

Clinicians and Relatives, Consensus, Uncertainty, Emergency and Trust: a continuation from a Journal of Medical Ethics paper

I have been discussing various things with a nurse recently, and we see many things similarly [despite our very-different backgrounds]. Discussing the difference between hospital and home, I commented that among other things you can almost feel ‘structure and process in the air’ within the hospital environment, but that isn’t true for home. The nurse agreed about the presence of structure and process in hospitals: it cannot really be avoided, because with clinicians working in shifts, and with many patients per clinician, it would be chaotic without that structure and process. We can also add ‘hierarchy’.

But those things apply more weakly, or ambiguously, for care at home, especially if ‘family carers’ are involved (‘family carer’ does not imply family – it could be care by a relative, but it could be care by a friend). Part of the necessary structure and process within a hospital environment, is a significant-reliance on written records: whereas at home, in my opinion family-carers will normally use conversation, not written records. Formal hierarchies are unlikely to exist for care-at-home – and there isn’t, despite ‘implications to the contrary’ which you might come across, a hierarchy between family-carers and clinicians.

The nurse and I also discussed what I shall describe here as ‘providing the care wanted by the patient’ - we both agree, again using my phrasing here, that to achieve that objective ‘people supporting the patient will need to surrender ‘some control/authority’’. Which I think in practice, means clinicians will need to dispense with any attitude of ‘I’m in charge – I make the decisions’.

The discussion with the nurse was ‘in private’, but I have also been openly-tweeting with Dr Kathryn Mannix, and ‘the invisibility of assumptions’ has popped-up as a topic (apparently Kathryn’s book ‘Listen’ includes something on this theme).

These things, definitely influence what I write about: End-of-Life, the Mental Capacity Act, and Cardiopulmonary Resuscitation (EoL/MCA/CPR). As does something I will describe as ‘Legacy Thinking’ - by which I mean, being influenced by how things were in the past, even if the present is different (most easily seen in the context of law changes, which can take much longer to influence the behaviour of clinicians than one might expect to be the case). And often many things ‘mingle’ - so clinicians might have an assumption that ‘we possess authority’ and this can be reinforced by legacy thinking.

I was one of the authors of a paper titled ‘Family members, ambulance clinicians and attempting CPR in the community: the ethical and legal imperative to reach collaborative consensus at speed’ which was published by the Journal of Medical Ethics in 2020:

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

The paper discusses a scenario when a wife phones 999, and her husband’s heart stops beating while the 999 Ambulance is en route to her home – the paramedics start cardiopulmonary resuscitation (CPR) and the wife promptly objects:

She reiterated that the 999 call was due to a seizure, and had it been for the purpose of providing resuscitation, she would not have called the emergency services ...

In our paper, we did not discuss the issue which that sentence raises – that if the wife thought her husband’s heart had stopped, she would never have called 999 until after her husband had died: in the paper, we only discussed how a 999 paramedic decides whether or not to attempt CPR ***once the paramedic has become involved***.

The issue raised by that sentence in our paper, is similar to the issues raised by my ‘Father and Son’ scenario:

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

The father in that scenario, is explicit – after a conversation the father tells his son to not phone 999:

One evening, the father initiates a conversation with ‘Son, I’m really struggling here. I really can’t put up with this. Would it upset you, if I’m just allowed to die, if you think I have stopped breathing?’. It could end with ‘We’ll sort this out with the GP tomorrow, but if I die before then, don’t phone 999’.

Neither of the patients in these two scenarios is technically ‘expected death’ (despite the JME paper perhaps implying that to be the case – in error) but the patients are in a state of health such that a cardiopulmonary arrest is by no means unexpected, and in the JME paper there had been discussions within the family but not with the patient’s GP. In Father and Son the father initiates the discussion, and then arrests before the GP has been informed of the father’s decision to refuse CPR.

This does seem to be reality as opposed to hypothetical: Rob Cole, the senior paramedic who wrote the scenario for the JME paper, stated ‘This is a composite case study from my experience of many such calls’ and after I had created Father and Son for a survey, someone posted the following during a discussion in Nursing Times (online):

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.

Before discussing these events and scenarios, I will mention that while we have not as a group (i.e. Rob, Zoe, Alex and I) written a follow-on paper covering the ground which I alone will investigate in this piece (so this piece represent my own views), I have published a blog in the Journal of Medical Ethics which highlighted some of the issues I will go on to examine:

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

It will be helpful, for me to point out the common features of both scenarios, and of the real-life story posted on Nursing Times. These are:

- 1) The patient was mentally-capable either until the cardiopulmonary arrest (CPA) itself removed capacity, or until some sort of pre-CPA 'collapse' rendered the patient incapacitous. So, the patient could make and express his own decision to forbid future CPR (see footnote);
- 2) It isn't necessary for the patient to formally be 'expected death', and in Father and Son I explicitly stated that the father isn't 'expected death'. Nor do we need to consider whether or not any 'advance care planning' which involves clinicians has taken place (in the Nursing Times story, and in Father and Son, there might be some sort of 'EoL/ACP' in place – but in the scenario in our JME paper there isn't);
- 3) But, either just before the CPA the patient had told one or more relatives that CPR was being refused, or there had been discussions 'within the family' which mean the relatives know the patient would not want CPR.

In the scenario in our JME paper, it is made clear that while the family know their loved-one would not want CPR, the family have very little understanding of things such as 'NHS ACP' or the law (the law for CPR being in essence the Mental Capacity Act (MCA)).

And, while clinicians are likely to want 'a specified refusal of CPR', I strongly suspect that often what a patient will explain to family and friends is 'If I'm dying, just let me die in peace' - **which amounts to** 'don't attempt CPR'.

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

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

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

It is an unfortunate truth, that unlike Kate Masters, most relatives and probably patients, will be involved in discussions without possessing a good understanding of the legal issues involved.

FOOTNOTE:

There is an argument, that a legally-binding refusal of CPR must be by means of a written Advance Decision (ADRT). This looks 'very odd', and I consider unsatisfactory, when you investigate its consequences:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/407/>

A fellow 'lay NHS campaigner' sent the following to me, in the context of this 'understanding the law and what should [and shouldn't] happen' issue, and this is in my view absolutely true of interactions with clinicians:

When things go well, it's something we are blissfully unaware of.

When things don't go well we get a painful and steep upskilling of knowledge.

This piece will now become a bit complicated, because many things come into play, and ideally I would look at them 'all at once' - but, of course, I am forced to examine things one-by-one. Which, as it happens, probably **isn't** how you 'think about' this topic after you understand things: then you probably 'have in mind everything at once'.

I will start, by explaining what the MCA actually does, in the situation of a patient lacking capacity. The MCA **provides a legal defence** against charges of either intervention without the patient's consent, or of 'inaction'. The MCA imposes a requirement in order for that legal defence to apply ('satisfaction of' section 4(9) to use my phrase here) and it also explains when the defence cannot be claimed (see sections 6(6) and 6(7)).

Typically, guidance and protocols will state that 'the person who will make the best-interests determination needs to be identified in advance' - but nothing in section 4, states that. And it **could be argued** that the logic of section 4 in fact means '*if you think you might be forced to make a best-interests decision/determination at some future time, you should take steps to enable you to comply with section 4 at the time a best-interests determination becomes necessary*'. Of course – within the complex clinical-hierarchy of a hospital environment, that is deeply problematic: **but for family-carers at home** it is much more achievable in my opinion.

It is not clear that a best-interests decision/determination can even be made, before it is acted on. See my piece here for some discussion of that issue:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Is-the-power-of-a-Welfare-Attorney-LPA-largely-an-illusion-a-response-to-39-Essex-Chambers/1103/>

And the idea that a DNACPR (do not attempt cardiopulmonary resuscitation) decision can be made and recorded in advance of a cardiopulmonary arrest is very problematic – see:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-documentation-of-DNACPR-decisions./1104/>

There is 'a piece of awkwardness' within the MCA. It is clear from section 4, that everyone who seeks the legal protections described in section 5, needs to act in accordance with section 4. But, *technically* (and once you are aware of this, some of the wording in the Act makes more sense) only Welfare Attorneys, Court Deputies and Judges can make best-interests **decisions** – everyone else (so most family-carers, doctors, 999 paramedics etc) can only make best-interests **determinations**. However, anyone who has 'satisfied' 4(9) can 'claim' the protections in section 5 [subject to 6(6) and 6(7)].

Who falls within the scope of the MCA?

If 'the patient of' a clinician is mentally-incapable, then a clinician is required to try and act in accordance with the MCA (some clinicians will argue this stems from 'duty of care' - but I think it stems from the MCA itself and the job of the clinician (see MCA section 42)). So in the situations I am discussing in this paper, once present with a person who is in cardiopulmonary arrest, an attending 999 paramedic **is required to** try and act in the person's best Interests.

The family-carer of an already mentally-incapable loved-one, is [in theory at least] also required to try and act in the person's best interests. But in our scenarios, the person is mentally-capable until the CPA occurs: and the legal situation is as I have described elsewhere:

<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/>

In theory - and I have discussed this with a lawyer - because England does not have 'a Good Samaritan Law' it seems that a relative is not legally obliged to do anything: you can just 'watch your loved-one die'. You are obliged to report your loved-one's death, once the person is definitely dead. But 'you are under no legal obligation to help'.

I HATE this 'defence' for letting your loved-one die without intervention. One reason, is the Samaritan was a stranger, passing by: we [relatives and family-carers] are not "strangers". We are INVOLVED. We are instinctively 'active'. My second reason, is that irrespective of not being legally-required to 'be involved', I feel sure 'I decided to just watch' would go down very badly with the emergency services, who probably would be involved post-mortem.

So, I prefer 'a defence' based on following the Mental Capacity Act (MCA). Once your loved-one has lost consciousness, there is nothing to prevent a relative from 'opting in to the MCA' - from saying 'I followed the MCA'.

What does MCA Best Interests say about CPR?

The law applies the two principles of Patient Autonomy and Preservation of Life. For CPR, in the situations I am considering in this paper (a cardiopulmonary arrest from a situation of patient capacity) we can transfer the reasoning and conclusion of Mr Justice Charles in 'Briggs' across to CPR. I explain this in my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/435/>

What it comes down to, is if the person considering CPR is sufficiently sure that the patient would have refused CPR in the circumstances of the arrest, then CPR should not be attempted – and if it isn't clear enough whether the patient would have refused or accepted CPR (or if it is clear the patient would have wanted CPR) then CPR should be attempted. This assumes that there is a possibility that CPR might restore life.

For practical purposes, the MCA's Best Interests has become, in this type of situation, 'Substituted Judgement'.

What are the Relatives and an involved 999 Paramedic likely to know?

Obviously, a clinician such as a 999 Paramedic should be able to quickly establish if a patient's heart has stopped beating – if the patient is in cardiopulmonary arrest.

I think that is more difficult for a typical relative: you can 'see a collapse', and you might believe there is no evidence of breathing or heartbeat – but I suspect 'certainty' will not necessarily be present for most family-carers. What some family-carers will be 'certain of' is that their loved one does not want CPR to be attempted.

So, quite often the relatives/family-carers are sure of what the patient would want to happen, but are not sure of the clinical situation: whereas an attending 999 paramedic would very quickly be pretty-sure of the clinical situation, but much less sure of what the patient would want to happen.

So, quite often the relatives/family-carers are sure of what the patient would want to happen, but are not sure of the clinical situation: whereas an attending 999 paramedic would very quickly be pretty-sure of the clinical situation, but much less sure of what the patient would want to happen. This introduces a problem – as I pointed out in the piece referenced immediately above:

*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 is a paper by Iain Campbell titled 'Paramedic delivery of bad news: a novel dilemma during the COVID-19 crisis' (Campbell I. J Med Ethics 2021;**47**:16–19) and in it he describes a 'model' by Brown for 999 paramedics and CPR, which Campell summarises as follows:

The Brown model suggests actions during resuscitation:

(1) *On arrival*: Introduce yourself. Gain a brief history. Stress need to treat immediately. Promise an update;

(2) *Soon after resuscitation attempt established*: Advise relatives of the situation. Invite the family in if not already present. Summarise treatment;

(3) *Further into resuscitation*: Advise of possible outcomes. Allow questions;

(4) *Recognition of life extinct (ROLE)*: Invite the family to be present for termination. Tell them when death is recorded.

My problem, is the above ignores that in theory there should often be a best-interests decision made about CPR, and also it is, if modified, a model which would become 'the paramedics start CPR and continue until they become convinced that CPR is inappropriate'.

The relatives in the scenarios, know that CPR should not be started in the first place. I doubt that anybody has ever said 'I don't want to be punched in the face – well, perhaps a few punches would be okay, if then the punching stopped'. And our relatives, know that CPR should not be started on their loved-one – not 'started and then stopped' but never started at all.

We cannot resolve this by means of improved advance care planning (ACP) – in these scenarios, either there would not be an expectation for ACP to be in place, or else the patient has expressed a decision to relatives, and it is unreasonable to expect that decision to have found its way 'into ACP records' prior to the cardiopulmonary arrest.

The problem, is the training/attitude of some clinicians, as revealed (I admit about a decade ago) by my Father and Son survey, answers from clinicians being:

Q1 What 'should' the son do, if he thinks his dad has stopped breathing, before anyone else has been told of the conversation?

Answers to Q1

GP: *He should do what his father asked him to do.*

Consultant Doctor: *Wait and call GP later to certify the death*

Paramedic no 1: *Preferably make a quick note in care package AND/OR do not call 999.*

Paramedic no 2: *Respect father's wishes, in the event and contact and discuss with GP ASAP, call 999.*

Nurse no 1: *If an Advance Decision to Refuse Treatment (ADRT) has not been made and the father has not verbalized his wishes to a professional involved in his care then the son would have to call 999 as his conversation with his father has not been witnessed and not evidenced as "in his best interests"*

Nurse no 2: *respect his fathers wishes and not phone 999*

Nurse no 3: *Either ask his father to document his wishes in some form, or if possible contact the out of hours GP, and see if that would be an appropriate course of action*

Nurse no 4: *He should dial 999 as there is nothing formal that acknowledges his dads wishes. If he does nothing he will be in trouble as it will be classed as neglect also dad may have been having a bad day and if resuscitated may go on to live the rest of his life pain free, with dignity and in control by completing an advanced directive.*

As a family-carer, I am not going to question my own integrity, am I? So answers such as those from nurses 1 and 4 anger me – they imply that we should start from 'relatives cannot be trusted'.

How many clinicians 'look at' these scenarios

When I show this type of scenario to doctors, nurses and paramedics, and ask 'was the relative right to not phone 999 [or the GP] until after their loved-one had died?', often I will be told various things which are not true for these scenarios. Such as 'there would be advance planning in place' - **not true for these scenarios**. Or 'It is an expected death' - **not true for these scenarios**. Eventually, some doctors will say the family were correct to not call anyone – at least, if the patient does indeed die quite quickly.

I don't believe the police, who might subsequently become involved, have the same understanding of patient autonomy as legally-aware clinicians possess.

It isn't helped, by things such as the ReSPECT form which stubbornly continue to exclude the signatures of Welfare Attorneys and family-carers – this, to my mind, gives the impression that the doctors 'make all the decisions'.

What I myself would do – and where we are perhaps going

It seems very unlikely that I will ever be faced with the problem confronting the family-carers in these scenarios – I no longer have close relatives, so I will not be in the situation of the son in Father and Son.

But, **if I were in those situations**, I don't think I would call 999 or a GP (if you call a GP, you are quite likely to end up with 999 anyway: I would call the GP after the death).

And, although it should not affect your decision as to whether or not to call 999, I think that **afterwards** it would help if you (the relative of family-carer) were a Welfare Attorney with authority over life-sustaining treatments.

There is a core-problem here: whereas a 'moral' relative should not call 999 if the relative knows their loved-one would refuse CPR and if the relative suspects 999 paramedics would attempt CPR once involved, 'the system' wants 'to be summoned'. And, when I ponder this, it seems to me that if increasing numbers of layfolk come to understand the problems I have discussed in this paper, the friction between relatives and clinicians (and also police) will become more common and more forceful.

So, it is a problem which needs to be resolved – it is difficult to resolve, and as I stated on page 1, I think a solution is impossible unless clinicians relinquish an attitude of 'control', start trusting relatives more, and stop 'requiring more certainty than is logically possible'. I think it is very challenging for 999 paramedics, as 'historically' there was an assumption that 999 paramedics are summoned to treat – whereas the family-carers in these scenarios would be summoning paramedics to provide clinical information.

Written by Mike Stone, October 2021.

Twitter: @MikeStone2_EoL

PS Note that it is only for life-sustaining treatments, in situations which do not involve a long period of 'mental-incapacity but 'engagement with life'', that MCA Best Interests effectively becomes Substituted Judgement (the reason is section 4(5)). In other situations, we simply cannot clearly describe MCA Best Interests – my own attempt to do that can be found at:

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