I should also mention sections 6(6) and 6(7) of the MCA as well), and in particular it involves trying to understand the individuality of the patient as described in section 4(6):

4(6) He must consider, so far as is reasonably ascertainable—

- (a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and*
- (c) the other factors that he would be likely to consider if he were able to do so.*

The MCA also includes section 4(7), which covers consultation:

4(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).*

I myself like to present this, in terms of discussions between a wide group of people, after which some of those people – which can include doctors, relatives, nurses, friends, etc – could individually claim to have ‘satisfied’ the requirements of section 4 of the MCA: ***each individual being able to reasonably claim ‘I have put in enough time and effort, to be able to properly understand and defend my own decision about CPR/DNACPR’.***

Section 4(6) of the MCA is anything but simple – you cannot, in my view, ‘understand 4(6)’ by reading a ‘DNACPR document’ during a cardiopulmonary arrest.

Imagine a room in a hospital, with an unconscious patient, and the patient’s consultant, a junior doctor, the nurse in charge of the ward, the patient’s spouse, two brothers of the patient, and three children of the patient all in the room discussing whether or not CPR should be attempted if the patient arrested. After 30 minutes of the people in the room discussing this, ‘a passing nurse’ enters the room. If the nurse suddenly announced ‘You should attempt CPR if he arrests’ we would legitimately comment ‘On what basis has the nurse concluded that – she hasn’t been in this room for the last thirty minutes, trying to work out whether CPR should be attempted?!’.

It is the discussion which makes the opinions about CPR/DNACPR INFORMED – the people in the room possess informed opinions, and the suddenly-intruding nurse is expressing (for reasons which are hard to guess at) an UNINFORMED opinion. In reality,

any clinician external to the patient's immediate care team, would not express a view about CPR – such a clinician would realise that only the people in the room understood the situation in a meaningful way.

Assume everyone in the room, who was involved in the discussions, agrees that if the patient arrested now, DNACPR would be correct: nobody in the room would attempt CPR, or would in any way 'promote or support' CPR. Having 'cast the net wide' (involved, as much as possible, all of the people who best-understand both the clinical situation and the patient as an individual person) we can reasonably believe that the right decision about CPR/DNACPR has been arrived at by the people inside the room. So the next question is this:

'If the patient/person had a cardiopulmonary arrest (CPA) tomorrow, or next week, would you yourself attempt [or support the attempting of] cardiopulmonary resuscitation (CPR)?'

Only if everyone says they would almost certainly not attempt CPR tomorrow or next week, can we correctly and usefully document the 'DNACPR conclusion' of the group. In effect, if the group believes that nothing is likely to happen between now and next week to change their opinion, we can document 'our position now is DNACPR, and it will almost certainly still be DNACPR next week'. All such 'ACP' will contain a provision, to the effect of 'provided nothing significant changes' (see the second sentence in Kathryn's tweet).

I must point out, from my own position as a family-carer while my parents died at home, that if you are present for much of the time – so a family-carer living with the patient, or a ward nurse caring for a patient daily – then you will probably notice 'if something significant changes': **because of your ongoing involvement.**

We now get to the 'legally tricky' bit. This 'group of informed individuals' wants to share its understanding that DNACPR probably should not be attempted, with 'suddenly-introduced' clinicians such as a cover hospital doctor at 3am or a 999 paramedic. But the law does not allow for the group to document 'an order' (or an 'instruction') that CPR should not be attempted. It just cannot be done – and this is why legally-aware clinicians no longer refer to 'DNACPR Orders'. But, the purpose of the documentation is still to try and prevent 'comparatively uninformed clinicians' from attempting CPR – and, much high-level CPR guidance still tends to describe the DNACPR documents as 'instructions that CPR should not be attempted'. The closest thing to an order that CPR should not be attempted, is an Advance Decision refusing CPR [and even then, section 25(4)(c) is problematic in practice].

The ReSPECT people, frame this as 'a recommendation to' the people who might read the documentation: I would prefer the documentation to be explicit that it was recording 'informed and agreed opinion'. **And that readers should then, if that informed opinion said 'we consider DNACPR is the right decision', ask themselves 'what do I know, which can justify me challenging that informed opinion?'.**

It is in reality, even trickier. Technically, if an emergency clinician such as a 999 paramedic decides to withhold potentially-successful CPR, the clinician's legal defence should be that of having made a best-interests decision in compliance with section 4 of the MCA. As I pointed out on page 2, in my opinion reading a DNACPR document during a cardiopulmonary arrest cannot equip a paramedic with the sort of in-depth understanding which a GP or family-carer might reasonably claim to possess. And section 4 of the MCA does legitimise what I shall term 'best-interests decisions made in **unavoidable** 'ignorance' - but in that situation the decision has to be to attempt CPR.

Two recent Journal of Medical Ethics papers which I have written or co-authored are relevant to this:

<https://blogs.bmj.com/medical-ethics/2021/02/21/is-there-only-one-mental-capacity-act-or-are-there-two/>

<https://jme.bmj.com/content/early/2020/12/02/medethics-2020-106490>

The court ruling which is clearest on this, is the 'Briggs' ruling by Mr Justice Charles. The legal concepts in that ruling, which was about the withdrawal on best-interests grounds of life sustaining CANH, can be directly transferred to the withholding of CPR which might be clinically successful. It is important to be clear about the Briggs ruling and its transfer to CPR, so I will do this in a separate font.

The Briggs Ruling applied to CPR

In the Briggs case, the patient had gone from being capacitous to long-term comatose very quickly, and the judge had to decide if it would be in the patient's best interests to withdraw the CANH which was keeping him alive. The judge in effect decided that in such a situation, the MCA's Best Interests becomes a version of Substituted Judgement, which amounts to, using my words here:

If the decision-maker is satisfied to a sufficient degree of certainty that the patient would have refused the intervention 'had the patient been in the same situation but capacitous', then the intervention should be withdrawn or withheld,

and,

If the decision the patient would have made is not understood with sufficient certainty, then the treatment is continued or applied in an attempt to preserve the patient's life (and, of course, if it is believed that the patient would have wanted the treatment if the patient were capacitous to decide, then the treatment is also continued or applied).

When these cases are considered by a judge, then there is always a matter of hours or days for the judge to collect information from doctors and from relatives and friends of the patient. That gives the judge enough time to form a view as to the reliability of both clinicians and family and friends, even though that time might be quite limited. Then the judge – because once a case is in court, the judge is *de facto* the best-interests decision-maker – makes and expresses a best-interests decision.

Mr Briggs was already being kept alive by CANH, and Mr Justice Charles in effect started his deliberations at 'preservation of life' **and having understood more about Mr Briggs as an individual** during the case, Mr Justice Charles moved to 'I am satisfied that Mr Briggs would have refused continued CANH – so CANH will be withdrawn'.

The significant difference between that case and situations when a 999 paramedic is about to attempt CPR and a relative forcefully says 'Don't do that – he would NOT want CPR!' is **a lack of time**.

Somehow we need to get to the best behaviour – the best decision between attempting CPR or not attempting CPR – in the face of the following complications:

- 1) There is not enough time, if the patient is in cardiopulmonary arrest, for anyone to 'prove' anything: a paramedic could not 'prove' that he or she was performing CPR competently, and a family-carer cannot 'prove' why he or she knows 'CPR is wrong!';
- 2) The family-carer/relative often STARTS with an understanding that their loved-one would not have wanted CPR – which is what Mr Justice Charles FINALLY ARRIVED AT (re CANH) in Briggs;
- 3) Whereas the suddenly-introduced 999 paramedic starts from the 'default preservation of life position' which is where Mr Justice Charles BEGAN.

I must stress: both 2 and 3 are correct – the family-carer's 'no CPR' position is correct, as is the 'attempt CPR until persuaded CPR is 'wrong'' position of the paramedic. But I return to the logic transferred from Briggs: the family-carer is against CPR because the family-carer understands the patient as an individual – the family-carer in effect has the type of understanding which Mr Justice Charles acquired during his court case. The paramedic does not possess that depth of understanding – so put another way

The relative is against CPR because the relative knows more than the paramedic – and the paramedic is [at least initially] pro-CPR because the paramedic does not understand enough to be against CPR.

It isn't obviously embedded in the MCA, but for me, there must be a concept that a decision made with a deeper understanding is 'better than' a decision made with less understanding – in other words, when viewed 'neutrally', the decision made by the family-carer/relative is in some fundamental sense 'better than the decision made by the paramedic'.

There are other complications in play here, such as: many relatives are 'panicked' and/or incoherent; many or most relatives are not aware of the MCA and of the concept of best-interests decision-making; some people suggest that because once involved a clinician such as a 999 paramedic must apply the MCA, then the clinician makes the decision about CPR (this is clearly untrue: the clinician is required to act in accordance with the MCA, but a relative who is aware of the MCA can also act in accordance with it – and if a person arrests when only a relative is present, then obviously the first decision {to call or not call 999, and/or to attempt or not attempt CPR if the relative has been trained in how to attempt CPR as first aid} will be made by the relative as there is nobody else present to make it).

If a family-carer realises that 'if I call 999, then paramedics will probably attempt CPR although I know my loved-one would not want CPR' then it is very difficult – a relative might be certain that CPR 'would be wrong' but not certain that the loved-one has collapsed in cardiopulmonary arrest. I admit that most relatives will not understand 999 behaviour well-enough to realise that: but I do keep pointing this out, on Dignity in Care, Twitter, etc, and in general I believe that Social Media is making the public more-informed about these things.

It could be argued, that in a way 'the system' in effect behaves as if 'once involved, the paramedics 'own the patient' and therefore make the decisions'. But two of my Twitter Polls, and stories of the way families actually behave, support a different viewpoint – that relatives do not consider that 'once involved the clinicians control things':

During a discussion on Nursing Times (online) a few years ago, someone – probably a nurse – posted this:

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounding by his family.

I carried out a Twitter Poll, and the result seems to be in line with my views:

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

In addition to the other issues, there is the fact that 'ongoing contact with the patient' allows someone such as a relative at home, or a ward nurse, to keep listening and watching – in particular a family-carer will sometimes be more up-to-date than any written records. See:

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

Especially for End-of-Life-at-Home, we need to properly incorporate relatives and especially family-carers into clinical mindsets, *such that the combined expertise* of both relatives and 999 paramedics is used to arrive at behaviour which is best for patients: this will require rather more 'trust', and rather less 'desire for certainty', on the part of everyone, but perhaps more so on the part of 999 paramedics.

I know that paramedics are doing their best to improve things – they set out to help, not to leave many bereaved relatives unhappy with the way 999 behaved – and a paramedic recently commented to me in an e-mail:

You're exactly right in what you are saying when you say "I want Paramedics and relatives to be working together".

Yes I appreciate progress is slow, but it is progress – we must continue to educate and improve our service for patients at the end of life.

Written by Mike Stone, 10 May 2021.

You can find me on Twitter at @MikeStone2_EoL

At least – if I've correctly remembered my 'Twitter Handle' then you can!

PS The references to my section of the JME paper (the one with four authors – not my short blog) are relevant, if anyone wants further reading. And my position, if we can get relatives and paramedics to 'work together', is as follows: if everyone agrees that DNACPR is the right best-interests decision, **then do not assert that any individual 'made the DNACPR decision'** - accept that 'in difficult circumstances, the family and the attending paramedics **MADE A DNACPR DECISION TOGETHER**'.

APPENDIX

There is an NHS England webpage, intended to inform readers about DNACPR. If you 'Google' 'NHS England DNACPR' you should be able to find the webpage.



The top of the NHS England webpage is as shown left.

The webpage has been reviewed recently: Page last reviewed: 10 March 2021 Next review due: 10 March 2024.

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions

CPR stands for cardiopulmonary resuscitation. It is a treatment that can be given when you stop breathing (respiratory arrest) or your heart stops beating (cardiac arrest).

CPR tries to get your breathing and heart going again.

CPR can involve:

- pressing down hard on your chest repeatedly (chest compressions)
- a machine to stimulate your heart using electrical shocks (sometimes more than once)
- equipment that helps move oxygen around your body (artificial ventilation)
- giving medicine by injection

How successful is CPR?

I mentioned on the first page of this piece, that many people ‘would like’ DNACPR documents to be instructions – and subsequently I have pointed out that legally that is nigh-on-impossible. On the NHS webpage we can read (my added bolds):

A DNACPR decision is usually recorded on a special form. Different doctors or hospitals might use different forms, but they all serve the same purpose. Some examples are a DNACPR form, a treatment escalation plan, or a recommended summary plan for emergency care and treatment (ReSPECT) process.

*All these forms are easily recognised by doctors, nurses and healthcare workers, **so they know what to do in an emergency.***

This form is kept in your medical records. It may also be printed and kept with you if you are at home or in a care home.

You and the people important to you should know that a DNACPR form has been put in your medical records.

*The form says that if your heart or breathing stop, CPR should not be tried. **This means medical staff will not try to restart your heart or breathing.***

It is misleading to mention the ReSPECT ‘process’ because in reality it will be the main ReSPECT Form which people such as 999 paramedics would be looking at during a cardiopulmonary arrest, but – as Kathryn Mannix and I were pointing out on Twitter – the ReSPECT form certainly isn’t ‘an instruction’ to readers. The ReSPECT form (see the penultimate sentence above) does not ‘say that if your heart or breathing stop, CPR should not be tried’. In fact, in legal terms, it is not actually the case (even for ‘traditional DNACPR forms’) that ‘All these forms are easily recognised by doctors, nurses and healthcare workers, so they know what to do in an emergency’.

I have pointed out to NHS England, that this webpage could mislead patients and relatives into believing ‘that I can have a ReSPECT form which will prevent people such as 999 paramedics from attempting CPR’: that isn’t true – and we should not mislead lay people into believing it is true.

In reality, what best prevents attempted CPR, is a conversation with someone who might be present when you arrest, and that person’s promise, subsequently kept, to not attempt CPR on you: so it is an instruction from the patient, but not via documentation.

I admit, that like so much of end-of-life, this is horribly complicated: but we do need to describe the situation correctly, so that patients and relatives can properly understand it.

In passing, I have also recently contacted the Care Quality Commission, objecting to the implication in their written material that only a senior clinician can make a DNACPR decision.