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Dear Covid-19 Inquiry,

I point you at an e-mail which I sent, and you should have received, at about 09:56 on Monday morning (21 October). The e-mail [or rather the PDF attached to it] explains in some detail, why I consider that it would be foolish and unhelpful for ReSPECT to be imposed on Wales. Instead, I think the current situation offers an unusual opportunity to 'pseudo-pilot' both ReSPECT and the FCP/DNACPR policy and documentation which Wales has been, and is, developing. As I wrote at the end of the PDF:

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'.***

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.*

It seems to me, that the 'ethical/legal' rules/guides for the attempting or withholding of cardiopulmonary resuscitation (CPR), should be the same whether the person being faced with the decision is a clinician or a family-carer. It is also clearly true, however much things are discussed, doctors and family carers will **inevitably** each be in different positions in the context of their understanding. Clinicians will always be the more expert in clinical things such as potential treatment and their prognoses: and family-carers and others who are 'close to the patient' will always be more expert in 'the patient as an individual' (the things which MCA 4(6) points at). Mr Justice Hayden explained that family and friends are the experts in 'the patient as an individual' with very clear wording (my added bolds here):

<u>http://www.bailii.org/ew/cases/EWCOP/2014/4.html</u>

The patient was in a minimally conscious state and the section of real interest is this one:

53. If ever a court heard a holistic account of a man's character, life, talents and priorities it is this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but ***he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left***

in any doubt what he would want in his present situation. *I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.*

If we want THE BEST-ATTAINABLE MCA best-interests determinations to be reached, then we need to accept that the process of making an MCA best-interests determination requires expert-input from BOTH clinicians and 'those close to the patient'. And we must accept that if relatives, etc, understand the MCA adequately, then they CAN arrive at perfectly defensible best-interests determinations.

The RC(UK) and ReSPECT, still seem to imply in their writing that relatives, etc, merely inform the best-interests determinations of the clinicians: that attitude is legally flawed, and in an internet age probably anachronistic – it needs to change, and my personal view is that Wales is changing faster than ReSPECT is.

The clinicians who are involved with things such as ReSPECT, typically appear to think more of situations such as hospital A&E than of End-of-Life-at-Home ; especially EoL-at-Home from the perspective of a family-carer. Whereas what I tend to think of 'instinctively' is the following:

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-foru m/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-re conciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./103 1/

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.***

I will also add, that the ReSPECT form – now in its third version, so one would assume 'properly thought out – does not stand up to logical interrogation:

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.

I have included some other print-outs, notably of my proposal for a different type of CPR/DNACPR document.

But mainly, I would point the Inquiry back at the PDF which you should have received at about 09:56 on the 21st October,

Yours faithfully,

Mike Stone

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'.