# Cardiopulmonary Resuscitation: the mess we are in, and some thoughts about why we are in such a mess.

Dr Mark Taubert recently wrote a paper, in British Journal of Hospital Medicine, February 2019, Vol 80, No 2, titled 'Cardiopulmonary resuscitation is leading a double life: are we giving it an alibi?'. His paper described some problems with CPR decision-making, and a few days ago a bunch of tweets coincided with some e-mails I've been exchanging with a doctor: I think I can use those things, with a few 'added extras', to explain why CPR decision-making is so 'problematic'.

I'll start with two tweets, one by Dr Trisha Elliott and the other by Sue Forsey, whose mum's death was traumatic for both Sue's mum and for Sue.

## https://twitter.com/Trisha the doc/status/1114069107396227074

Talking to a patient's family a while ago about why we needed a DNACPR form in place to protect their frail elderly relative. Got an interesting reply: "Oh no! I know what CPR is, I did a course at the church hall. You couldn't do that to mum, you'd break every bone in her body!"

## https://twitter.com/ForseySue/status/1114217565088374786

I'm not sure what inappropriate CPR is, before I witnessed what happens after CPR I would have thought it a miracle! She regained twice! I wasn't informed Now I wish it hadnt happened I'm sure the public don't know... like me

So, we can start with an obvious 'problem': to be frank, the process of cardiopulmonary resuscitation (CPR - those 'chest compressions and 'rescue breaths' you see in hospital dramas) is potentially very damaging, especially for the elderly: often CPR will only turn what would have been a 'peaceful death' into a death which 'lingers' for a few days, with relatives seeing their loved-one dying with broken ribs, infections and other irreversible clinical damage. Possibly conscious, perhaps not.

And the **best possible** outcome of CPR, is 'clinically identical to your situation before you arrested'.

Dr Gordon Caldwell, often tweets on the theme of 'CPR is NOT a treatment for end-of-life' - if you are old, very frail and your heart stops because as Gordon puts it 'your body has already died', then CPR is something that should not be attempted. Whereas, if you are young and healthy, and you are involved in a car crash and because of something like blood loss your heart stops, then CPR might give you a chance of a return to normal life (Gordon describes this as 'the heart stops first - and the body dies afterwards').

Gordon is correct in his description - although his description of the clinical situation introduces the question of 'how do we assess 'too frail or near-to-death for CPR to 'be

helpful", and there are issues around 'CPR wouldn't keep the patient alive, but the patient still wants CPR to be attempted'.

I was discussing CPR with Ken Spearpoint, and Gordon Cauldwell and Celia Kitzinger both joined in - Celia is healthy, but she has decided to refuse attempted CPR if her heart stops for any reason at all [and Celia takes quite extensive measures, to try and ensure that CPR wouldn't be attempted]. The series of tweets went:

Ken Spearpoint, posted a tweet:

https://twitter.com/K G Spearpoint/status/1114086946270273536

'CPR' is both 1st Aid & a medical intervention. For lay persons = 1st Aid. When conducted by healthcare professionals = medical treatment. In the absence of an advanced directive, they have seconds to make a decision - do CPR or withhold CPR, with no hindsight bias available!

I then posted:

@KitzingerCelia That raises an interesting issue re the refusal of CPR via an ADRT - an ADRT 'refuses a specified treatment' but presumably an ADRT should also prevent a relative from attempting CPR [which according to Ken would then be 'first aid - not treatment']. SIGH!

Ken:

CPR is recognised at 1st aid worldwide - not my definition!

Me:

It isn't a helpful 'definition' - it is [and we might reasonably assume a HCP would perform it more competently] the same INTERVENTION. See also re this 'treatment/care' issue https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-PDF-contains-my-Anne-David-and-Dr-Jones-scenario-it-poses-the-question-what-is-the-meaning-of-shared-decision-making-for-EoL-at-home/947/ ...

Ken:

I agree CPR is the same group of techniques, but the context of provision of CPR can be (and is usually) different. Lay rescuers are not ordinarily criticised / punished for withholding or conducting CPR - evidently very different for HCP's.

Gordon Caldwell then tweeted:

Rules are always in context It's OK to drive 70mph on a clear dry motorway but not past a primary school at 8:55 am It's OK to do #CPR on a healthy adult abruptly collapse striding down the street but not on a bed bound comatose person cachectic from metastatic cancer

## And Celia Kitzinger threw in:

Hi @doctorcaldwell - I have mentioned this before. It is NOT always OK to do #CPR on a healthy adult abruptly collapsing etc. if they have refused it (e..g in ADRT) I know you know this but you keep tweeting stuff that risks misinterpretation.

## Gordon replied:

I appreciate your decision and rights which however could prove difficult for a passerby to respect. If you collapse & look like you need #CPR how will the passerby know your wishes in the 10 to 15 seconds before he starts chest compressions?

#### Celia:

Thanks - agree difficult for a passerby to know if person has refused CPR and the presumption is in favour of life. Really just an alert about the message in your earlier email which seemed to make an incorrect claim!

#### Gordon:

Sorry! I am a great advocate for Autonomy the first principle of Medicine Ethics - the person's right to not take up a Doctor's recommendation (or a Target or Guidelines demand) @iona heath @mgtmccartney @valle erling

Dr Kathryn Mannix threw in a tweet, which I show here but I'll analyse it later (I disagree with this - in particular with the idea that these things 'are considered equally'):

Remember: Autonomy doesn't 'trump' the other 3 Beauchamp&Childress principles. Autonomy Beneficence Non-maleficence Justice ...are a quadrad of principles to consider equally. Currently, over-valuing of individual Autonomy threatens community Justice, i.e. others' autonomy. 1/

'I know you know this but you keep tweeting stuff that risks misinterpretation'

From Celia. There is a 'totally bonkers' actual misinterpretation 'out there' which many HCPs seem to believe: it is the idea that 'a verbal refusal of CPR is not legally-binding'.

I've been trying to correct that confused belief, since about 2010 – see pages 26 – 33 in my PDF at:

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

The perspective of the clinicians who attend emergencies in the community, is very much that CPR is often the only treatment which might keep people alive long enough for expert medical attention to be provided:

# Kevin Fong @Kevin Fong Apr 5

Which raises the interesting question: When we teach CPR as part of BLS should we also be teaching about DNACPR too?

# Dr. Mike Greenway @mikegreenway Apr 5

No. Not for lay people. Getting them to act is the hardest bit. Don't give them a choice. Have the 'no CPR' discussion with individuals about individuals, not populations.

# Kevin Fong:

Yes but not suggesting that pre-hosp lay, CPR providers should have an option. Rather that CPR training \*may\* be an opportunity to educate/discuss the difference between pre-hospital arrest when little/no information is available & in hospital when much more is known.

#### Mike Stone:

I'm not entirely happy with the thrust of this - from my 'family-carer during end-of-life at home' perspective! 'Would dad want CPR?' is a fundamental question, that family-carers will be asking themselves https://www.dignityincare.org.uk/Discuss-and-debate/download/363/ ...

#### Kevin Fong:

Fair point. This is intended as discussion rather than prescription. Out of hospital the challenge is getting bystanders to act. In hospital the challenge is the mismatch between expectation & reality So the engagement required, to meet everyone's best interests, is complex.

In my opinion, for end-of-life at home, the problems are very different from Kevin's 'out of hospital [and involved in a car crash]' and they are also significantly different from 'in hospital': both at home and in hospital, misunderstanding and misapplication of the Mental Capacity Act is a problem, but at home is also afflicted by a professional attitude of 'the family-carers should not be trusted by default':

#### Mike Stone:

I suspect that many people - most? - would, if towards the end of life or already 'very frail', forbid CPR if they understood the 'process of CPR' and its likely consequences. But we need to move towards 'the patient said no' instead of 'the attending clinician decides', I think.

# Ken Spearpoint:

That would be ideal Mike, but some people simply do not want to contemplate their own EoL decisions. I have met this on numerous occasions - people have said 'I don't want to decide - I want to leave it up to you'. Some don't want to discuss - we have to respect that too.

#### Mike Stone:

I am 100% aware of that - however, the current 999 guidance goes beyond 'most patients don't decide': current guidance effectively discounts 'my dad HAS made his decision clear - he has TOLD ME even if he hasn't yet told his GP'. <a href="https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/lf-l-a-patient-only-had-the-chance-to-tell-my-fami">https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/lf-l-a-patient-only-had-the-chance-to-tell-my-fami</a>

At this point, I will comment that currently we have end-of-life guidance which implies that ideally patients should have been asked if they would refuse CPR, that almost everyone 'who is part of the EoL 'world" knows that the conversations are very difficult to initiate, and from a personal perspective no such conversation would have been possible with my own father: even when he was clearly very close to death, he only ever said 'I know I'm very poorly'.

And, I will mention an excellent paper by Keith Cass @redsockcampaign 'Twitter helped me decide that I'm not for resuscitation' which you can find at:

## https://www.bmj.com/content/362/bmj.k2784

Mark Taubert wrote an 'extra' or 'insert' in Keith's paper, and while I'm not going to show Keith's part here, I will show what Mark wrote:

Viewpoint from Mark Taubert, consultant in palliative medicine, Velindre Cancer Centre, Cardiff, Twitter @DrMarkTaubert

Keith was taken aback when I first broached advance care planning topics, but we talked about it and he took the time to look at cardiopulmonary resuscitation and make a decision as to whether this was something he would want considered if he became unresponsive. Like many people I meet, I thought that Keith was worried that having a DNACPR form might also preclude him from consideration for other, more standard treatments such as antibiotics, chemotherapy, and blood transfusions. But he has had his DNACPR form for some months now, and we both know that it has had no impact on other treatment decisions.

Keith was easy to talk to, but many people, especially patients' loved ones, find these conversations hard, which is not surprising. We hope that the TalkCPR website will get patients to approach their doctor saying: "We need to have a talk about resuscitation." In the future I would like patients to be in charge of treatment decisions. I hope that DNACPR forms, which are still filled in and signed by a healthcare professional, are gradually replaced by Advance Decision to Refuse Treatment (ADRT) forms, which are completed by informed patients and are legally binding.

Note that Mark writes 'I hope that DNACPR forms, which are still filled in and signed by a healthcare professional, are gradually replaced by Advance Decision to Refuse Treatment (ADRT) forms, which are completed by informed patients and are legally binding' and, as is clear from my tweet 'we need to move towards 'the patient said no' instead of 'the attending clinician decides', I think' we both agree about that.

This is an appropriate point, to introduce some things a doctor sent to me in a recent e-mail, when we were discussing CPR. One thing he wrote, was:

This highlights a big issue for me when it comes to CPR- I think it is nearly impossible to truly impart the knowledge of what CPR involves and the potential outcomes to patients and their families. It's taken me 10 years and I am still learning- I edge towards a slightly paternalistic and guiding way in most patients unless clearly this is not the approach they prefer.

I can understand why many doctors, who see the often 'horrible outcomes' of CPR and are aware of how difficult the conversations can sometimes be, tend to 'edge towards paternalistic guiding of the decision'. But I'm not sanguine about that - despite its motivation being 'good outcomes' - because it simply does NOT fit with our law (the Mental Capacity Act) on decision-making, and it is also probably why we had the Janet Tracey law ruling. The Tracey ruling, in essence told doctors that they should inform patients if the doctors thought that CPR could not work for an existing clinical reason. One of the doctors I used to discuss end-of-life with, during the court case, told me that she hoped the ruling wouldn't force doctors to tell patients that 'we think CPR couldn't work'. Another of my lay contacts, has been told that the Tracey ruling makes it more likely that 'damaging CPR' will be attempted: the logic, which is very perverse, seems to be that 'because the conversations can be upsetting and fraught, in the old days doctors would place a DNACPR order in the notes without telling the patient or family - now, doctors are less likely to even discuss DNACPR with patients and families'. So, judges, who understood how upsetting it is for patients and families to discover DNACPR forms, tell doctors to disclose those DNACPR decisions to patients and/or families - as a consequence, doctors discuss CPR even less often than before: very peculiar, because Gordon has pointed out that 'CPR isn't a useful treatment for normal dying' and that is not affected by discussions with the lay side.

While I'm on the e-mail from that doctor, I'll point out that he is the first person to send me a comment on a DNACPR Justification Hierarchy which I have been publishing since about 2014. The doctor commented:

Firstly, I like the DNACPR Justification Hierarchy. Legally and ethically it makes sense.

This is my hierarchy, which assumes the MCA is the law [so it is for England and Wales].

# 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 his 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 (Note: for non life-sustaining treatments, a Court Deputy can fit here between 3 and 4 – see section 20(5) of the Act))

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

My DNACPR Justification Hierarchy is in my tweet at:

https://twitter.com/MikeStone2 EoL/status/1114077440446554112

I will point out a few things which might be a little less than obvious.

a) the top justification, is a face-to-face verbal refusal of CPR from a capacitous patient,

made during a conversation so that the patient's refusal can be clearly understood, and it is the most legally-binding of all refusals provided the patient subsequently arrests without 'ongoing contact' being broken (for example, if the patient makes his refusal while he is in hospital, it would be assumed that if he subsequently changed his mind he would tell a nurse or doctor: ditto, if a terminal patient at home explains to a person who lives with him 'I don't want CPR', then surely if the patient changes his mind, he will tell people sharing a home with him that he has changed his mind).

- b) the powers of Welfare Attorneys ('LPAs') can be either Joint & Several, or Joint. If the powers are joint, then all of the attorneys are legally required to agree, before their expressed decision carries legal authority. If the attorneys have joint and several authority, then they can individually make and express decisions which carry legal authority I am NOT saying that all of the attorneys must be consulted during an arrest if their powers are joint and several. If only one attorney can be contacted to make a decision, then the decision expressed by that attorney does carry legal authority: I'm saying that if more than one attorney can be asked, I think CPR should be attempted unless all of the attorneys who express a decision say 'DNACPR'.
- c) To my great and ongoing annoyance, many clinicians and clinical organisations seem to believe that relatives, friends and family-carers cannot fit in at no 4, and that emergency clinicians such as 999 paramedics and A&E doctors can fit in at no 4 'if assisted by notes'. I assert forcefully that anyone who is involved in a long-term and 'deep' way with the patient can fit in at no 4: so, family-carers and the patient's GP, during end-of-life for example. And that clinicians such as 999 paramedics and A&E doctors can only fit in at no 5. The challenge and I have explained how this could be done in my writing is 'how can people who fit in at no 5, and therefore could not defensibly make a best-interests decision, be legitimately guided to enact the right best-interests decision?'. But, I will not discuss that here (I discuss it in my thread about ReSPECT).

Returning to Twitter, the following tweets are also informative.

Kate Masters tweeted:

https://twitter.com/katemasters67/status/1115856676417150977

Why is it so hard for doctors to contemplate - without the full story - that a doctor can be convicted of manslaughter because they were criminally negligent? This really has dented my sympathies and question my efforts to help change the very real issues doctors face

Celia Kitzinger:

Equally, why so hard for doctors to contemplate that they might be convicted of assault/battery, civil trespass for giving medical treatment not in patient's best interests? Answer: Happens routinely with over-treatment at end of life + rarely challenged by lawyers or court.

Mike Stone:

Paramedics do seem to be getting the message - WMAS has definitely understood <a href="https://www.bmj.com/content/352/bmj.i26/rr-2">https://www.bmj.com/content/352/bmj.i26/rr-2</a> ... But it is harder to get doctors to accept

the same thing - see <a href="https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Can-other-people-see-what-I-can-see-in-these-different-descriptions-of-the-decision-making-authority-of-welfare-attorneys-/924/...">https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Can-other-people-see-what-I-can-see-in-these-different-descriptions-of-the-decision-making-authority-of-welfare-attorneys-/924/...</a> It might take the successful prosecution of a doctor to change things? <a href="mailto:QDrMarkTaubert">QDrMarkTaubert</a>

Mark Taubert:

as so often I think the unfortunate answer to that is Yes.

Mike:

So do I - I don't want paramedics or doctors to be prosecuted for following what is currently 'perspective-biased and legally-incorrect' guidance, but that guidance is sometimes horribly problematic for relatives: and 'I'm a relative'.

The above, is a discussion of doctors departing from what our law (essentially the Mental Capacity Act) actually says - the next series of tweets, illustrates that lay people also depart from the law [although lay people cannot be expected to be familiar with the law - whereas doctors should be!]:

Sue Forsey tweeted:

# https://twitter.com/ForseySue/status/1115597329451573250

Mike 'my' instructions to my family eg fall off a horse 'No cpr' My families reply No can do. Family members instructions to me 'you break my bones if you have to I want to live'

Mike Stone:

Mark and <u>@drkathrynmannix</u> This is the point - and it is why I'm not keen on Kathryn's 'it is more than simply autonomy' tweet: legally - according to the MCA -<u>@KitzingerCelia</u> it is up to Sue what happens if SHE falls off a horse, and ditto for her relatives: it ISN'T 'a vote'!

Celia:

IME family members often find it hard to bear witness+give 'voice' to a loved one who wld have wanted to refuse medical treatments. Own wishes for person, what they'd want for themselves in that situation + uncertainty about loved one's wishes all make it hard. They need support.

Sue:

All of my family trained in first aid emergency cpr Our profession dangerous If my daughters arrested after a fall I would try to resus How can you stop them doing the same for me?

Celia:

I can't (obviously!). But happy to support you by facilitating a conversation between you and your daughters about your wishes if you think that could help. I assume your GP has completed DNACPR + ADRT refusing CPR has supported statement concerning daughters' views?

#### Mike:

Celia - as you know, I bang on about this - why did you refer to Sue's 'wishes' and not to Sue's 'decisions'? <a href="https://www.bmj.com/content/354/bmj.i3888/rr/927045">https://www.bmj.com/content/354/bmj.i3888/rr/927045</a> ...

#### Celia:

Because I assume she has 'wishes' about end of life that extend beyond simply her 'decisions', and may both underwrite but also be in conflict with them. Exploring wishes, values, feelings, beliefs can help ppl understand decisions (+ may change decisions).

#### Mike:

As I understood it, Sue was saying ' if I fall from a horse and I arrest, do not attempt CPR' which for me is a DECISION - but her family were saying to Sue 'if we were there, we would attempt CPR despite you having told us not to'. Sue might clarify?

#### Sue:

It's non negotiable Celia It was quite an upsetting conversation There is no way either will not try to resusitate me. I have had a terrible experience re mum surviving cpr for a short time which clouds it for me

#### Mike:

The wife of one of my cousins, also seemed to think that whatever the [collapsed] patient had said on the matter, 'preservation of life' should always be attempted. Even if you agree with her, the thing is our law doesn't agree with her.

#### Celia:

An instinctive response to rescue you, borne of love + terror that you will die and they will lose you? Can be so hard to be 'heard' in that situation when there's so much distress. Worth another conversation perhaps at some point? (Meanwhile, LPA + DNACP + ADRT really matter!)

## **APPENDIX to the TWEETS**

Twitter is both useful and annoying: it can illustrate different perspectives and beliefs very clearly, but at the same time it is difficult to keep track of Twitter discussions, and those discussions also tend to 'fragment'. I went to the trouble of collecting these tweets, partly because Dr Mark Taubert sometimes 'uses Twitter' in his teaching, so he might find this piece of some use.

But, I now unashamedly point to some of my own recent pieces, which discuss CPR and also the Mental Capacity Act, from my own 'former family-carer during end-of-life' perspective.

I hope, that the tweets which I have already shown, have demonstrated how significant 'perspective issues' are when CPR is being considered. I sometimes express the difficulty as 'the ordering of the caveats': put differently, the role of a person, not only affects what the person knows and understands, but it also affects how the person orders priorities.

My own position about CPR/MCA/EoL, is of course strongly influenced by my own background as a family-carer while both of my parents were dying, and also by the deeply unsatisfactory experience which I suffered (I would say 'was inflicted on me' by various professionals) when my mum died:

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

I have never considered that the 'standard' description of decision-making during end-oflife, presented by most 'clinical bodies' such as the RC(UK) and ReSPECT, is correct: fortunately, from my perspective, several recent court rulings align with my assertions and not with the assertions of those clinical bodies. This disagreement, which is in essence about 'who can legitimately make decisions', should be clear to readers, if they look at my [very lengthy] thread which covers my disagreement with ReSPECT:

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

Recent court rulings, have allowed me to analyse the connection between MCA Best Interests and Substituted Judgement in the context of CPR:

https://www.dignityincare.org.uk/Discuss-and-debate/download/353/

I have also suggested a sentence which describes the objective of best-interests decision-making, and my sentence has received a reasonable amount of 'support':

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

I have built on those pieces, by writing several recent pieces which concentrate on the interaction between family-carers and 999 paramedics in the context of CPR at home during known end-of-life situations – I would like to thank Kieran Potts @NWAmb\_Kieran for a particularly useful tweet – and these two pieces

https://www.dignityincare.org.uk/Discuss-and-debate/download/354/

https://www.dignityincare.org.uk/Discuss-and-debate/download/363/

should ideally be read and thought about, before reading a piece in which I propose 'rules for' the decision-making for CPR when family-carers and 999 paramedics are interacting and a loved-one is in cardiopulmonary arrest (CPA):

# https://www.dignityincare.org.uk/Discuss-and-debate/download/360/

And to close this piece - which I offer mainly 'as food for thought' - I would point to my PDF at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/362/

In it, you will find some tweets that started with one posted by Lucy @TheSmallPlaces at:

https://twitter.com/TheSmallPlaces/status/1103944978223505408

The tweets that Lucy and I exchanged, reveal yet another 'perspective difference' in the context of the Mental Capacity Act and its purpose.

Written by Mike Stone, April 2019

@MikeStone2\_EoL