The Ambitions Framework, Signatures, Authority, Recommendations and Contributions to good End-of-Life-Behaviour

A contact of mine, recently suggested that I would be familiar with '**Ambitions for Palliative and End of Life Care:** A national framework for local action 2021-2026' and I wasn't sure if I was, so I checked. It is the second version of something which rings a few bells – I've a feeling I read the original version some years ago. You can find Ambitions at:

https://www.england.nhs.uk/eolc/ambitions/#:~:text=The%20Ambitions%20framework%20was%20developed,at%20local%20level%20throughout%20England

If you follow the link, the webpage outlines what Ambitions is:

Ambitions for palliative and end of life care

The Ambitions framework was developed by a partnership of national organisations across the statutory and voluntary sectors. It sets out our vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England.

- **Ambition 1 – Each person is seen as an individual**
- **Ambition 2 – Each person gets fair access to care**
- **Ambition 3 – Maximising comfort and wellbeing**
- **Ambition 4 – Care is co-ordinated**
- **Ambition 5 – All staff are prepared to care**
- **Ambition 6 – Each community is prepared to help**
-

National palliative and end of life care (PEoLC) aims and objectives align to the Ambitions for palliative and end of life care national framework and further information is available on the Future NHS PEoLC Network. To request access, email: england.palliativeandendoflife@nhs.net

There is also an Ambitions catalogue available via Health Education England, which hosts all of the Ambitions Partnership publications.

The actual Ambitions PDF can be downloaded from:

https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf

Ambitions lists who is part of its ‘partnership’ on its page 3:

National Palliative and End of Life Care Partnership

Age UK
Association for Palliative Medicine
Association of Ambulance Chief Executives
Association of Chartered Physiotherapists in Oncology & Palliative Care
Association of Directors of Adult Social Services
Association of Palliative Care Social Workers
Association of Supportive & Palliative Care Pharmacy
British Geriatric Society
British Lung Foundation
Care Quality Commission
College of Health Care Chaplains
General Medical Council
Health Education England
Hospice UK
Local Government Association
Macmillan Cancer Support
Marie Curie
Motor Neurone Disease Association
National Bereavement Alliance
National Care Forum
National Palliative Care Nurse Consultants Group
National Voices
NHS England and NHS Improvement
Palliative Care for People with Learning Disabilities Network
Patients Association
Public Health England
Queen's Nursing Institute
Royal College of General Practitioners
Royal College of Nursing
Royal College of Occupational Therapists
Royal College of Physicians
Social Care Institute for Excellence
Sue Ryder
Together for Short Lives

I like Ambitions – whereas I dislike the ReSPECT form in its current version – although I am not persuaded that the co-operative working sought by Ambitions is in reality achievable, across so many different groups. Myself, I have spent years trying to get NHS guidance and protocols to sensibly describe ‘co-operative working’ between the regularly-involved clinicians (GP and District Nurses), family-carers and relatives, and suddenly-introduced clinicians (usually 999 Paramedics). And so far, I have failed – because ‘the NHS’ seems unable to accept that ‘family-carers have agency’.

Much of my reasoning and analysis, is based on the Mental Capacity Act – see a long piece I wrote about a year ago (the PDF you can download), that seeks to explain MCA Best Interests **(ref 1):**

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-think-we-need-a-different-way-of-explaining-and-teaching-the-Mental-Capacity-Act-MCA/1114/

The NHS is increasingly committed to the idea of 'forward planning' and in particular to documentation of forward planning, so Future Care Plans, Advance Care Plans, Emergency Treatment Plans and other things which end with 'plan' abound. As I pointed out at the end of one of my recent pieces **(ref 2)**

https://www.dignityincare.org.uk/Discuss-and-debate/download/454/

I will stress, that it isn't the usefulness of 'planning ahead' which I object to – my objections are to 'clinical control of the documentation of that planning ahead'. As I wrote in that BMJ rapid response:

Once, husbands 'owned their wives' - but no longer: and clinicians do not 'own their patients'. Until patient records contain within them the 'right' signatures (at the very least, the possibility of the right signatures being present: I accept that it might be difficult for patients and family members to sign such documents, but they should definitely not be prohibited from signing them) - signatures based on authority, responsibility and involvement, and not simply on whoever happens to be 'the senior clinician' - there will in my opinion never be satisfactory integration between the many people who are typically involved in supporting, and caring for, patients.

I will also point out, that I am very suspicious [based on my own limited experience in 2008] about the understanding of EoL-at-Home within the police. I am not persuaded that the average police officer understands the complexity of the situation when patients are dying at home, with the extremely complex issues around both communication and 'who can legitimately make which decisions'. By excluding the signatures of family-carers [and patients] from 'NHS documentation' that gives the impression 'that the doctor [or sometimes the nurse] makes the decisions' - it simply isn't true, and family-carers are not 'mere passive observers'.

I'm not quite clear, exactly how 'a recommendation' – and the ReSPECT form presents itself as being 'a recommendation' – fits in with the law-and-logic of End-of-Life-Decision-Making, so I will be looking at that. I will also be looking at the issue of planning ahead, and what exactly it is which can 'be projected forwards in time': which will involve considering how decisions are made **in the now**.

I am hugely vexed by the current attitude – as I must stress as I discern it from the guidance, policies and protocols which I come across – **around whether family-carers and relatives should be trusted by default**, by 999 Paramedics. I recently sent a question to Coroners **(ref 3)**

https://www.dignityincare.org.uk/Discuss-and-debate/download/469/

after a brief conversation I had with a Paramedic who was 'reception staff' at a Coventry University Open Day. As I said in my e-mail to the coroners:

I was recently talking to a Paramedic at a Coventry University open day. It was a brief conversation, during which he said what amounts to 'I would never accept a relative's word that the patient wouldn't want CPR - I would always [if it appeared that CPR might be clinically successful] attempt CPR unless there was documentation'. He also said, that he believed he would be in trouble with the Coventry Coroner, if he did believe the word of a relative.

As it happens, as a coroner helpfully pointed out in a reply to me: 'It is not within the coroner's remit to advise paramedics how they should approach their professional practice'. So coroners cannot, within their remit, 'tell 999 Paramedics that the word of a family-carer should not be accepted as being truthful'.

On page 10 of Ambitions, in its Executive Summary section, we can read:

The need for honest conversation and the importance of joined up care are as important for carers and families as individuals. The need for support from, and for, empathetic and competent health and care staff is as important for carers, families and those who are bereaved, as it is for the dying. As is the help that can be given by the communities of which we are part.

We need to have a nation where each death matters. This means extending our concern beyond the care required by those living with predictable life-shortening illness, to ensure a better response from the health and care system and from society, to sudden, unpredictable or very gradual dying.

It was a well-known fact, over a decade ago when I used to discuss EoL/MCA/CPR with the head of an EoL Care unit at the DH, that care and planning was [often much] worse, if you were not dying from something 'predictable' – and unpredictability should not be 'a shock' in the context of end-of-life. As I pointed out in a piece I wrote about Advance Care Planning in 2018 **(ref 4)**

https://www.dignityincare.org.uk/Discuss-and-debate/download/325/

In EoL, sometimes things can happen – clinical deterioration or clinical improvement which wasn't predictable, or a 'clinical development in an unanticipated direction' – which can throw a spanner into 'the best-made plans of mouse or man'.

I also pointed out, that 'organise a meeting' – which prima facie seems to be a 'directive' within a lot of ACP guidance – isn't how EoL-at-Home will in reality work:

Often there is no alternative to the decision being made by a group which is a happenstance mixture of patient, family, GP and nurses [depending on who happens to be present] and very often 'common-sense compromises' will be adopted: not 'idealised decision-making' and not 'theoretically-perfect decision-making', but decisions which 'everyone settles for'. It is a case of 'compromising and 'muddling through'' in many situations.

I will now consider how decisions about life-sustaining interventions are made [in the context of English Law] and where 'a recommendation' fits in. The place to start, is to consider how a decision would be made **NOW**. And, as it is the situation at the heart of my objections to the current 'professional mindset', my chosen situation will be the one I frequently write about **(ref 5** – the **first** PDF you can download there) https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/

of a 999 Paramedic and a family-carer standing next to a collapsed loved-one/patient, who the paramedic determines is in cardiopulmonary arrest, and the paramedic moving to attempt cardiopulmonary resuscitation at which point the family-carer forcefully says 'Don't do that – I know he wouldn't want CPR'.

If the paramedic believes that CPR could definitely not be clinically-successful, then the paramedic probably would not move to start CPR – so, we will assume that in our scenario it is possible that CPR might restore life by restarting the patient's heart. It follows, that we need to understand why, if CPR might restore life, it would be legally-correct to **not attempt CPR**. If you prefer, think of it as we need to understand why it would be legally-correct to attempt CPR – however, it seems clearer to me to think of the legal-justifications for withholding a potentially life-sustaining treatment.

For much longer than I believe was helpful, we knew that it must be possible to form a legally-justifiable best-interests decision to withhold potentially-successful life-sustaining treatments, but it wasn't clear 'what the justification is'. The 'Briggs' ruling by Mr Justice Charles can now be referred to when we seek to answer that question. I have frequently written about the significance of the Briggs ruling in the context of CPR decision-making, and understanding Briggs is so important that I have devoted Appendix 1 to the Briggs ruling. I will also discuss it here, in the text, and I will also point the reader at **(ref 6):**

https://www.dignityincare.org.uk/Discuss-and-debate/download/459/

The only accessible way of describing that ruling amounts to what I have been writing since the ruling, and it is 'If we feel sufficiently certain that the patient would have refused the treatment, then the treatment should be withheld – and if we are not sufficiently certain the patient would have refused the treatment [or if we believe the patient would have requested the treatment] then the treatment should be applied'. There are some caveats around what I've just written – it is probably only true in a specific type of situation, and there is an issue with what Mr Justice meant when he used the word 'generally' - but it is aligned with something the BMA and RCP told 'family and friends': '*A best interests decision is based on the person's past and present wishes, feelings, values and beliefs. It should be the decision the person would make for themselves if they could.'.*

The BMA and RCP, in their leaflet 'Clinically-assisted nutrition and hydration: your role in decision-making - A guide for family and friends', states:

A best interests decision is based on the person's past and present wishes, feelings, values and beliefs. It should be the decision the person would make for themselves if they could.

Now, as I point out both often and forcefully, the BMA and RCP are wrong to assert that 'the role of the family and friends is to help the doctor to make the best-interests decision', but here I will point out that the leaflet seems to be describing, with no clear qualification, 'substituted judgement' with the sentence '*It should be the decision the person would make for themselves if they could.*'.

Substituted Judgement is the legal concept of 'working out what the patient would have decided, and doing that'. Best Interests is different, in a way that nobody can clearly explain: Best Interests requires the decision-maker to work out what the patient would have decided, but 'conceptually there are then other considerations as well'. What Mr Justice Charles wrote in Briggs, is close to stating that Best Interests is Substituted Judgement, but he did add 'the caveat':

62. But, in my view when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self determination which an individual with capacity can lawfully resolve and determine by giving or refusing consent to available treatment regimes:
i) the decision maker and so a judge must be wary of giving weight to what he thinks is prudent or what he would want for himself or his family, or what he thinks most people would or should want, and
ii) if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.

In 62 ii) Mr Justice Charles uses the word 'generally', which to a scientist means 'always' - here, however, I think Mr Justice Charles intends 'generally' to mean 'almost always'.

Whether Mr Justice Charles meant 'always' [in this type of situation] or 'almost always', the rationale he arrived at - 'I am persuaded to a sufficient degree of certainty that this patient would have refused the intervention' - does seem to be the only obvious way to withhold a potentially life-sustaining treatment, while complying with section 4 of the MCA.

PLEASE NOTE: IMPORTANT This is NOT 'understanding that the patient has made and expressed the decision in advance of incapacity' - that is a part of the law of self-determination/informed-consent, and in the MCA that is where the provision for Advance Decisions comes from. The point being, that there 'the patient was the decision-maker'.

What Mr Justice Charles was stating, is that **without the patient having clearly expressed** 'the decision he would make in this situation', the person making the best-interests decision should 'work out the decision which the patient would have made, if the patient had considered the situation': here the decision-maker, is still the person making a best-interests decision.

The relevant law for best-interests decision-making, is given in sections 4(6) and 4(7) of the Mental Capacity Act:

[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.

[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).

It might be possible, to argue that 'recommendations recorded in the past, which I am reading now' do fit somewhere within 4(6) and 4(7), even though 'recommendations' are not specifically mentioned: I will return to this later. I will at this point, discuss section 3 of the current version of the ReSPECT form.

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me	**Quality of life and comfort matters most to me**
What I most value:	What I most fear / wish to avoid:

Surely this, on any document, is in fact what is described in MCA 4(6) in the context of something written – and the Act says that a person making a best-interests determination 'must consider … in particular, any relevant written statement made by him when he had capacity'. It says MADE BY HIM – which to me, means 'written, and then signed by, the patient' in the clearest case of a written record. So – **why does ReSPECT not allow a capacitous patient to complete and sign section 3 of the ReSPECT form?**

In Ambitions, on page 15, we can read:

2. Shared records

To ensure the plan can guide a person centred approach, it has to be available to that person, so that they can review, change and update it themselves. Subject to that person's consent, or, if they lack mental capacity, in their best interests, the plan should also be shared with all those who may be involved in their care. All electronic systems for sharing health related preferences must encompass the recording and sharing of preferences at the end of life.

I point to the end of the first sentence above: [the plan] **has to be available to that person, so that they can review, change and update it themselves.**

It seems to me – and unquestionably ReSPECT is a variety of 'plan' which can be involved during end-of-life situations - that Ambitions says, <u>or at the very-least</u> **<u>implies</u>**, that capacitous patients must be given direct control over written descriptions of their 'preferences/wishes', whereas ReSPECT stubbornly refuses to allow patients to do this: so, surely the ReSPECT form is not in line with something (Ambitions) which both NHS England and the Association of Ambulance Chief Executives, not to mention the General Medical Council, seem to be 'signed-up to'.

To return, briefly, to 'recommendations' as an MCA concept. Section 42 of the MCA says that clinicians 'must have regard to any relevant code' and the relevant code is the MCA Code of Practice, the original version of which tells us in its section 5.31 'Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.'. It could be argued, that professional guidance **could say** 'consider recommendations recorded by a doctor' when making a best-interests determination. But the MCA does not say what that 'professional guidance' should say – and logically, professional guidance **could say** 'any document which in effect records best-interests recommendations, should ideally have those recommendations written and signed by any legal proxy who would if present have legal authority over best interests decisions'. I point the reader, back at page 3 of this PDF.

Returning to our scenario/s, with the loved-one/patient in cardiopulmonary arrest, and a 999 paramedic and a family-carer. Such scenarios are described in my ref 5 (the URL at the top of page 6 goes to ref 5). Here, I will 'use' what I included in my e-mail to coroners (ref 3) – the situation is at the start (in bold text) of the text in the box on the next page.

In a nutshell, imagine that I am sharing a home with my terminally-diagnosed father. On a Sunday evening, my dad makes it crystal-clear to me that he would never want CPR to be attempted. Suppose at the end of a [lengthy] conversation, my dad says '... we'll sort this out when the GP visits tomorrow afternoon'. Now suppose, that the following morning (so before the GP's visit) my dad collapses, and I think his heart has stopped. I might not be 100% certain that my dad's heart has stopped: I would like to summon 999 to confirm the collapse is due to cardiopulmonary arrest [and not, for example, a collapse with a stroke - which my dad would want treatment for if the stroke wasn't going to kill him]; I would be 100% sure that my dad didn't want CPR if it was a cardiopulmonary arrest; so if I also believe that if I involve 999 Paramedics they would attempt CPR whatever I said to them, should/could I 'risk' calling 999?

It is stressful when a loved-one is dying. The paramedic I was talking to, correctly said 'I don't know the relatives - how do I know they are trustworthy'. Clearly paramedics and relatives will not know each other: but, I suspect that the majority of relatives are trying to do their best in sometimes very stressful situations. I find it intolerable, to add '... and we will distrust the family by default because they cannot prove they are honest'. It is 'accusation of all, based on a minority of 'bad apples', and with NO POSSIBLE 'DEFENCE'' (i.e. it is impossible to prove that you are being truthful, when talking to a 999 paramedic, standing over a collapsed loved-one).

If I could attempt CPR on my dad (and many people are taught CPR as first aid), then I shouldn't be attempting CPR if he had told me not to (as an aside - I know of someone who told her daughter 'don't attempt CPR on me' and discovered that her daughter said 'well - I'd attempt CPR anyway, whatever you've said to me'): and if I could attempt CPR but I wasn't going to do it because my dad had told me not to, I wouldn't phone and involve someone who might then attempt CPR, would I?!

Do we want a co-operative future, with well-informed relatives and 999 Paramedics working together to support dying loved-ones/patients? Or do we want a confrontational future, with well-informed relatives and 999 staff increasingly 'at war with each other'? So far as I can see, relatives are not required to involve 999 staff:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/DNACPR-at-Homeand-a-Twitter-thread-what-is-the-legal-situation-for-relatives/1110/

At the moment, I find that I have to tell relatives what amounts to [for the scenarios of the type I've described] '999 Paramedics are not told to trust you as the default position - so, unfortunately, you can't 'trust' 999 Paramedics, and you need to consider whether to involve them or not'. Which ISN'T what I would like to be writing. It is not the fault of relatives and family-carers that sudden and unanticipated clinical events sometimes happen during EoL.

It is not the fault of relatives that we are often there to listen during EoL-at-Home, while clinicians are not normally present in the home. I suspect, that if you asked EoL doctors 'what is the most-important thing?' most of them would say 'listening to the patient'. It simply isn't either reasonable or acceptable, to imply/suggest that our listening to our loved-ones 'doesn't count because no clinician was also present to listen' when a clinician will [almost] inevitably not be present to listen.

When I come across the assertion that 'we should not trust any relatives, because some relatives are nefarious' I am angered whoever is making the assertion - doctor, nurse or paramedic. Nurses, around CPR, tend to think '... but if I don't attempt CPR, then the NMC ...'. And nurses have, unfortunately, got good reason to be terrified of the NMC.

It is paramedics, who say '... if I accepted what I'm being told by the family, the coroner would ...'.

Regards, Mike Stone

I have had paramedics say to me ‘If the relative didn’t want us to treat the patient, then why did the relative call us!’. The answer is that relatives are not clinicians. A relative or family-carer can be as certain as it is ever possible to be, that their loved-one does not want CPR if the heart has stopped – but, we might not be certain that our loved-one’s heart has stopped beating. And refusing CPR, is not the same as refusing other treatments – an obvious one, would be if the collapse was not cardiopulmonary arrest and in fact was a collapse due to a stroke, the loved-one would probably want prompt treatment if the stroke was not going to be rapidly fatal. So – **we might have called 999 to establish the clinical situation**.

Thinking about how my scenarios compare to the Briggs ruling, Mr Justice Charles had to, during the court case, convince himself that Mr Briggs would have refused the continuation of CANH – whereas my relative is already sure that if their loved-one’s heart has stopped beating, their loved-one wouldn’t want CPR. The 999 Paramedic who arrives, has no idea about what the patient would have wanted until he or she has arrived – there is no relevant documentation about CPR, but a family-carer is telling the paramedic that CPR wasn’t wanted by the patient.

On page 16 of Ambitions we can read:

6. 24/7 access

Every person at the end of life should have access to 24/7 services as needed as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for ‘opening hours’. This is a necessary system-wide expectation and good end of life care cannot be achieved without it. All commissioners and providers have to engage in defining how their services will operate to ensure expert responsiveness to needs at any time of day and night.

I can’t believe, as I write in January 2023, that the above is not still an aspiration in the context of the ‘immediate availability’ of GPs to contribute to records. I have heard of cases when a near-to-death patient is in agony, and a family-carer struggles to obtain prompt pain-relief for their loved-one – **so ‘24/7 attendance by a GP to update EoL records’ seems to me to be something which isn’t going to happen**.

What options, are in reality available to the father and son in my scenario on page 10 – which is in fact the scenario I used in a survey about a decade ago **(ref 7 – ‘Father and Son’ scenario)**:

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

Even if the father and/or the son is aware of the provisions for an Advance Decision to Refuse Treatment inside sections 24 – 26 of the MCA, it doesn't help. It is a Sunday evening – who would witness an ADRT even if the father wrote an ADRT refusing CPR? They can hardly 'drag in a stranger off the street' to witness an ADRT. So the only option would be for the son to witness the Advance Decision. The MCA does not prevent a relative from being the witness on an ADRT – from ref 1, pages 48/49:

Professionals could reasonably stop 'going beyond the Act' and writing 'guidance' which merely makes life simpler for them. For example, it isn't reasonable to assert (and I do come across this assertion – certainly, I used to come across it) that close relatives cannot witness a written Advance Decision – that isn't reasonable because it isn't present in the Act:

(From a lawyer when I mentioned this issue of the Act simply requiring a witness, but various professionals 'claiming' a close relative cannot be the witness in 'guidance')

From me to the lawyer:

Yes, in a sense re rabbit hole.

You have not yet told me whether you tell protocol writers that any person over 18 can witness an ADRT? If policies said that R can witness an ADRT, even if R is a spouse, child or family-carer, then I would tend to spend less time going down rabbit holes! It is hugely problematic adopting an approach of 'explain the MCA without getting all legally nerdy' when at some point lawyers (not pointing any fingers here - but you are a lawyer!) will get legally nerdy when talking to HCPs! It is a problem I have not yet resolved (and, getting nerdy, section 42 makes it legally impossible to 'advise' most relatives - despite that the BMA etc does keep 'stating what the law means' in its material for patients and families).

From the lawyer to me:

Witnessing of ADRTs is an area of real difficulty. The Act is silent as to witnesses (except that you need to have one), and the current Code doesn't say anything either way about who can do it. It is a bit like the situation with contemporaneous assessment of capacity to make the ADRT, which doesn't feature in the Act or the Code. But given the deep distrust that still exists amongst many about ADRTs, and the fact that they can be 'broken' and not considered to be binding if they are found to be invalid/not applicable, my view is that it's always sensible for the person completing the ADRT to think about how best to insure that they are binding.

Choosing someone as a witness who has a personal connection always *and inevitably (even if it shouldn't) opens the door to someone who wants not to follow the ADRT to challenge the role of the witness (for instance that they might have coerced the person into signing).*

So, my view is that you can always stick to the letter of the law and have anyone you want (because the Act says so) but that you should be aware that if you do then you are potentially opening the way to a problem later, at a point where (by definition) you won't be in a position to do anything about it.

I think, if time allows (and sometimes it wouldn't – in my Father and Son scenario, even if they knew about ADRTs and the father wanted to create one, who except the son could witness it: are you expected to 'drag a witness in off the street' at 9pm of an evening?!), it would be useful to add subsequent 'witness' signatures to ADRTs anyway. If created by a patient who asked a relative or friend to initially witness it, subsequently as events allowed to add the signature of a GP or District Nurse – and, if an ADRT were created in hospital and witnessed by a clinician, as events allowed the signatures of family-carers could be added.

If subsequently-attending 999 Paramedics are unwilling to accept the signature of the son as the witness on an Advance Decision which the father wrote, then those paramedics are not going to accept that the son's description of the conversation the evening before is true – and if paramedics will accept the truth of what the son tells them, then the written ADRT is pointless in the situation of the scenario, anyway.

It is clear – and this is true even if relatives and family-carers have never even heard of the Mental Capacity Act – that any family-carer or relative who is honestly saying '… I'm SURE my dad would be refusing CPR!' is in reality 'expressing a best-interests 'outcome''. As the BMA and RCP stated, (page 7) '*A best interests decision is based on the person's past and present wishes, feelings, values and beliefs.* ***It should be the decision the person would make for themselves if they could****.'* It is absurd to not regard the family-carer as being 'the expert in the patient as an individual' and the paramedic as the expert in the clinical situation. Two relatives, if both present, might have different opinions about whether a loved-one would have accepted or refused CPR – and I'm sure those relatives would be 'unhappy' that for some reason, they were not agreeing with each other. But those <u>disagreeing relatives would both be disagreeing from an informed position</u> – **we cannot have what amounts to 'a 999 paramedic saying to the family 'I understand what your dad would have wanted better than you do''. And unquestionably, the logic of the Briggs ruling means that it is 'the people who know the patient as an individual' who are best-equipped to make a best-interests determination around CPR** (the family-carers are also the people who have been the most-present-to-listen to their loved-one). **If 999 paramedics simply refuse to believe 'the unsupported word of' family-carers and relatives, then the logic of the Briggs ruling cannot be applied to the situations I write about – and, from the perspective of a family-carer, I/we must surely conclude 'The 999 Services do**

not trust us – so we cannot trust them, and we need to decide if we can involve 999 or not'.

The objective during a cardiopulmonary arrest at home can be stated in various ways – here, I will state the objective as being 'to allow the patient to die in peace, without CPR being attempted, if that is what the patient would have wanted'. In Briggs, the objective of Mr Charles was to decide if Mr Briggs would have wanted CANH to be withdrawn, if I use comparable phrasing. The **process** in Briggs, is that during a court case Mr Justice Charles established the clinical situation and then formed a view as to what Mr Briggs 'would have wanted'. Judges typically ask clinicians to explain the clinical situation, and judges ask 'family and friends' to describe the values and beliefs of the patient: **those things are what clinicians and relatives <u>contribute to</u> the process**. Also, the judge is de facto 'the decision maker' and however brief the time available for the court to arrive at a decision, there is much more time available in a court, than there is in my relative-and-999 Paramedic scenarios. But the CONTRIBUTIONS must logically be the same as in a court: the paramedic contributes 'the clinical situation' and the relative contributes 'understanding of the patient as an individual'.

There is in fact one other difference: there is not 'a decision maker' in my scenarios. It is often implied, or even explicitly stated, in clinically-authored 'guidance for relatives' that in my scenarios the paramedic is the best-interests decision-maker. This isn't true – that isn't what the MCA says. Many things are true in the scenarios I write about, including: the paramedic is expected to apply the MCA; the relative might never have even heard of the MCA; the relative cannot 'order' the paramedic to do, or not do, anything; the paramedic cannot 'order' the relative to do, or not do, anything; many relatives will be unfamiliar with the way the 999 Services behave; and the legal situation is different for the relative compared to for the paramedic.

The legal situation for the relative, is so far as I see (and I've discussed this with lawyers and doctors) is what I have described online, and I will [with a considerable degree of annoyance!] point out that we relatives are almost never told this by clinical authors – **(ref 8*)*:**

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/

See also **(ref 9)**:

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

A long PDF, which examines the issues in detail, which I'll label as **ref 10** and which I would recommend to readers, can be downloaded from ref 9:

https://www.dignityincare.org.uk/Discuss-and-debate/download/468/

Ref 8, unusually, is not a long PDF but instead is a fairly short webpage – it will be useful for me to reproduce it here:

> During a recent Twitter thread, Dr Kathryn Mannix posted some tweets, and I want to analyse one of them. It will be much easier to do that here, than on Twitter. Two of Kathryn's tweets, joined together here, were:
>
> 'if in the same emergency, a family that knows a person doesn't want CPR should be able to access HCP help (eg for symptom management) & have their knowledge of the patient's wishes respected, with or without that guidance document*. Also if family understand either that a person is dying (CPR won't work) or that person declines CPR, they should not feel obliged to start CPR or to send for emergency services if the person dies. The person's decision should be respected. HCPs should respect that too.'
>
> * Earlier in the Twitter thread we had been discussing documentation - things such as the ReSPECT form and DNACPR documents - which relate to CPR/DNACPR.
>
> I am going to briefly analyse:
>
> '... if [the] family understand either that a person is dying (CPR won't work) or that person declines CPR, they should not feel obliged to start CPR or to send for emergency services if the person dies. The person's decision should be respected. HCPs should respect that too.'
>
> I will start with a general observation: some relatives, however 'prepared', will I suspect 'panic'. And in the situation of a loved-one dying, nobody should be overly-critical of 'how relatives react or behave'. So, I can now do 'should the relative/s feel obliged to attempt CPR and/or to call 999'?
>
> 1 THE PATIENT WAS CAPACITOUS PRIOR TO THE ARREST
>
> 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'. And if your loved-one was lacking in mental capacity before the arrest, then a relative is probably already 'engaged with' the MCA - so I will now discuss that situation.

2 THE PATIENT WAS NOT CAPACITOUS PRIOR TO THE ARREST

If your loved-one is already living with severe dementia, as an example, then family-carers are legally required to apply the MCA (technically, properly applying the MCA provides a legal defence - here a defence for not attempting CPR and not summoning 999). We know that lay folk are capable of applying the MCA: because suitably-empowered Welfare Attorneys can be given authority over best-interests CPR decision-making. And there is no reason to believe that being appointed as a welfare attorney magically improves your understanding of the MCA: it is reading the MCA, etc, that allows a relative to understand its best-interests concept. Being appointed as an attorney, gives you AUTHORITY - it doesn't magically impart a better understanding of the MCA.

I will point out - if a clinician becomes involved before your loved-one is definitely dead, the clinician is also required to apply the same MCA: so, we have relatives and clinicians both trying to apply the MCA, but usually with each being sure of very different things. Ideally, we would have only 'a single mind' which understood what the relatives know, and also what the clinicians know: a mind that knew the patient as an individual and which had been 'listening to' the patient, and which also understood the clinical situation.

This situation of incapacity before the arrest, is also one in which 'advance planning' is much more likely to have already taken place - the family and the GP may well have discussed things, with 'supporting documentation'.

But - if a relative involves 999 before the loved one is definitely dead - then we have relatives and paramedics, who each usually know different things, interacting 'in a fraught situation and when nobody involved has much 'thinking time''.

3 SOME FURTHER COMPICATIONS

A lawyer, insists that a verbal refusal of CPR is not legally binding, so however-clearly my dad has told me 'I would NEVER want CPR', if he arrests without having created a written Advance Decision refusing CPR, then I have to make a best-interests decision about CPR. From my family-carer and 'present much of the time' position, I can't 'swallow that' - I know my dad has refused CPR, and I am 'just going to respect his decision'. For me, I am respecting my dad's autonomy - which is not part of the MCA's best-interests framework. I think, that looks different at 1pm in a court on a Tuesday, compared to 1am in a bedroom on a Tuesday. And, there is also a complication in that relatives talk and listen to become informed, while HCPs spend a lot of time reading written notes.

For further reading, try my pieces here;

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

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

https://www.dignityincare.org.uk/Discuss-and-debate/download/325/

As I have already pointed out, the MCA doesn't allow relatives and clinicians to 'order each other to do, or not do, things' – the MCA simply provides a legal defence for anyone who can defensibly claim to have 'satisfied' section 4(9) of the MCA. Only if a Welfare Attorney or Court Deputy is involved, and section 6(6) of the MCA applies, can a person (the legal proxy) 'tell other people what to do, or not do'.

How can a newly-involved 999 paramedic, decide whether or not to attempt CPR in scenarios such as those I write about? I have pointed out, in **ref 11**,

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

how it is possible to arrive at ‘rules for 999 paramedics’ without any assessment of a relative’s honesty, and without any assumption that the relatives understand the MCA. I will reproduce part of ref 11 here:

> Obviously, the newly-introduced 999 paramedic cannot understand the 'mind of' a collapsed patient, who they had never met before. I will concentrate on decisions about CPR - which is where this discussion started.
>
> During some recent e-mail discussions of Dr Taubert's paper, a paramedic threw in: '[if] CPR was not the reason I was called, was not what was requested, and what most certainly is not what was wanted by the family, and more often than not the patient themselves (says who – well the person who firstly called me, and secondly spent every night in the company of said individual for the past 60 years – it must be assumed they know the deceased better than me! – having never met them before!!)'
>
> How do we turn the obviously correct logic of that - 'it must be assumed they know the deceased better than me!' - into acceptable behaviour, when the paramedics cannot be certain of the background?
>
> Now, unfortunately, even if we trust everyone, and accept that all family-carers are acting 100% honestly, it doesn't follow that all family carers will agree about what the patient would have wanted to happen: often, the family-carers will all agree, but 'honest disagreements' are possible even within 'well-informed family-carers' and must be accepted. What I cannot accept, is the idea that a 999 paramedic can understand what is in the patient's best interests, better than the patient's close family and close friends.
>
> How might this be joined together, applying my 'first do not insult' principle, but also respecting the situation of the 999 paramedics and the law's 'preservation of life' fall-back position?
>
> This is what I would suggest - I started to describe this sometime around 2014. The paramedic, after describing the clinical situation, treatment options and prognoses, asks all of the carers present 'are you sure of what the patient would want us to do?' - so, for CPR that simplifies to 'do you know if he would want us to attempt CPR?'.
>
> Then, the paramedic believes the answers [by default] assuming the carers are reasonably 'calm and composed', and:
>
> **If all of the carers say 'I know she wouldn't want CPR' then the paramedics DO NOT attempt CPR;**
>
> **If some of the carers say 'I don't know' but one or more firmly say 'I know she wouldn't want CPR' then the paramedics do NOT attempt CPR (this one is perhaps contentious - it requires debating: see the footnote);**

If all of the carers say 'I don't know' then the paramedics DO attempt CPR;

However many carers say 'I'm sure he wouldn't want CPR', if even one carer says 'I'm sure he would want CPR' then the paramedics DO attempt CPR.

Footnote: the premise, is that any family-carer who promptly and 'forcefully' says 'I'm sure my dad wouldn't want CPR' will have a good reason to say that – but not reasons which could be elaborated during an arrest beyond 'because he's made it clear to me!' - so, presented with such 'certainty' from one or more relatives, any other relatives who are only willing to say 'erm … I'm not sure' are not refuting the assertion strongly enough.

The first of those [rules above] respects the family-carers 'by not insulting them' - and the final one respects the 'fall-back of preservation of life when things are uncertain' principle.

And, I myself would never say 'my dad wouldn't want CPR' unless I had a very firm understanding of that - quite why it should be assumed that relatives are likely to give 'firm answers' without 'certainty that they are right' puzzles me.

And: this is **much simpler for CPR** - it is much more difficult for things such as strokes in my opinion. You can be sure that 'CPR isn't wanted': either because your loved-one has made it very clear to you that CPR is not wanted, or because your loved one has made it clear 'I would now prefer to be dead'. It is probably also 'simple' for a refusal of blood transfusion made on religious grounds. **It isn't simple**, if it turns out your loved-one has collapsed, seems to have suffered a stroke, and the paramedic says 'looks like a stroke - might be dying, but might live on with a lot of clinical damage - if we don't treat he might die within minutes but he might not die, and he might live on with clinical damage which would be reduced if we did treat him'.

That level of certainty is in reality not 'making a best-interests decision during an arrest' – it is in fact the application of the patient's self-determination during the arrest. And although it seems clear that conceptually, if it were possible to 'consider a best-interests decision during an arrest' then that decision would in fact be the answer to 'would dad want CPR or not?', it is in reality unrealistic to expect genuine best-interests decision-making to be taking place during a cardiopulmonary arrest (CPA).

If we change my scenario by replacing the 999 Paramedic with a GP, the situation is still as I have already written: the GP cannot 'order relatives about' and relatives 'cannot order the GP about'. If we **add** a GP to my scenario – so now we have the relative, the paramedic and a GP – then section 42 of the MCA (see page 9) might give a sort of [to use my term here] 'weird pseudo-legal authority' to one of the clinicians over the other. But that is so complex, it is not really worth investigating here. We can add more relatives – they cannot ‘order each other about either’.

Everyone, should be trying to do what is best for the patient/loved-one, which here I will assume is to apply the MCA’s concept of Best Interests: applying the MCA’s best-interests requirements correctly, gives **each individual** legal protections. The reason things change if we introduce a Welfare Attorney [whose powers extend over life-sustaining treatments] to the mix is that once the attorney has expressed a best-interests decision, sections 6(6) and 6(7) of the MCA apply – summed-up correctly in the final two sentences of section 7.29 of the original Code of Practice:

If they cannot settle the disagreement, they can apply to the Court of Protection (see paragraphs 7.45–7.49 below). While the court is coming to a decision, healthcare staff can give life-sustaining treatment to prolong the donor’s life or stop their condition getting worse.

Now, if the attorney says ‘do not attempt CPR’ and there isn’t already an application to the Court of Protection, then I don’t see that life-sustaining treatment can be given because the situation wouldn’t be ‘**while** the court is coming to a decision’.

If we assemble these various combinations of people before an arrest but after the loved-one/patient has already ‘lost mental capacity’ - so it would presumably be relatives, GP and perhaps district nurses in the home – then there is time to discuss ‘what should happen **if the loved-one/patient’s heart stops in the near future**’. They might all agree, or there might be disagreement. If a ReSPECT form which had been created previously was present – perhaps a ReSPECT form created a fortnight before when the patient/loved-one was in hospital – then it might be looked at. But it would surely be viewed as information. I would much-prefer the ReSPECT form to present itself as ‘information to be considered’ and not as ‘a recommendation’. Sticking with CPR, and ‘projection forwards of this group’s considerations’, I stand by what I wrote in the first of the PDFs which can be downloaded from my thread critiquing ReSPECT:

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/

It is surely logically the case, that **in the absence of an attorney or deputy with authority** over best-interests decision-making conferred by 6(6), after the discussions between the various parties involved in the ongoing care of an already incapacitous person, **there will often be a group of people** – loosely, I’ll here write ‘ a group composed of family and clinicians’ - **who can each individually say** ‘my decision would be ‘whatever’ - and I think I can claim to have made that decision in compliance with section 4(9)’

That situation is only clear, if all of that group believe the same recommendation would be in the patient’s best interests: but in such a situation, logically the most ‘compelling and legally defensible’ thing on the form, which would then be read by someone such as a 999 paramedic, would be along the lines of:

‘We the undersigned, have discussed whether it is likely to be in this patient’s best-interests for CPR to be attempted, and we hereby sign to confirm that we all believe that DNACPR is in the patient’s best interests – we also confirm that to the best of our knowledge, no sufficiently well-informed person has expressed the opinion that attempted CPR would be in the patient’s best interests’

SIGNED BY EVERYONE – family and clinicians.

If there is disagreement, then even if the doctor believed that attempted CPR would be in the patient’s best interests, if a welfare attorney had said ‘DNACPR is in the patient’s best interests’, it looks very ‘dodgy’ for the doctor to ‘recommend’ on a document that CPR should be attempted. Thinking in a non-nerdy way, surely the patient wanted the welfare attorney to make any necessary best-interests decisions – so presumably, the patient would also want the attorney to be the person making any ‘recommendations about best interests for the future’. There is a rather nerdy, and somewhat unsatisfactory in my view, argument about the authority of a legal proxy only being present at the time the treatment is being applied or withheld – see my piece here **(ref 12)**:

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/

More nerdily, ‘the past ended a second ago – and the future starts a second from now’. So could a doctor, in that situation of the doctor disagreeing with a welfare attorney who is present, record on a form ‘a recommendation’ which contradicted the attorney’s best-interests decision? The recommendation on the form, wouldn’t be what the doctor would actually do her/himself if the patient arrested as the doctor signed the form – assuming the doctor had any sense and had read the MCA.

Some Comments about Welfare Attorneys

Sometimes, it is implied that ‘if you don’t want the clinicians to make the best-interests decisions, then you should appoint a welfare attorney under the LPA’. That ‘idea’ can even lead, in extremis, to ‘the mindset that if the relative was trusted by the patient, then the relative would have been appointed as a welfare attorney’.

This is nonsense, and very bad thinking, for several reasons. One is that many layfolk will not be aware that they can appoint attorneys – Ambitions does say that this option should be pointed out to end-of-life patients (on page 14 of Ambitions – although its use of the word ‘offer’ could be taken to imply that the ‘offer’ comes from the Ambitions Partnership, when in fact it ‘comes from the Law’).

More crucially: some trusted people, do not want to become welfare attorneys. A friend of mine, floated the idea to two of my friend’s children, that they might become welfare attorneys. One child said ‘Fine’. The other child said ‘No – and never talk to me about this, again!’. Some trusted people, will be unwilling to be put in the position of ‘making a final decision during disagreement’. And that is the point – the attorney’s decision, sits above the views of everyone else. I suspect what troubles some people who are close to their loved-one, and who refuse to be appointed as a welfare attorney, is the thought of ‘making’ decisions about their loved-one. I suspect that ‘following their loved-one’s instructions’ is something they would be willing to do. So, if a daughter told her dad ‘Sorry – I really can’t be your attorney’ then if dad said ‘Well, if you think my heart has stopped beating, will you let me die in peace without phoning anyone until after I’m dead’ I think the daughter might say ‘Okay – I will do that’. Presumably with some consideration of the ‘it might not have been a cardiopulmonary arrest’ issue – the dad might say ‘Well, if my skin isn’t getting colder after 20 minutes, phone 999 then’.

I will throw in – **anyone who wants to be** a welfare attorney, probably shouldn’t be one. Nobody should be enthusiastic about exercising control over best-interests decision-making – **but even worse**, is to be unable to prevent clinicians from doing things which you know your loved-one would not have wanted.

The Current Mess with ‘Anticipatory DNACPR Decisions’

There is an unsatisfactory mess at present, which arises from the conflict [as I perceive it] between the obvious logic of ‘if future CPR would be the wrong thing to do, then somehow it should be prevented’ and the actual legal-situation that **the only document which in a real legal-sense ‘projects a DNACPR Decision into the future’ is an Advance Decision Refusing CPR**. I analyse this idea of ‘projecting ‘we wouldn’t attempt CPR if the patient arrested now’ into the future, as some sort of ‘DNACPR instruction’, in my piece ‘We Decide in the Now’ **(ref 13)**:

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

I point out that the most-recent CPR Policy for Wales which I've read, seems to be a bit confused about the situation of a patient still wanting CPR to be attempted when the doctors have said 'we think CPR almost-definitely couldn't work' **(ref 14)**:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-Policy-in-Wales-now-seems-to-be-to-offer-CPR-to-patients-who-request-it-even-if-the-clinicians-believe-CPR-could-not-work-and-I-approve-of-that./1116/

I have also written an Open Letter to the RCGP (and as it happens, sent an e-mail to the Kamila Hawthorne of the RCGP which includes the URL to my open letter about 30 minutes ago as I type this) pointing out that ref 2 implies that GPs have got some sort of control over whether or not a family-carer attempts or withholds CPR – the open letter, **ref 14**, is at (you need to download the PDF):

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

I've pointed out to NHS England, that its 'DNACPR webpage' (at least it did when I complained about it) is misleading for patients and relatives – it implies that a ReSPECT form will prevent CPR from being attempted: but that form is only a recommendation – it isn't 'an instruction to not attempt CPR'. The NHS webpage doesn't distinguish between the traditional 'DNACPR form' and the ReSPECT form either – which is a flaw (although traditional DNACPR forms were also very dodgy legally, they did at least 'want to be 'an instruction'' – not, as ReSPECT is, 'a suggestion').

As it happens, I would like CPR to be attempted if the patient while capacitous had requested that CPR be attempted, even when the doctors think CPR couldn't be clinically-successful **(ref 15)**:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-I-believe-that-CPR-should-be-attempted-if-a-mentally-capable-patient-had-asked-for-CPR-to-be-attempted/1051/

CONCLUSIONS

Rob Cole, the Paramedic who wrote the scenario in a Journal of Medical Ethics paper (there is a URL to the paper in ref 5) which Rob, Zoe Fritz (doctor), Alex Ruck-Keene (lawyer) and I co-authored, constructed a scenario where the patient was elderly but who wasn't ill enough for it to be expected that 'end-of-life documentation' would be in place. The crucial features of the scenario, as stated in the JME paper, are:

'An emergency call was received by the ambulance emergency operations control room. … The caller identified that her husband was experiencing a seizure, and this had lasted for 5 min prior to her calling the ambulance. An ambulance was immediately despatched on this information alone (known as pre-alert dispatch). The location was some 4 min from the crew and they therefore arrived on the scene 5 min post call (in fact, on the crew arrival, the caller was still on the phone with the ambulance control centre).

The crew were met by a female in her 70s (call with control ended on crew arrival). The crew were, as often is the case, provided with no further details other than that of a male in his 80s with a prolonged seizure. … The female greeted the crew (who had approached the property with full life-saving emergency equipment). She stated "I think he has gone" in a calm and clear voice. She allowed the crew into her home and quickly explained (during the journey to the patient, who is on a bed in the dining room downstairs) that the patient was her husband, that he had been generally unwell for some time (increased frailty, heart failure and developing dementia) and while she had not expected him to die at this point in time, she was not particularly surprised that he had. One member of the crew (double crew) prepared the patient for resuscitation, post a period of assessment while the other crew member continued to speak with the patient's wife to better understand the situation. … The member of the crew that spoke with the wife of the patient and ascertained that the patient was being treated by a general physician for a simple urinary tract infection, that there was no DNACPR in place as there was no specific requirement for one to have been put in place; no advance decision to refuse treatment (the female had no idea what this was) nor was there any legal power of attorney (the patient until this point had been broadly of sound mind with occasional episodes of confusion). As the other member of the ambulance crew commenced resuscitation (CPR), the patient's wife angrily stated that her husband would not wish for this, nor did she or any member of her family. 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 and all agreed that this was not the wish of the patient. Accepting this is not documented anywhere, the patient's wife explained that these were conversations that had taken place within the family environment, that her *husband had a clear view that he would not want to be subjected to any resuscitative efforts should he die, and funeral arrangements had been explored recently by all.'*

Rob also stated 'This is a composite case study **from my experience of many such calls** to protect the anonymity of those involved in any individual case.'.

In my own Father and Son scenario, the father is it appears rather more engaged with the NHS, and the issue is that when the father decides he no longer wants CPR to be attempted, he decides to explain this to his family first: something I suspect many patients would in fact do. I don't know how common that is – but I see no reason why it shouldn't happen.

So, we cannot argue that there is not a problem to be addressed here.

I am usually told by senior 999 Paramedics, what amounts to 'We don't distrust relatives as a mindset'.

And, the BMA and RCP tell us in their CANH guidance 'It (a best interests decision) should be the decision the person would make for themselves if they could.'.

So – **what is going on?**

Nothing that the relatives are saying is prima facie unreasonable – and if the word of the relative/s 'is trusted' then that is the only information available to guide '[whether we attempt CPR or not] should be the decision the person would make for themselves if they could'.

It isn't as if a husband says to a paramedic 'My wife collapsed a couple of minutes ago' and it turns out the wife is stone-cold and rigid – I think that would look suspicious. But 'not knowing something, when you could not reasonably expect to know it' is entirely reasonable. Something which happened very recently, not having yet become embedded within a records system, is a perfectly normal state of affairs.

If I know my dad would not want CPR, and 999 paramedics refuse to believe me and attempt CPR, it is both 'insulting to me as a person' and they are doing something my dad would not have wanted them to do.

Sadly, until I can see guidance from the College of Paramedics, the Association of Ambulance Chief Executives and the Joint Royal Colleges Ambulance Liaison Committee, which says that '999 Paramedics should believe the word of relatives and family-carers, unless there is actual evidence of dishonesty' (and similar wording in protocols and policies which pertain to deaths in the community) I will be forced to tell patients and relatives that 'in this sort of situation, 999 Paramedics do not trust the relative – so, you cannot trust 999: and you will need to think quite hard about whether you can 'risk' calling 999'.

I don't want to be in the position of being forced to explain to relatives, that they must assume that once involved in this type of situation '999 staff will in effect not trust your word' – I point to my e-mail to Coroners as shown on page 10:

Do we want a co-operative future, with well-informed relatives and 999 Paramedics working together to support dying loved-ones/patients? Or do we want a confrontational future, with well-informed relatives and 999 staff increasingly 'at war with each other'? So far as I can see, relatives are not required to involve 999 staff:

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/

At the moment, I find that I have to tell relatives what amounts to [for the scenarios of the type I've described] '999 Paramedics are not told to trust you as the default position - so, unfortunately, you can't 'trust' 999 Paramedics, and you need to consider whether to involve them or not'. Which ISN'T what I would like to be writing. It is not the fault of relatives and family-carers that sudden and unanticipated clinical events sometimes happen during EoL.

It is not the fault of relatives that we are often there to listen during EoL-at-Home, while clinicians are not normally present in the home. I suspect, that if you asked EoL doctors 'what is the most-important thing?' most of them would say 'listening to the patient'. It simply isn't either reasonable or acceptable, to imply/suggest that our listening to our loved-ones 'doesn't count because no clinician was also present to listen' when a clinician will [almost] inevitably not be present to listen.

There is, of course, the issue that some relatives are nefarious. I will examine that issue in Appendix 1 when I describe the Briggs ruling (I will also mention an issue with 'expected death', which also needs to be addressed from my own family-carer perspective), but in essence my position is that 'You ('the system/the coroner) can retain the loved-one's body until the Coroner has decided on a cause of death'.

Remember: family-carers are not legally-obliged to call anyone – why would a 'clued-up' relative, who believed in 'the right CPR/DNACPR decision is the decision my loved-one would make for themselves if they could', involve Paramedics [or anyone else] if it seemed likely that CPR would be attempted despite the relative feeling sure their loved-one would not want CPR?

APPENDIX 1: The Briggs ruling and how it logically-applies 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, and 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.

A couple of years ago, a different senior paramedic had commented in an e-mail when some of us were discussing this type of situation:

Unless the paramedic has reason to consider that what the person on the scene is telling them is ‘off’ in some way then they should proceed on the basis that they are reliable in relaying what the person would have wanted; our starting point should be belief – if we start at any other point we would fail throughout all of this.

The paramedic wrote ‘belief’ and I write ‘trust’ – but I completely agree with that position.

Professors Celia and Jenny Kitzinger had permission from Mr Justice Charles to report on what was happening during the Briggs ruling, and they have put-together a teaching tool about the case:

https://cdoctortraining.org.uk/paul-briggs/

I discussed their teaching tool at greater length in my piece (ref 10) at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/468/

What most strikes me, is that the judge seems to be drawing-out that the treating doctor simply does [did] not understand MCA best interests:

5. Judge questions treating doctor: "You have not carried out a best interests exercise - instead a significant factor has been your own ethical views".

In the published judgment the judge said that he thought her ethical approach was understandable and commendable, but pointed out that it was not an approach that Mr Briggs himself would have taken. The courtroom discussion reflected that fact *that: 'best interests' are not the same as the patient's 'medical interests' and it is not correct to assume that one must continue to provide life-sustaining treatment for a patient simply because they have potential for recovery. The discussion also highlighted that believing that a particular course of action is 'always' right for patients in a particular category is not compatible with making person-centred best interests decisions for individual people in your care and that healthcare professionals should not impose their own ethical values on their patients.*

I myself, have a visceral dislike of the term 'medical best interests' which I come across far too often – it doesn't fit with the MCA best-interests 'process'. It seems as if Mr Justice Charles was making that very clear during the hearing, but he only 'weakly' critiques the term in his published ruling [in his sections 37 and 38]. The MCA's Best-Interests Concept involves 'medical best interests', a term I take to mean 'the actions which would result in the best medical-outcome for the patient' **but only as a factor to be considered**. It is better to think purely in terms of [descriptions of] the medical situation, the possible medical interventions and the prognoses for the various combinations of treatment and non-treatment. The term 'medical best interests' should in my opinion 'be banned' during any discussion of an incapacitous patient's MCA section 4 Best Interests.

I will now BRIEFLY discuss the issue of some relatives being nefarious. In many of the situations I describe, the police would probably become involved post mortem: which isn't, to my mind, a reason to allow the police to 'harass' a just-bereaved relative. My own position, is that the police should be allowed to ask relatives to describe 'what happened' **once.** And, that the body can be retained by the coroner, until the coroner is happy to release it. But police **should not be allowed to** repeatedly and at length 'interrogate the family', or to remove the family from their home *unless there is some <u>clear evidence</u> of wrong-doing having occurred*.

We need to change the way 'expected' and 'unexpected' death is handled in records and policies – see my PDF at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/275/

This – interactions between a family-carer and police officers – is very tricky. There are deliberate attempts within 'policy' to try and prevent the police from attending 'expected deaths' - as a consequence, most police experience is of 'sudden' death. The 'mindset' and behaviour of relatives will be very-different for expected death, compared to for sudden death. So, if police officers become involved with expected death, their own expectations of 'how relatives should behave' is often inappropriate

– an ‘ignorance’ which is reinforced by the fact that these days so few people have personal experience of caring for a dying loved-one, at home, and all of the way to the death itself. There is not an easy answer to this – although training might help. It is what I alluded to in the JME paper

https://jme.bmj.com/content/47/10/650

when I wrote:

I have only mentioned a few of the more significant problems, and those I have mentioned could, in theory, be addressed by consensus followed by improved training. Other fundamental problems—notably the fact that relatively few people have personal experience of caring for a loved one all the way to a death at home—are more problematic.

There is ‘horrendous scope for escalation’ in these situations, if the family-carer does understand the law and the family-carer considers the police are ‘being unreasonably ‘aggressive’’.

https://www.dignityincare.org.uk/Discuss-and-debate/download/377/

But, in my opinion we should sort out the initial interaction between family-carers and 999 Paramedics: then, having achieved some sort of perspective-balanced-compromise in that, we can then consider the problems of possible subsequent Police involvement.

Written by Mike Stone,

January 2023

Twitter: MikeStone2_EoL