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The Mental Capacity Act must be our trusty compass as we voyage across a choppy sea of medical ethics and competing objectives, and perspective-balance must be our sail.

Dear Covid-19 Inquiry,

I would like to start by thanking the Inquiry for its very generous invitation.

https://covid19.public-inquiry.uk/contact/

'If you would like to provide feedback to the Inquiry, or wish to get in touch with us about any aspect of our work, you can email us at contact@covid19.public-inquiry.uk.'

My own experience of attempting to contribute, as a former family-carer during End-of-Life-at-Home, to the debate about End-of-Life [care/behaviour], the Mental Capacity Act and Cardiopulmonary Resuscitation, is that we layfolk are very rarely asked to contribute beyond supplying answers to questions which have been posed by the professionals. To become involved at a deeper-level of discussion, 'we' often need to attempt to 'elbow our way in'.

I am going to initially make some comments on the submissions to the Inquiry by 'ReSPECT/RC(UK)', in other words the submissions of Professors Wyllie and Lockey. I will then make some comments about EoL-at-Home and the legal and logical situation of family-carers, and about joined-up-thinking/behaviour.

I do not wish to traduce ReSPECT/RC(UK) so I have copied-in an e-mail address which I believe is Professor Lockey's. I am also not an expert on the current situation of the relevant policy and documentation in Wales, although I have periodically examined and commented on it. I have copied-in Professor Taubert because he is an expert on the situation in Wales.

Nobody, if there were two alternative treatments for a particular medical condition, would order clinicians to always use one of those treatments and not the other, unless a rigorous comparative-evaluation had made clear the superiority of one of the treatments. It is not clear to me (and I must admit, it seems clear to me that Wales is ahead of the RC(UK)/ReSPECT in the area of ACP/FCP and CPR/DNACPR planning) that a rigorous comparison of the merits of ReSPECT and the Welsh 'system' has been made.

I am firmly in agreement with Wales, that documentation should be tailored to the situation in which the document will be used. I also believe that one of the best ways to impart an understanding of 'the law' to clinicians, is to construct documents so that the clinicians completing or reading them are 'led by the document itself towards a correct understanding'. The ReSPECT form fails that test – I will explain why, later. But clearly it is easier to do that if you have a range of forms which are customised to the different working-situations of different groups of clinicians (Wales, as I understand it, is doing that – whereas the RC(UK) and ReSPECT are promoting a single form for all patients and all environments).

Clinicians and the NHS, love to 'label' things. Advance Care Planning, has been labelled – defined is probably a better term – as being created when the patient is mentally-capable. I spent years tweeting, etc, the question 'What do clinicians call planning ahead which is created when the patient is not capacitous – for example, if the patient is comatose?'. I could never get an answer.

Wales – so not the RC(UK) and ReSPECT, but the people who think about forward-planning and CPR/DNACPR in Wales – has belatedly led the way on this, by moving to Future Care Planning which can be made when the patient is not capacitous. Taubert and Bounds have explained (I strongly recommend that this paper, which explained how Wales had arrived at its policy as of late 2021, is read by the recipients of this e-mail):

https://spcare.bmj.com/content/14/e1/e608

(Lockey 6)

As the organisation responsible for issuing resuscitation practice guidelines and standards for the healthcare sector throughout the UK, our guidelines development process is conducted to the highest standards. Our guidelines are developed through extensive processes of reviewing existing and emerging research evidence, both nationally and internationally. The process for development of these guidelines is accredited by the National Institute for Health and Care Excellence (NICE), follows best practice for guideline development, and the guidelines are implemented across the National Health Service (NHS), social care, and the community.

Taubert and Bounds explain that Wales references NICE:

NICE (National Institute for Health and Care Excellence) Quality Standards on End of Life Care for Adults states that people approaching the end of life should feel satisfied that they have been able to discuss, record and review their needs and preferences if desired.[3] In addition, NICE guidelines on care of dying adults in the last days of life[4] state that healthcare providers should record individualised care plan discussions and decisions in a person’s record of care and share the care plan with the person, those important to them and all members of the multiprofessional care team.

I have not spotted any reference in the statements of Wyllie and Lockley to a **comparative study** of the way that Wales is tackling FCP/CPR compared to the alternative of ReSPECT/RC(UK).

I did notice this (Wyllie 17/20 to 3/21):

So I think there is a risk of not having standardised approach. Originally, when we went into ReSPECT, the Resuscitation Council UK has a remit for guidelines teaching in terms of resuscitation. We didn't at that time have the same remit for ReSPECT, although we recognised its, what we thought was its worth, and have supported its development. Now, I think one of the lessons out of the pandemic, I would say, is that we do need a standardised approach. I am not here to sell ReSPECT, but I think that as a country with four nations, we do need a standard approach that would work for patients wherever they are.

Dr Suntharalingum (9 October 12/23 to 13/8) stated:

An[d] "Advance Decision to Refuse Treatment" is different, isn't it, as I understand it?

DR SUNTHARALINGAM: Yes. So that's a legal instrument. Not so in Scotland but it would still be taken into account, so the sort of legal framework may differ but they, unlike these other documents which broadly can be considered called treatment escalation plans, the advance decision to refuse treatment is legally binding -- for the condition it applies for, it is important to say. So it may be for particular circumstances only.

There is definitely a risk in having a single form – such as the ReSPECT form – which is intended to cover all four areas of the United Kingdom: there are three different legal regimes involved. Wales and England are both subject to the same Mental Capacity Act: which describes the legal situation for Advance Decisions, Welfare Attorneys and Court Deputies. Wales, is creating guidance and documentation which is legally correct for the legal situation in Wales – whereas if the ReSPECT form were written so as to most-correctly reflect the law in England, then we would run into Dr Suntharalingam's 'So that's (an ADRT) a legal instrument. Not so in Scotland but it would still be taken into account...'.

While clinicians do move around, my personal view is that documents and guidance should be legally-robust for the country within which they are being used: and clinicians who move between countries need to familiarise themselves with any changes when they change country. Whereas the ReSPECT form seems to betray the problems of a UK-wide jack-of-all-trades-and-master-of-none approach in its wording. For example. In Box 6B we can read:

This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

In England and Wales, welfare attorneys and court deputies are logically the individuals who do the consulting if they possess MCA section 6(6) authority: so that final sentence should indicate that empowered legal proxies [in England or Wales] will have consulted the clinicians.

NOTE. In strict theory, the legal proxy is the individual who DID the consulting as soon as the legal proxy **has expressed** a decision. Section 4 of the MCA requires that a person who claims to have arrived at a legally-defensible best-interests determination should where possible have consulted various other people: it is only at the point when a legal proxy says 'my determination is that 'whatever' is in the patient's best interests' that the legal proxy needs to claim to have 'satisfied' MCA 4(9), and when MCA 6(6) and 6(7) become relevant.

If we remove the legal proxies from that sentence on the ReSPECT form – which here I am doing to illustrate a legal point – then we would be left with:

The plan has been made, where applicable, in consultation with relevant family members/friends.

That is not prima facie objectionable, except for a lack of clarity, and what I myself consider is the misuse of the word 'consult' if the plan's basis is that a clinical intervention could not be clinically successful [I am aware that a judge is perhaps responsible for the use of 'consult': but the words 'inform' and 'discuss' often make more sense]. See below where I discuss something Professor Summers said for a discussion of 'consult – or discuss?'.

From this point on, having I hope pointed out that wording which is already tricky if we are seeking to impart a correct legal understanding to readers, can become deeply-problematic if a document seeks to cover several differing legal jurisdictions, I am going to mainly concentrate on CPR/DNACPR and the law for England and Wales.

Wales, and I, have concluded that stand-alone 'DNACPRs' cannot helpfully be replaced by the ReSPECT form: clearly ReSPECT and the RC(UK) seem to disagree. I do not like the DNACPR forms which have traditionally been used by the NHS – I have proposed a completely different approach:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-a-proposal-for-a-different-type-of-DNACPR-document./1142/

One of the issues with the ReSPECT form, is that it states that it is a record of AGREED recommendations. As I have recently been asking:

The ReSPECT form claims to be a record of AGREED recommendations. Which presumably means that in the absence of agreement, the ReSPECT form cannot be created (or if already existing, must be deleted). I want you to check, preferably within 30 minutes of searching, the ReSPECT website for two things:

1) Who needs to agree [with the recommendations], for the ReSPECT form to be created?

2) If a patient is mentally-capable and says 'I don't want a ReSPECT form' does that mean a ReSPECT form cannot be created?

It is extremely difficult to explain exactly who is required to agree with a DNACPR 'recommendation' for a number of reasons, and it is also difficult to clearly explain how a clinician reading another clinician's 'recommendation' should take such a recommendation into account.

My alternative form does not make a recommendation: however, one thing it does is to tell readers what the individuals who are likely to be present when the patient arrests would do. So **the situation itself** tells us [in part] which individuals are relevant. And, **my form does not require agreement to be present**, in order for it to be created.

I have explained previously, and so does the paper by Taubert and Bounds which has been mentioned above, that before Wales developed Future Care Planning most guidance was about Advance Care Planning – and that ACP requires a capacitous patient. This could explain another peculiarity of the ReSPECT form (please recall, that I like forms to convey a clear and legally-correct understanding to their readers). Near the start of the ReSPECT form, we can read:

The ReSPECT process starts with conversations between a person and a healthcare professional.

We are told that the ReSPECT form is the outcome of the ReSPECT process – so presumably we can conclude that ReSPECT is ACP, not the more comprehensive [and much superior] FCP, so if for example the patient is comatose a ReSPECT form cannot be created. And yet – in Box 5 we can see a tick-box to indicate that the form has been completed when the patient was not mentally capable.

Such contradictions should not be present on the documents which Wales has developed, because Wales is using FCP and Wales customises its documents to suit particular situations.

I also have an issue with the way that ReSPECT uses the term 'ReSPECT conversation' to describe conversations which are the requirements of law, objective and logic: it isn't because of ReSPECT that clinicians should be embarking on those conversations if we are in England and Wales – those conversations are required by section 4 of the Mental Capacity Act. It isn't 'historical good practice' that patients or 'relatives' are informed when their clinicians do not intend to attempt CPR because the clinicians believe CPR could not restart the heart (and many clinicians objected to being forced to do this by court rulings), it is the Tracey and Winspear court rulings. It was the Montgomery court ruling, which made it clear that the whole of the UK is now subject to what I describe as 'genuine Informed Consent'.

Before the MCA and those court rulings, it could have been argued that it was 'good and progressive practice' to do many of the things which are common to both Wales and ReSPECT: but NOW that 'best practice' is largely a legal requirement.

Professor Summers, October 9 29 – 32:

I'm usually very clear that I'm not asking the family to make a decision, that the burden of that decision is made about what's clinically appropriate by the doctors, and explain very clearly that that's my responsibility, I'm not asking them to carry that burden and nor should anyone because you are asking them to make a decision about someone whom they love and care for very much at a time of great distress.

This is NOT what the MCA and some blindingly-obvious logic leads to – although it is a position which has been adopted by at least some editions of the BMA/RCN/RC(UK) Joint CPR Guidance, and also by the GMC, as I mention and discuss (page 10 onwards) in the PDF you can download from my thread at

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/

The wording the GMC used is 'If they do not have legal authority to make the decision, you should be clear that their role is to advise you and the healthcare team about the patient's wishes and preferences to inform the decision about whether attempting CPR would be of overall benefit to the patient. You must not give them the impression that it is their responsibility to decide whether CPR will be of overall benefit to the patient, or that they are being asked to decide whether or not CPR will be attempted.'.

This is absolutely NOT how I would view those conversations, and we should remove the word 'responsibility' if we want to analyse this correctly. We should also remove 'of overall benefit to the patient' and replace it with 'in the patient's MCA Best Interests'. I intend to return to this later, but in brief we can show that the above is flawed as follows:

Firstly, if one of those relatives Professor Summers is talking to thrusts LPA documentation into her hands, proving that the relative is a welfare attorney with section 6(6) authority over life-sustaining treatments [including CPR], would Professor Summers still claim the decision about CPR/DNACPR was ‘her responsibility’?

Secondly, there is not an examination in understanding of the MCA before a relative is appointed as a welfare attorney: as I often say ‘being appointed as an attorney does not suddenly and magically improve my understanding of MCA best interests’. I will add, that being appointed as an attorney does not remove ‘the distress of’ your loved-one dying, either. **What being an attorney should ‘remove’ is the extreme ‘angst’ which a relative can feel ‘if I’m sure the clinicians are doing something which I am certain my loved-one would not want [or which I am convinced would not be in my loved-one’s best interests].**

It logically follows, that provided they understand enough about the clinical situation, ‘those close to the patient’ CAN form legally-defensible best-interests positions.

I have recently written about this in an addition at 09/09/23 to my thread at

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/

We should regard close family and friends as ‘experts in the individuality of the patient’ – my piece in Dignity in Care was subsequently published as a BMJSPC blog:

https://blogs.bmj.com/spcare/2024/02/01/best-interests-a-term-that-covers-many-concepts/

As I wrote in that blog:

We should regard these conversations about MCA best interests, as involving **TWO DIFFERENT TYPES OF EXPERT** in conversation with each other: the clinicians are experts in the clinical situation, what treatments are available, and prognoses, and the family and friends are experts in ‘the patient as an individual who had views on all sorts of things in life’. The objective of the conversations is to apply section 4 of the MCA in order to arrive at properly-considered best-interests determinations. That necessarily involves a third type of ‘expertise or understanding’, which is an adequate understanding of the MCA: a LEGAL understanding, which is neither the type of expertise specific to the clinicians, nor the type of expertise specific to ‘those close to the patient’.

We have, when thought of in this way, two different *groups* of experts, the knowledge and understanding of both groups being necessary to properly achieve an objective which requires a third type of understanding (an understanding of the MCA) – and, that third type of understanding is not an understanding which is necessarily solely possessed by either group of experts.

Viewed in this light, those close family and friends who DO UNDERSTAND the MCA, should RIGHTLY take offence if clinicians say ‘you need to understand, that *your* role is only to inform *our* decision-making’.

In a PDF targeted at the Ministerial DNACPR Oversight Group

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/A-Submission-to-the-Ministerial-DNACPR-Decision-Oversight-Group/1145/

I wrote the following:

I get the impression, from many of the things I read, that doctors think section 4(7) says ‘the doctor must consult a welfare attorney’. If the attorney possesses MCA s6(6) authority over CPR, then as soon as the attorney has indicated ‘I’ll make and express a decision about CPR’, very obviously the attorney is from that point onwards consulting the doctor. After all, it is absurd to say ‘you must consult yourself’. If the attorney doesn’t have authority over CPR, then the doctor [or anyone else who wishes to claim to have satisfied s4(9)] would need to consult the attorney. Although, I don’t think the word ‘consult’ is helpful if there isn’t an attorney whose authority extends over CPR – in that situation, I think the concept of DISCUSSION is much more useful than the concept of CONSULTATION.

It is interesting, although this seems to be a sort of breach-of-moral obligation on the part of the patient’s attorney, if the attorney tells a doctor ‘I don’t think I’m going to express a decision about CPR’. We could have a room full of relatives, this ‘reluctant attorney’ and a doctor, discussing whether attempted CPR or DNACPR would be in the patient’s best interests. The doctor might – most current guidance would lead the doctor to think this – consider that she is ‘consulting’ the other people in the room. I think the conversation, if properly performed, would allow legally-aware family and friends to also arrive at best-interests determinations – so I think there is not ‘a consultation’ but rather ‘a discussion’ happening in that room. And, if at the end of the discussion the attorney decides to make and express a best-interests decision about CPR/DNACPR, then ‘who if anyone, had been consulting whom?’.

In fact, my ‘reluctant attorney’ might have a valid reason for initially stating ‘I don’t think I’m going to make and express a decision’. The nature of the conversations, is I feel likely to be different if everyone believes the attorney will be making the decision. If the attorney ‘withdraws’ then a more complete thrashing out of what everyone believes would be in the patient’s best interests might happen – something the attorney would want to consider before making a decision.

The other thing about 4(7), is in a situation when a welfare attorney has made it clear that ‘I’m consulting people, to make a decision about CPR’, where does the doctor appear in sections (a) to (d)? The answer, is in section (b). If a doctor claims to be making a best-interests determination, where do relatives appear? Again – in section (b). The MCA is much more symmetrical, in fact, about the legal situations of doctors and normal family-carers than we are usually told: when I read it, it looks as if the ‘rules’ for doctors and normal family-carers (i.e. family-carers who are not also welfare attorneys) are in essence identical – it is ‘more-junior clinicians within a clinical team’ whose situation is different [because of the consequences of section 42]. If we read what clinicians and clinical bodies write about best interests, it looks as if there is a pyramid with doctors at the top, then nurses lower down and with relatives and family-carers at the bottom. But if we simply read the MCA itself (the Act), that pyramid is split into two halves: one half of the pyramid has got doctors at the top and nurses lower down, and the other half has got family-carers and relatives at its top, at the same level as the doctors.

Lockey:

64. ReSPECT can be instigated in hospitals, care homes, or in the community by the primary care provider. They are signed by the clinician and can be countersigned by the patient or others who were involved in the discussion if they wish, but this is not required; the option for patient and other signatures was introduced in Version 3 (see paragraph 76) following patient feedback.

To me, the form does NOT allow for ‘countersigning’. The form allows for signatures in its section 8, which is ‘Emergency contacts and those involved in discussing this plan’. **To me, ‘countersigning’ would be to put those signatures in section 4 to indicate agreement with the recorded recommendations.**

I would also want the patient to be able to complete and sign section 3 of the form. Because section 3 would be considered during MCA best-interests determinations, and section 4 of the MCA tells us (my emphasis):

In determining for the purposes of this Act what is in a person’s best interests, the person making the determination … must consider, so far as is reasonably ascertainable— the person’s past and present wishes and feelings (and, in particular, **any relevant written statement made by him** when he had capacity),

The normal method to confirm that ‘a statement was written by a person’ is for the person to sign it.

I will only briefly touch on the suggestion that stand-alone DNACPR forms can be conflated with ‘no other escalations or treatments’, and also with a [literature] claim that putting ‘DNACPR’ and treatments the patient would want on the same form, improves the quality of end-of-life conversations. For the latter, the paper which I think is usually cited dates [unless memory fails me] from about 10 years ago, and crucially the research was done before the Tracey and Winspear court rulings: which makes it dubious in the context of behaviour now, in 2024. As for the ‘conflation’. Professor Wyllie said that such conflation does not occur in his workplaces among the clinicians. He said it did sometimes occur with patients and families (presumably families for him – he is a neonatologist). It isn’t obvious why relatives would ‘make that conflation’ unless they were reading a DNACPR form – which is surely a situation when the clinicians could make the absence of such conflation clear to any concerned laymen. And, my own clinical contacts tell me that such conflation among clinicians is not, in 2024, as much of a problem as ReSPECT and the RC(UK) imply it is.

In section 89c of Professor Lockey’s piece, he says the RC(UK) recommends

that the ReSPECT process is fully adopted throughout health and social care settings in all four nations of the UK so that there is a standard patient-centred practice with familiar and accessible outcomes available to all, regardless of location or socio-economic situation.

It will be clear to the reader by now, that I disagree with the suggestion that the ReSPECT process is ‘adopted by’ Wales. It would be an insult to the clinicians, patients and other layfolk who have worked so hard to develop the approach to planning ahead and CPR which is being used in Wales: **remember that it was Wales which developed the vastly superior concept of Future Care Planning, something which the RC(UK) never did. And, as I’ve pointed out above, I haven’t seen any published evidence that the outcomes for patients [and, in the context of their experience of interacting with clinicians, for the patient’s family and friends] in Wales is any worse than the outcomes for patients in regions which are using ReSPECT.**

I will at this point, explain something which clinicians hardly ever seem to make clear in their writing. **Family-carers cannot be ordered to do things**.

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/

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/CPR-and-DNACPR-am-I-following-orders/1159/

If family-carers during EoL-at-Home cannot be ordered to do things by doctors, and if we hope to have joined-up-behaviour around and supporting the patient, then we need family-carers and clinicians to be working together.

It isn’t obvious where else to put the following, but I want to include it somewhere – and I’ve settled on here. Something written probably by a nurse, and two Twitter Polls which I carried out. This is pasted-in from something I wrote a few years ago, so the Twitter Polls are now not ‘recent’ (I’m not certain, but probably ca 2018).

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 recently 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

It is blindingly-obvious to me, that for End-of-Life-at-Home to work properly, we need the clinicians and the family to be working together – within an atmosphere of co-operation and mutual trust, and mutual respect.

The idea that planning during EoL-at-Home is made between a patient and the clinicians, as opposed to being made between the patient, the family-carers and the clinicians is, to use the technical term, bonkers!

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

How I Became Involved

The reader might be wondering how I became involved in EoL/MCA/CPR debate.

I became involved when my mum died in 2008, and I have described what happened in my piece at:

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

I wrote towards the end of that piece:

Death at home is hugely complicated – only the people 'on the inside' (the family carers, district nurses and GP) have got even the remotest chance of really understanding any given 'dying and death' - and whereas with hindsight the 999 service staff protest 'but – we didn't know that at the time' and 'the system's 'solution' is 'better records'', MY ASSERTION is that the situations are often [or at least sometimes] too complicated for 999 staff to properly understand whatever records you have, and I assert that the solution is 'you have to accept that the GP, relatives and nurses are the only people who understand it, and they almost certainly only each understand it in part – the problem is that the 999 services are not being told to believe family carers'.

And this is the issue which concerns me – from my family-carer perspective, and with my own experience in mind.

Everyone inside 'the EoL world' knows that conversations during end-of-life are difficult. And it isn't possible, to control those conversations: a clinician might attempt to initiate a conversation and the patient might decline it, and a patient might initiate the conversation – and not necessarily with a clinician.

If my dad makes it entirely clear to me, on a Saturday evening, that if his heart stops beating for any reason at all, he does not want CPR to be attempted, then I cannot ignore that – my moral position is that I must support my dad's autonomy. At the end of the conversation, we might decide that we will inform the GP on the Monday.

If my dad collapses before we have informed the GP then I must still respect my dad's decision. But, I'm not a clinician: I would like to involve 999 to make certain that my dad's heart has stopped beating, as opposed to [for example] him having collapsed with a stroke – my dad would want prompt treatment if he had a stroke which wasn't going to kill him, because he would want to avoid living with avoidable clinical damage.

Paramedics do use a model which amounts to 'start CPR while deciding that CPR is inappropriate'.

So, **if I know that 999 Paramedics are not going to trust my word** – and it is peculiar logic 'to expect to have been able to listen to a conversation when you cannot reasonably have expected to be present – **what am I supposed to do?**

I am currently being forced into a corner, which I would prefer to not be in: I am being forced to tell relatives that in some situations 999 paramedics will not believe what you tell them, so relatives must think hard about whether they can 'safely' phone 999. In essence, we've got 999 paramedics seeking 'proof' that family-carers are telling them the truth – and family-carers who know they are telling the truth, and must [because of that 999 mindset] consider how to best-protect the autonomy of their loved-one.

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-reconciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./1031/

I will add two things. The first, is that the outcome of a CPR attempt which does restart the heart, is so uncertain that it really doesn't require a clinician to explain the outcome spectrum: it isn't very challenging to work out that it amounts to [for the vast majority of arrests] 'If you are really lucky you will be exactly as healthy as you were before the arrest: if you are very unlucky you will be alive but permanently comatose; and you could be anywhere between those two possible outcomes'.

The second, is that I cannot believe that any relative or family-carer has ever been told by their loved-one 'I don't want CPR to be attempted – although I'm happy for 999 paramedics to start CPR, while you try to persuade them to stop'. That is akin to someone saying 'I don't want to be punched in the face – although a few punches in the face would be okay, if the punching then stopped'. **What 'we' know, is that our loved-one does not want CPR to be started.**

A Journal of Medical Ethics paper which was written in 2020 by Zoe Fritz, two others and me, ends with:

'the default assumption should be that clinicians and relatives have a shared goal of what is best for the patient, and work together as 'us and us' as opposed to 'us and them'.'

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/

Zoe can be described as 'the Mother of ReSPECT' - what is now called ReSPECT, started with a different name (from memory UFTO) and was developed by Zoe [and Zoe was awarded a doctorate on the basis of that work – so Zoe is, re Peter Ustinov, 'a Doctor Doctor Fritz'].

I have also recently co-authored a Letter to the Editor of the BMJ with Mark Taubert

https://www.bmj.com/content/386/bmj-2022-071661/rr and one of the points it made, was that words carry implications:

'… we hope to continue to refine, focus and improve our language, which after all acts as a code for our actions and intentions.'

There is also an implication – at least to my eyes – from the fact that on the ReSPECT form only a clinician's signature is attached to the recommendations. This implication is not relevant during 'academic discussion' but I think it is significant during situations such as the one I found myself in: trying to explain to confused police officers [and also to a strangely-behaving 999 paramedic, whose behaviour none of my contacts including a senior paramedic from the relevant Ambulance Service can understand] why 'the eventual death of a loved-one after 4 days in a terminal coma does NOT require a family-carer to immediately phone someone'. Because that recommendation signed by only a clinician wrongly implies that the decision-making rests with the clinician – **at least, it to my mind carries that implication when read by readers who do not understand the complexity of, and law of, EoL-at-Home.**

There are a few things which need clearing up, around CPR/DNACPR.

One is the issue of a verbal refusal of CPR, the often stated 'a written ADRT refusing CPR is legally binding', and whether a verbal refusal during a situation of ongoing contact is more legally-compelling than a written ADRT.

I've discussed this issue passim, and I point the reader at pages 22 – 24 in my PDF at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/449/

The issue is the degree of certainty which is possible – and the answer is that a verbal refusal of CPR can definitely be more legally-binding than a written ADRT. From the PDF:

The problem is this: while a verbal refusal of CPR clearly cannot be a valid Advance Decision, it can nevertheless be 'more legally binding' than a valid written Advance Decision refusing CPR.

The correct way to think about this, is to consider how certain the listener is of the fact that the patient has refused CPR in the circumstances of the cardiopulmonary arrest.

If a hospital patient explains during a 30-minute conversation with a hospital doctor, that the patient would never want CPR, whatever the reason his heart had stopped beating, during the conversation the doctor can ask and exhaust all of the '... have you considered ...' and '... but if [whatever], would you still refuse CPR' questions. So, if at the end of that conversation, as the doctor turns to walk away from the bedside the patient suddenly arrests, **then the doctor has no thinking to do** – the doctor is as certain as it is ever possible to be, that the patient has forbidden CPR in the situation.

If we swap the hospital doctor for a GP, and the location to the patient's home, and we have the same conversation at the end of which the two of them create a written Advance Decision refusing CPR, then what is the situation if a month later the patient walks in to the GP's Surgery, and just after entering the GP's office the patient arrests and collapses with his written ADRT in his hand? If the GP sees the written ADRT, does the GP know why the patient was holding it? Was the patient about to say 'I've changed my mind – I want to retract this ADRT' or was the patient about to say 'Are you sure that if I arrest at home, and my wife shows this to a 999 paramedic, it will stop the paramedic from attempting CPR?'.

The gap of a month, between the patient and GP creating the written ADRT, and the ADRT being read when the patient subsequently has a cardiopulmonary arrest, **introduces doubts which are not present in the verbal refusal in the hospital scenario**. And without the ARDT in the patient's hand, the GP still cannot be certain whether the patient has changed his mind about CPR during the month since they last talked to each other.

Similarly, if a wife makes it very clear to her husband that she would never want CPR, because they are sharing a home the husband can reasonably assume 'if she changes her mind, my wife will tell me'.

THE GREATER UNDERSTANDING MAKES A VERBAL REFUSAL [and no subsequent verbal retraction] **THE MOST** 'LEGALLY BINDING' OF ALL INSTRUCTIONS FROM THE PATIENT/PERSON.

If 'technically' a person should make a best-interests determination, but in reality the understanding of the person is such that 'there is no determination to be performed – I am already absolutely sure of what I should do’, then there is not a best-interests determination being carried-out in any meaningful sense.

It does follow, that if patients read ‘Advance Decisions are legally binding’ then the patients are being misled. It should be ‘Once the reader of an Advance Decision has decided it is applicable, the decision is legally binding’. And it is hard to imagine that any clinician would ever say ‘I considered there was a valid and applicable ADRT refusing CPR, but I attempted CPR despite that’.

Also, there are many situations when an ADRT will fail to prevent attempted CPR: see pages 18 and 19 in the same PDF.

I think the ‘classic’ Advance Decision to ponder – and clinicians do seem to like rational patients – is this one. We know that however healthy you are before your heart stops beating, if it has stopped beating for any reason at all, unless oxygen is getting to your brain, your brain starts to ‘irreversibly die’ (I’ve put the quotes in, because these days the view seems to be that [sometimes] to some extent the brain can recover). I think many doctors would say that accumulative brain damage starts to build after a couple of minutes without oxygen. So, how does a ‘rational’ patient forbid CPR from being attempted, if he arrests in the community, after a time-period specified by him/her between the arrest and the potential start of CPR? It seems to me, that ‘I refuse CPR unless CPR has been started within 2 minutes of my cardiopulmonary arrest’ is perfectly sensible, but could an ADRT achieve that for the patient?

There is also an issue around the idea/belief that doctors can decide to not offer ‘futile’ CPR. I have written about this at:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-non-offering-of-Futile-CPR-by-doctors-a-concept-past-its-use-by-date/1154/

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/

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/

SUGGESTIONS

I am not going to make recommendations. But, I usually describe myself 'as an analyst with a family-carer perspective, who writes about EoL/MCA/CPR'. And my analysis of the situation, leads me to the following suggestions.

1) Let Wales continue to develop its own approach, guidance and forms for FCP and CPR/DNACPR. If and when ReSPECT has been used sufficiently-widely in all three other countries of the UK – so in England, Scotland and Northern Ireland – for several years (I would suggest 5 years as a minimum), perform some studies to ascertain how satisfactory the situation is in each of the four countries: as viewed [at least mainly]from the patient and 'family' perspective. The way the system is working for clinicians is of course also relevant – but it seems to me that if ACP/FCP/CPR/DNACPR is problematic for the clinicians who are involved, it is likely that the patients and families will not be very satisfied either.

During the interim – while Wales is using its own approach, and while some parts at least of England, Scotland and Northern Ireland are using ReSPECT – establish a 'loose but committed' group comprising clinicians from all four countries, with the remit of discussing how well things are working out in each of the countries. The discussions can be relatively informal but must not be 'tick box': what matters is that the clinicians are committed to the objective of trying to discover 'what is working the best'.

2) It seems to me that we are probably heading for a requirement that the clinicians who routinely 'work with' FCP/ACP/CPR/DNACPR receive greater training in FCP/ACP and the decision-making for CPR/DNACPR.

I'm 'an MCA nerd' and in my experience, all MCA nerds consider that understanding of the Mental Capacity Act among clinicians is worse than we feel it should be: and most of us cannot understand why that is the situation.

And it seems likely that understanding of the MCA among the general public, is very limited indeed.

I would suggest, that if training of clinicians is improved, then for clinicians working in Wales or England, **there is a requirement 'that clinicians who work 'with' ACP/FCP and CPR/DNACPR are capable of explaining the MCA to patients and relatives'.**

I consider this to be possible – and it is something I have been trying to do for years (the solicitor Ben Troke has also been trying to explain the MCA in a recent book: 'A Practical Guide to the Law of Medical Treatment Decisions' (Paperback: 978-1-912687-89-3 published 2020 by Law Brief Publishing)):

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/

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

Kathryn Mannix commented on the single-sentence: I like your sentence because it helps decision-makers and those participating in a decision-making process to be clear about the task.

We definitely know that normal people must be able to understand the MCA – because it would be ridiculous for the law to allow normal people to be appointed as welfare attorneys with section 6(6) authority if that were not true – but it is not clear how normal people are to acquire an understanding of the MCA.

This (a requirement that clinicians involved in FCP/ACP and CPR/DNACPR could [and would] explain the MCA to patients and relatives) would improve understanding of the MCA among clinicians – and it would dramatically increase the understanding of the MCA [and doubtless of the consequences of attempted CPR] among the general public. As an aside, whenever I read those investigations into why relatives were so unhappy with the behaviour of clinicians (Gosport, LCP etc) **it strikes me that one issue is that the relatives were unable to assess whether the clinicians were behaving properly at the**

time. If relatives understand MCA best interests, then they can question why it seems to them that the clinicians are getting it wrong **at the time**: and frequently, it will turn out that a proper discussion at that time, will prevent a complaint later.

Transparency Statement

At this point of an academic paper, there is usually a Conflict of Interests statement.

I'm confident that there are 'interests' within my writing, which reflect my background as a family-carer: everyone's role and experience influences their writing. One of the most difficult problems within debate of what would lead to the most-satisfactory behaviour for EoL/MCA/CPR is the placing of, and balancing of, the 'borders' between different issues: for example, the interface between the MCA's 'autonomy of capacitous patients [and their legal right to make 'bad and self-destructive decisions']' and the 'safeguarding 'duties'' which are imposed on various professionals. It amounts to a hugely more complex version of the well-known issue 'Do we have a border between Northern Ireland and the Republic of Ireland – or do we have a border down the Irish Sea between England, Wales, Scotland and Northern Ireland?'.

Kate Masters, a daughter of Janet Tracey, used to give talks to clinicians about the ruling. Eventually Kate expressed her vexation in a magnificent BMJ rapid response, which in my opinion all doctors should read:

https://www.bmj.com/content/358/bmj.j3831/rr-10

Kate commented: In addition, a note to all doctors; if you want patients to be part of the solution to the issues you face (not just this CPR debate) you may have to reach into their (our) world a bit more, rather than expecting us to adapt to yours.

Prior to that rapid response, I used to suggest to Kate that she wasn't, using my phrase here, 'being forceful enough'. Kate effectively said 'Well – the doctors are the experts, I'm not'. Kate is a generation younger than me, and she is female.

I’m elderly, male, I was very annoyed by my own experience, and I’ve got a science doctorate. I also think I’m ‘a bit Asperger-ish’. Some years ago two of my [married] friends said ‘We think you might have autism’. I pondered that, and decided that I’m probably Asperger-ish. When I mentioned to another of my friends, a social worker, that I might be Asperger-ish, I immediately got ‘That isn’t a might – you always go straight for the logic!’.

I might be less keen on ReSPECT than I am on Wales, because of my experiences of attempting to provide feedback to them: in my personal experience ‘Wales listens better than ReSPECT/RC(UK) listens’. But that isn’t relevant to what I’ve written above: the question is whether the analysis I have presented above is unbiased.

And so far as I can see, it is. It is surely an OBJECTIVE conclusion, to question whether an organisation claiming to be composed of experts, which creates a form stating that it is the outcome of conversations involving a patient and then subsequently has a tick-box for ‘the patient could not contribute’, is in fact an expert organisation. Ditto with the claim that the ReSPECT form records agreed recommendations, but with no evidence on the form to support that statement other than the signature of a clinician.