

# Mike's Little Book of Thoughts

## about End-of-Life v2



# Thinking Clearly

### **What advice would you give someone starting out?**

The patient/carer is always right until proven otherwise. I have seen nurses forget this, resulting in serious errors of judgement.

Nursing Times online publishes a series called '60-second Interview', and one dated 19 July 2012 was with Vicki Leah, consultant nurse for older people at University College Hospital, and lead dementia nurse at NHS London, who has been a nurse for 30 years. Vicki gave that answer to the question above it.

## Introduction

I wrote a series of PDFs a few years ago – from memory 2012 – which I called ‘Thinking Clearly’: the title was a variation on ‘Deciding Right’ which was the title of some pieces written by Claud Regnard. The title page of this ‘booklet’ shows the start of no 3 in my Thinking Clearly series, and it expresses my own position.

Since I wrote the Thinking Clearly pieces, there have been developments in ‘end-of-life’ (EoL) such as the withdrawal of the Liverpool Care Pathway (LCP) in England, quite a lot of work on what was to ‘replace’ the LCP, and at the moment there is something called ReSPECT being developed and rolled-out across the UK. I dislike ReSPECT for many reasons: as the graphic on the title page should make obvious, I agree with ReSPECT about the need for more and better conversations when people are dying. My differences of opinion with ReSPECT hinge on certain legal and logical issues, but mainly because when I look at the ReSPECT material from my patient or family-carer perspective, it does not embody:

*‘The patient/carers is always right until proven otherwise’*

Instead of accepting that relatives, friends and family carers have the greatest background of contact with patients, and sometimes also the greatest opportunity to listen to terminally-diagnosed patients, and in consequence ‘understand the patient as an individual more than the clinicians can’, ReSPECT ‘seems to over-value decisions made by clinicians, and documents signed by clinicians, and to under-value the role, position and understanding of family carers, relatives and friends’.

This ‘little book’ will draw together some of my ‘thoughts’ and some of my analyses of end-of-life behaviour in one place, with some links included to my online pieces where the arguments and considerations which I hope to express relatively concisely here, can be found in greater detail.

Keep in mind that I write as someone living in England, and that I am often assuming that the Mental Capacity Act (MCA) is applicable law.

Written by Mike Stone, spring 2018.

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## The relevance of 'mindset' to end-of-life

The longer I have been involved in 'debate about EoL behaviour with 'the NHS'' the more it has become obvious to me, that 'as a group' the way that doctors tend to think, is significantly influenced by the fact that they are doctors. Ditto for nurses, 999 paramedics, etc. Also true but rather less so – because the 'shared background factor' is less among relatives and family carers – for family carers and relatives when a loved-one is dying.

Three other factors are obvious to me, when I debate EoL with doctors in particular, and these are:

### The MCA is deeply 'awkward' if you are a working doctor

The MCA includes our law *for the whole of* 'consent' whether or not the patient is mentally capable – and its description is deeply 'problematic' if you are a working doctor. The MCA states that patients must be assumed capacitous until proven otherwise, and 'being self-destructive' is not sufficient to 'prove mental incapacity'. Interpreted 'neutrally', if a patient who is part of the way through a suicide attempt 'washes up in Accident & Emergency' and refuses to be treated, the doctors should not treat the patient – according to the MCA 'if the person seems capacitous, the person should be allowed to die'. So, suppose there is such a suicidal patient who unless treated will die, who is refusing treatment: if the doctors in A&E do not treat him, and he dies, you can imagine the conversation the following day with an angry relative - **'What the hell do you mean – you could have kept my brother alive, but he told you not to so you just let him die !!!'**.

But – judges have explained that the MCA does say 'no – you cannot treat a capacitous person without consent'.

<http://www.bmj.com/content/350/bmj.h2883/rr-2>

*But whichever way you go, law or ethics, there is a 'sticky wicket' lurking somewhere. Ethics does not lead to clarity: consider the assisted dying debate, and for example the fact that the pro camp tend to call it assisted suicide whereas the anti camp tend to call it euthanasia. If we instead use law, and return to CPR, the law states that mentally-capable patients can refuse CPR, but it isn't at all clear how mental incapacity can be established if a patient seems lucid. There was a report in The Independent (newspaper), June 24th 2013 (carried on pages 1, 6 and 7), when Sir Mark Hedley, a recently-retired judge, explained that 'I decided at 10pm that a suicidal man*

*with mental health problems could be allowed to die of an overdose rather than order doctors to pump his stomach ... I decided he had capacity [to refuse treatment], so he died that night. That's exactly what he wanted to do ... That one never found its way into any report of any sort'. Sir Mark was the out-of-hours Court of Protection judge.*

*So the law, seems to be clear about patient self-determination, and allows patients to be, to use my phrase, 'self destructive': not an easy thing for clinicians to 'live with'.*

Mr Justice MacDonald used very clear words to explain this patient self-determination in a case you can find at:

<http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWCOP/2015/80.html&query=court+and+of+and+Protection+and+Justice+and+MacDonald+and+sparkle&method=boolean>

*C's decision is certainly one that does not accord with the expectations of many in society. Indeed, others in society may consider C's decision to be unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society in general. None of this however is evidence of a lack of capacity. The court being satisfied that, in accordance with the provisions of the Mental Capacity Act 2005, C has capacity to decide whether or not to accept treatment C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists). As a capacitous individual C is, in respect of her own body and mind, sovereign.*

The MCA is even more awkward for doctors, and for 'NHS 'protocol designers"', to work with if the patient is not mentally-capable: however, that situation is harder to analyse, and much of this entire piece will involve an analysis of decision-making during mental incapacity. So, I will not dwell on that here, beyond stating:

Perfectly normal people – relatives, friends – **can** make best-interests decisions about the application or withholding of medical interventions;

**Only** judges and individuals empowered by section 6(6) of the MCA **can impose** their own best-interests decision on other people;

The MCA imposes a legal duty on everyone ‘involved with [*presumably involved with relatively long-term* in reality] an incapacitous person’ to make all decisions which affect the incapacitous person ‘in the person’s best-interests’;

I write ‘endlessly’ about the MCA, and here I would point the reader at:

<http://www.bmj.com/content/352/bmj.i222/rr-0>

[https://twitter.com/MikeStone2\\_EoL/status/906073527236907009](https://twitter.com/MikeStone2_EoL/status/906073527236907009)

I will also comment: even the MCA itself describes the role of welfare attorneys and court deputies incorrectly in section 11 (it describes those individuals as ‘consenting to or refusing’ offered treatments, when a moment’s consideration of section 4 will make it clear that they neither consent nor refuse an offer of treatment – they make and express a best-interests decision in the knowledge that the treatment is on offer [the difference might seem trivial – it isn’t as trivial as it seems, because describing it correctly ‘sharpens understanding of the MCA’]).

## Safeguarding – a problem

It is possible to argue that it isn’t possible to easily separate ‘safeguarding’ from ‘lingering clinical paternalism’, but neither can logically be fitted to the decision-making autonomy of mentally-capable but self-destructive patients [which I described on pages 2 and 3]. Many professionals ‘have safeguarding thrust upon them’, and a London GP summed it up when we were discussing the MCA by e-mail a few years ago, when the GP wrote in an e-mail to me:

*I recently had MCA training and it was made clear that the hope of the act was that it would be empowering of the patient and perhaps the development of the IMCA role demonstrates that aspiration.*

*We also have the whole ‘safeguarding’ agenda pushing in the opposite direction.*

999 paramedics tend to thwart the purpose of written Advance Decisions during ‘emergencies’ when patients are at home, because they want certainty **which cannot be available to them** about things such as signatures – I am very vexed by this ‘mindset/attitude’ because it makes creating an ADRT

pointless:

<http://www.bmj.com/content/356/bmj.j1216/rr-1>

*If I consider such a ‘sudden CPA’ and then I write an ADRT refusing CPR for it, I would be doing that in the knowledge that if I were in CPA when 999 paramedics arrived at my home [after, probably, having been called by another person such as a spouse, who had seen me collapse], I would not be conscious – so, I would have written the ADRT with the intention that it should be followed, in exactly that situation (of an unexpected arrest, and when there was no time to look at my ADRT beyond confirming its Prima Facie validity).*

*Clinicians seem to think, that in this situation – when there is ‘an emergency’ – my ADRT can be ignored, because there is no time ‘to confirm it’. But to the author of such an ADRT, surely that is exactly the opposite of what you would expect – as I wrote in ‘ReSPECT is incredibly DISRESPECTFUL’:*

*‘An ADRT which appears prima facie valid should be accepted as being valid, if there is not enough time to check in more depth: it is during a non-emergency that the prima facie apparent validity of a written ADRT should be further examined !’*

## Law or Ethics

Doctors tend to discuss ‘medical ethics’ a lot, and law much less. I avoid discussions of medical ethics, because if we accept that family carers not only can make, but **are required** by the MCA to make, best-interests decisions, then introducing medical ethics becomes deeply problematic. If, as our judges are increasingly stating explicitly in their rulings ‘we are all required to apply the MCA’, then it would seem strange if when equipped with the same understanding of the incapacitous person’s situation, different decision-makers could ‘legitimately’ arrive at different best-interests decisions. There surely has to be ‘the concept of a ‘best’ best-interests decision, *which should be arrived by any similarly-informed best-interests decision-maker*’. So ‘in principle’ a Court of Protection Judge, a patient’s relative, the patient’s nurse and the patient’s doctor, if they each understand the same about the patient’s situation, and the patient’s ‘individuality’, should each make the same best-interests decision. Relatives have no background in medical ethics – so, ‘medical ethics cannot be a factor in best-interests decision-making’.

The same reasoning, makes it clear that an extensive knowledge of case law, and also clinical training, cannot be things which a best-interests decision-maker is required to possess – see my piece here:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/A-paper-by-Kitzinger-et-al-about-the-Briggs-ruling-and-MCA-best-interests-is-well-worth-reading-and-my-but-if-you-were-a-welfare-attorney-analytical-tricktool./950/>

*I can't really take issue with the paper – it is very much in line with my own writing – but, I think people who analyse the Mental Capacity Act's 'best-interests' are missing a trick. The trick is this, and if you start from this question, 'it all becomes simpler':*

*'If I had just been appointed as a Welfare Attorney, and I was a 'normal person untrained in either law or medicine', then WHAT WOULD I CONSIDER that section 4 of the MCA was asking me to do?'*

*We can throw in some reality: most welfare attorneys will surely (I don't have the evidence, but this seems 'intuitively obvious') be appointed during end-of-life situations or 'dementia', and will not be making best-interests decisions (or, more correctly, will not have legal authority over best-interests decision-making) within the rather 'specialist' 'coma-type' situations such as the Briggs case. And it surely cannot be 'our intention' that end-of-life decision-making is routinely 'sent to court for a ruling'. IF WE USE MY STARTING POSITION (the question I pose above), then some obvious things follow, including:*

*a) if you have just been appointed as a welfare attorney, because a loved-one is 'dying' or is starting to develop dementia, you are likely to be concerned with helping your loved-one: you will NOT be spending a lot of time on 'boning up' on medicine, or studying court rulings;*

*b) so [from a)] whatever we need to know about best-interests decision-making, we must surely be able to discern that by reading the MCA itself, and perhaps the MCA's Code of Practice;*

*c) it follows that any 'normal person' who takes the trouble to read the MCA and its Code of Practice, should be capable of 'satisfactorily performing whatever 'process' best-interests decision-making requires' [that MUST BE TRUE – the appointment as a welfare attorney imparts decision-making authority, it DOES NOT 'magically impart decision-making 'expertise'"].*

I wrote a BMJ rapid response, which explained why I dislike any 'resort to ethics' and the relevant part is:



<http://www.bmj.com/content/353/bmj.i2230/rr-7>

*The reason I am so keen on people sticking to the informed consent described in our English law, is not that I am ‘against happy endings’, nor am I sanguine about young adults, ‘exercising their legal right to kill themselves’. I am so insistent about the application of informed consent, because I became involved not in a general ‘ethical debate’, but in a debate about end-of-life behaviour. And the ethics which many professionals seem to apply during end-of-life, offend me. I am offended that most guidance seems to imply that if a terminal patient has clearly expressed a refusal of a future treatment to a member of his family, ‘somehow this counts less than if he had expressed it to a GP’. I am offended that even if I write a very clearly worded Advance Decision refusing cardiopulmonary resuscitation irrespective of why I arrest, if I arrest at home and the death could not be certified, attending 999 paramedics would be likely to ignore my instruction and would probably attempt CPR. I am offended that for known end-of-life but not yet ‘expected’ home deaths, the police tend to become involved, and to treat the family as if they are suspects – but I feel sure that deaths which happen in identical clinical situations, but in hospital, do not result in the police attending and interrogating the nursing staff. These things all offend me, and they also ‘offend my ethics’. My ethics include things such as ‘no accusation without some evidence’: people should be assumed honest until proven otherwise; decent end-of-life support for patients requires that clinicians and family carers should be working together; etc. So my ethics, appear to be different from the ‘ethics’ of 999 paramedics, police officers, etc.*

*If my [hypothetical] 82 years old, but seemingly ‘healthy’, father had made it very clear to me that under no circumstances would he want CPR to be attempted, I might not think he was making the ‘right decision’ but I would respect it because it is his life, and he would experience the consequences if he arrested and CPR was attempted – if he collapses, I tell 999 paramedics that he had made it clear to me that he would never want attempted CPR but the paramedics attempt CPR, ‘then I’m not happy with the ethics of 999’.*

*When EoL patients are at home, and capacity has been lost, discussions about ‘what should happen’ can lead to disputes, for example between a GP and a family carer. The only thing I am 100% certain of, is that a family carer’s ‘well, I’m not going to do that, because my dad made it perfectly clear*



*to me he would have refused [that course of action]', is legally (and in my opinion morally) correct. It has to be legally correct: because it follows the fundamental 'a person is sovereign over his or her own body' legal principle. There is no such clarity, once 'professional ethics' [and professional objectives] are applied to disputes between relatives, clinicians and police officers: and while 'arguing the ethics' with a GP is one thing, 'arguing with police officers about ethics' is a wholly unsatisfactory experience (for a live-with relative), immediately after a death, and when 'the police officer is confused'.*

## **The Ethics of the Mental Capacity Act**

To be clear, I am certainly not asserting that 'the MCA is ethics-free' - but I am asserting that the ethics which informed the Act, are to be found **within the Act itself**: the MCA's ethics can be discerned from its Principles and by 'thinking backwards from the wording of the Act as a whole'.

Surprisingly, some court rulings which were made after the MCA was enacted, seem to have been applying some sort of 'external ethical concepts' to the Act – I am pleased to write, that since about 2014 court rulings are increasingly 'applying the MCA as it is written'. I started one of my pieces, with that observation:

<http://www.bmj.com/content/352/bmj.i222/rr-0>

*I first read the Mental Capacity Act in 2009. Between 2010 and the present, I have found it dismaying that my understanding of the Act, was not reflected in the writings of clinicians and other professionals. Since 2014 a series of court rulings have encouraged me, but possibly dismayed clinicians, because it seems to me that judges are now agreeing with my interpretation of the MCA. If the MCA were a painting, it would be inconsequential if it looked different to different viewers: but, that is not the case for a law as fundamental as the MCA.*

In the context of my own understanding or interpretation of the MCA, it is worth thinking about what I have already written here, and the relatively recent ruling by Mr Justice Charles in the Briggs case. I have commented on that ruling, and there is a URL to the full ruling in my piece at:

<http://www.bmj.com/content/355/bmj.i6829/rr-0>

In comparison to what I have already written in this piece, it is worth noting that Mr Justice Charles said in his ruling:

*It is the application of the MCA, rather than the common law and inherent jurisdiction set out in the earlier cases that matters. However, the earlier cases remain relevant because they provide useful analyses of the relevant issues and form a central part of the background to the recommendations of the Law Commission on which the MCA was based and so to the MCA.*

[Compare to b\) on page 6](#)

*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,*

[Compare to what I wrote at the bottom of page 5](#)

The ethics of the MCA as they apply to mentally-capable individuals, and in the context of this piece individuals who are usually patients, can be summed-up as ‘adequately-informed people make and express their own decisions’ and this was expressed very clearly by Mr Justice MacDonald (page 2).

The ethics of the MCA as they apply when best-interests decisions are being made during incapacity, start from a strong implication that ‘if at all possible the decision must incorporate the patient’s individuality – and ‘the individuality of the patient’ can over-ride ‘the sanctity of life’’. It is very difficult indeed to clearly describe ‘best interests’ (it is much easier, to explain why a description of best interests is flawed, than to write a description which is correct!), but I have posed a ‘challenge’ to describe the objective of MCA best interests in a single sentence, at:

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

The sentence I came up with is:

*The objective is to make the best-interests decision which would result in the most satisfactory future when considered from the perspective of the incapacitous person as an individual.*

## The Logic of the Mental Capacity Act

As well as internal ethics, the MCA contains an internal logic: and one point in particular, is something which I was asserting as 'logically obvious' well before a judge stated the same thing. This is starting to get to something I will look at later: the 'logic of how the best-achievable best-interests decision can be arrived at', but here I will simply point out that I had a disagreement about MCA 4(6) with a Palliative Consultant during 2012/13. This is section 4(6) – it is the only guidance within the MCA, about 'how a best-interests decision is to be made':

*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.*

The consultant claimed that a doctor who did not 'know the patient as an individual' could apply section 4(6) just as well as a close friend of the patient could apply it – to me, that seemed absurd, when I look at sections b and c. Of course, *it is easy to understand why doctors, who traditionally assert 'we make the best-interests decision' would find it problematic*, if family and friends can understand [and, more to the point, **apply when arriving at a best-interests decision**] 4(6) better than the patient's doctors.

I used an analogy involving a dog to make my point:

*Life experience of someone - 'knowing the person' - gives you a different position from that of a reporter of mere observation: it is the clinicians who are limited to merely reporting on observation.*

*And knowing someone, or knowing something, allows you to conclude things, but not to 'explain why you know these things so that other people could work them out'.*

*If you see a strange dog and its owner, and you are considering stroking the dog, you DO NOT interrogate the owner about 'how the dog thinks and behaves', and then try yourself to work out if it is likely to try and bite you if you try to stroke the animal. You ASK the owner 'Can I stroke your dog, or will he bite me if I try to stroke him ?'.*

**It is ridiculous to claim that you 'work out if an incapable patient would want a treatment by asking those close to the patient to explain how the patient 'thinks''.**

**Logically the clinicians should describe the clinical outcomes, and then ask the wife, children, close friends, 'Do you think you are reasonably sure of what he would decide in this situation'.**

**And having asked, only Welfare Attorneys or Court Deputies 'can legally act 'like a judge' to 'impose' a best interests decision'.**

Mr Justice Hayden, in 2014, explained the same thing in his piece (my own added bolds):

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

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.

I will depart, at this point, from consideration of the MCA, and deal with a different issue:

## **Can Healthcare Professionals be easily ‘distinguished from’ Family-Carers?**

What I hope I have done so far, is to prove that ‘normal people’ can make perfectly legally-defensible decisions about the application or withholding of potentially-clinically-successful treatments which are on offer. In fact, it can be argued that family and friends are perhaps better-placed than clinicians to make best-interests decisions [but I will explore that in some detail, later in this piece].

I will now establish, that often any distinction between clinicians and family carers breaks down even for the application of a treatment.

An obvious situation, is that of cardiopulmonary resuscitation (CPR), the generic term for interventions intended to re-start a heart which has stopped beating (conceptually, the situation we are considering [which I describe as ‘in CPA’ - ‘in cardiopulmonary arrest’] is one in which the heart is pumping either no blood, or so little blood that unless adequate circulation is restored by some means, the patient will start to die within a few minutes, and will probably be dead within perhaps 10 or 15 minutes – that is **not** ‘a heart attack’). CPR is quite widely taught as first aid – so, a family carer who has been taught CPR can apply CPR.

I will discuss CPR at some length later – not how it is performed, but when it should be attempted.

I constructed a scenario ‘Anne, David and Dr Jones’ which involved the patient, Anne, living with dementia, and it features a disagreement between her husband David and her GP, Dr Jones. The scenario is online in various places, and I will point at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/271/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-Anne-David-and-Dr-Jones-scenario-who-is-deciding-what-in-this-scenario-/913/>

## The Anne, David and Dr Jones scenario - who is deciding what in this scenario ?

Here is the scenario, and the questions:

Anne is married to David, and they share a home together. David is Anne's 'sole [or at the very least, 'main'] carer'. Anne has been suffering from dementia for several years, and her dementia is now quite advanced. Anne's GP is Dr Jones, and Dr Jones believes that Anne should start to take a tablet every morning, and the tablet must be taken 30 minutes before breakfast. The clinical consequences of taking this tablet, and of not taking it, have been explained to David by Dr Jones.

Anne already takes two different tablets after her evening meal, and she isn't always happy to take the tablets: David sometimes has to coax her to take the tablets, and perhaps once or twice a week Anne becomes very angry with David when he tries to persuade her to take the tablets, and Anne will then be very unsettled for, sometimes, an hour or more. Dr Jones is aware of this. Both David and Dr Jones agree that Anne is not able to understand the clinical advantages of taking the new tablet every morning, but when David and Dr Jones mention it to her, she immediately says 'I don't want any more tablets !'.

David believes Anne should not take this new tablet, and he tells Dr Jones that he is not going to give the tablet to his wife: as they live alone, and if Anne is to take medication it falls to David to administer it, this means that we are in a situation where Dr Jones believes that Anne should start taking this new tablet, but David is refusing to administer it. Discussion Points:

*Who is making decisions here ? Do both Dr Jones and David have decisions to make, and if so, are they the same decision or are they different decisions ?*

*What can, and should, happen next, if Dr Jones and David cannot see eye to eye however much they discuss this new tablet, and they continue to hold opposing views about whether Anne should be taking this new tablet ?*

So far, I have not tempted anyone to explicitly state 'Dr Jones' opinion is the correct one, because Dr Jones is the professional'.



If someone had suggested that, I would have thrown in this to ponder.

Suppose that Anne had been capacitous, and while capacitous she had sent off an application for David to be made her Welfare Attorney under the LPA. The application can take several weeks to be processed: let us assume that after sending the application off, Anne's dementia suddenly became much worse, creating the situation in my scenario, *while the result of the application is unknown*.

Suppose that Dr Jones is in Anne and David's home, that Dr Jones and David are still disagreeing about the best-interests decision, **and it is claimed that** 'the decision of Dr Jones is the right one, because Dr Jones is the healthcare professional'. Then, while they are still arguing about whose decision is the better, an envelope with the LPA documentation confirming David's appointment as Anne's welfare attorney drops through the house's letter-box: **instantly 'David's decision becomes the right one'**.

It is impossible to decide whose best-interests decision 'is the right one' - and the MCA does not explain how it could be established 'whose best-interests decision is better': the MCA explains how a best-interests decision can be made defensibly, and it imparts best-interests decision-making authority via its section 6(6) - apart from that, all the MCA provides is the option of appealing for a court ruling to settle disputes.

There is a rider to the previous paragraph: there is a deeply 'problematic in practice' sentence in the MCA's Code of Practice. Note that the Code of Practice is not 'law' in the way that the Act itself is: the Act explains 'It is the duty of a person to have regard to the Code' if the person falls within certain categories - and 'normal family-carers and relatives' are **not** required by the Act (see section 42) to 'have regard to' the Code. This is the 'deeply problematic' sentence in the Code - it is the final sentence of 5.31:

*Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.*

So, if the professional guidance for nurses says 'you should not attempt CPR if a doctor tells you not to' then, if we give weight to 'have regard to', the nurse probably should not attempt CPR. But nothing in the Act

supports the suggestion that 'don't attempt CPR' from a doctor to a family-carer, can prevent the family carer from attempting CPR.

We should be looking at best-interests decision-making differently: instead of starting by thinking about 'who the decision-maker is' we should be thinking about 'how do we arrive at the best decision?'

And the first question everyone should ask himself or herself is:

<http://www.bmj.com/content/352/bmj.i222/rr-0>

**' Am I sufficiently well-informed to properly consider section 4, and thereby to defensibly claim compliance with section 4(9) ?'.**

If the answer is 'no' and it seems clear that someone else could more reasonably answer 'yes', then you should probably defer to the other person's decision, while providing them with any information you have which would help the other person to make a better decision.

It turns out, that it is possible to arrive at a best-interests decision – in fact, to arrive at what looks as if it must be 'the best achievable' decision – without there being an individual who can be identified as 'the decision-maker'. See one of the pieces in a composite PDF (the piece titled 'Decision-Makers and the MCA') which can be downloaded from:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/264/>

The PDF contains more than I show here, but this gets the idea across:

*In particular, if there is uncertainty about 'who the decision-maker is' then the idea that 'the decision-maker consults other people' is impossible to apply - so section 4(7) becomes 'a lot of deeply-involved people need to talk to each other, in case any one of them is faced with a decision to make [and other less-involved but potentially informative people must also be talked to]'. And in the same way that the Montgomery ruling has made it clear that the adequacy of the information supplied to a mentally-capable patient during a conversation about consent has to be judged from the patient's perspective, the decision about 'who to discuss things with' [for section 4(7)] then has to be looked at 'from the perspective of the decision being made' (and not from the perspective of a person who makes that decision). Section 4(6) then becomes 'and try to consider everything reasonably discoverable which might affect the decision being made'. Put at its simplest, the whole 'ethos' of section 4 then becomes:*

Best-interests decision-making involves asking everybody who could contribute to a better decision being made, to contribute whatever they can towards the making of a better decision.

## **A Royal College of Physicians end-of-life care podcast**

There is a recent RCP podcast, which features three doctors and a patient discussing EoL. I will be sending an e-mail to the three doctors, asking if they are willing to discuss the podcast with me, and two PDFs will be attached to the e-mail. The PDFs are already available online:

### **Comments on the RCP EoLC podcast by Mike Stone**

<https://www.dignityincare.org.uk/Discuss-and-debate/download/314/>

### **My Own Story by Mike Stone**

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

The 'My Own Story' PDF explains the things that happened when my mother died at home, which 'inform my own thinking about EoL Behaviour'. The 'Comments' PDF contains the link for the RCP Podcast.

I wish to insert some extracts here:

*I liked the talk, but it was clear to me that three of you were 'thinking like clinicians' whereas I think like a patient, family-carer or Welfare Attorney.*

I have performed a couple of Twitter Polls, which while limited are worth pondering:

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 surrounded 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](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](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

Another PDF which I have recently posted, commented on the video of lawyers addressing the Supreme Court's Judges, and it can be downloaded from:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/312/>

I will here extract the following, from that piece:

*This video, offers me an opportunity to make a few points. I have never seen a video of such a court case 'as it happens', nor been present at such a court case, and previously I had only read court judgements. But, in general I would point out that:*

*\* In court cases, there will be lawyers who are arguing in favour of their client's opposing positions, and there are judges who are attempting to make a ruling which fits the law – and these court cases are always about a specific real-world situation;*

*\* Although I stand firmly in the patient and family carer position, I do attempt to analyse the MCA 'neutrally' - and I construct hypothetical scenarios, 'thought experiments', which are intended to help with analysis of the MCA.*

*The judges, can only make a judgement that 'makes clearer' an aspect of the MCA, if they can do that within the confines of a particular court case: they lack the freedom to 'explain the MCA 'as a whole'".*

I will now digress a little, and briefly comment on

## **Does the NHS 'learn from the experiences of Service Users'?**

The answer must surely be 'yes' - so, I am really asking 'does it learn as much, and as quickly, as it could if feedback was truly valued?': and, I am not persuaded the answer to that is also 'yes'.

Since joining Twitter relatively recently, I have discussed various issues with other people who are trying to 'improve NHS behaviour'. It seems that we have had some shared experiences, when we have attempted to prod 'the NHS' into learning from our experiences.

Kate Allatt posted a couple of tweets, in response to one of mine, and this seems to be a common experience:

<https://twitter.com/KateAllatt/status/980029188164988928>

*Yes. I have personally come across some very, very rude, dismissive, presumptuous, #fixedmindset health professionals during my activism work over the last 7 years! Deeply upsetting, in it to help everyone be the best they can be.*

*Thank you Mike. It's upset me over years especially when you health professionals misjudge my work 4 years. They judge me on my shoot-from-the-hip truth 1st book 7 years ago! It's ignorant. My experiences were my truth. It was written as my kids legacy, not 4 anyone else at time*

Personally, I have noticed that 'the NHS seems to like consultations [asking the public to answer its own questions, or to send in comments about something] but it is not so keen on conversations ['the NHS' isn't so good at 'talking back-and-forth with service users – I ask, you answer: you ask, I answer; etc]'

There is an excuse for this – there isn't 'an NHS' so to talk to the NHS you need to be discussing an issue with someone who works within the NHS: with nurses, doctors, etc. And the people who 'sit at the top of' many 'NHS groups' are often senior clinicians, who are very (even absurdly) busy – so they do not have much time for discussions.

However: if the professionals 'consult the public' but the professionals then withdraw into a room and 'haggle among themselves over policy or protocol', you inevitably seem to end up with, to at least an extent, what I have described as '*the professionals huddling together under the umbrella, and the laymen being pushed out into the rain*'.

Put another way, if only the professionals are sitting around the table when the protocol is being argued over, the 'balance points' will almost certainly be different from where they would be if the laymen were also sitting around that table: see for an example, the piece at the top of page 5 about whether or not a written Advance Decision should have its 'authenticity' checked during 'an emergency'. Nobody can say where those 'balance points' between competing objectives should be – but, it can be reasoned that they will depend on 'how many groups with competing interests are around the table'.



Myself, I can't see how ReSPECT, which was previously called ECTP, can have been created with the depth of 'lay input' which the clinicians leading the development of ReSPECT tell me has been the case. Because when I talk to other lay people, they seem to usually agree with me about 'my complaint' here (I have not, of course, 'talked to everyone'):

<http://www.bmj.com/content/352/bmj.i26/rr-5>

*The recent ruling by Mr Justice MacDonald (see ref 3) has made it clear that mentally-capable patients make their own decisions, which are not then to be questioned by others, and I have pointed out above that sometimes it is legally clear that a welfare attorney [or, but never for CPR, a court deputy] is the decision maker. The Winspear ruling starts its point 4 with 'Although the precise terms of that conversation are a matter of dispute,' and exactly who said what during Tracey, is very uncertain indeed.*

*The ECTP prototype does mention conversations between clinicians, patients and relatives - but it does not suggest that such records of conversations, should be 'signed off' by 'all sides': the ECTP wants only clinicians to sign. Similarly, the ECTP does not seem to want attorneys and deputies to sign to confirm their decisions - again, it wants the clinicians to do the 'signing off'. This is both legally dubious - people should sign for whatever they are responsible for, so a clinician signs for a clinical prediction, a welfare attorney signs to 'authenticate' his/her own best-interests decision, etc - and anachronistic. This type of 'clinical control' of 'patient records' reinforces inappropriate distinctions between clinicians and involved laymen, it potentially introduces 'bias', and it definitely does not promote the necessary cooperation and integration between the clinicians, family, friends, and if they are present attorneys and deputies, which decent 'joined-up' care requires.*

*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.*

ReSPECT seems determined to keep non-clinical signatures off its main form – while I am determined to get those 'lay signatures' on the form. **Absurdly**

ReSPECT has even *contrived an illogical justification* for preventing a welfare attorney or court deputy whose legal authority covers an anticipatory best-interests decision which is recorded on its form, from signing the form:

<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/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/283/>

*I'll be sending the PDF to Alan Eccles, the Public Guardian for the Mental Capacity Act, later today: no need to go into details, you can read the PDF. But in brief - any recommendations on a ReSPECT form which are made on 'best-interests grounds' should not be 'signed off' by the senior clinician.*

*The form does that - only has clinical signatures on it - which seems to me to indicate that those learned clinicians who developed ReSPECT, do not accept that the MCA has moved 'decision-making' to patients, people chosen by patients, and other lay people involved in caring for mentally-incapable patients, and that 'clinical paternalism is supposed to be dead now'.*

I would point the reader to my two Twitter Polls on page 17 – I can't see much evidence from those, to support the 'only the senior clinician should be signing things' attitude *that I myself discern* when I read the ReSPECT material.

I must admit, that personally I do have ongoing discussions with various clinicians, and in the past have had similar discussions with civil servants at the Department of Health. Usually by e-mail in the past, more recently using Twitter. In my experience, the doctors, nurses and civil servants who I discuss end-of-life issues with all want to improve things, but there is something slightly perverse about these interactions. If the NHS is to optimise its learning via 'lay input', probably the most important thing should be the 'validity and importance of the layperson's issue'. That is a different thing, from the personal qualities of the person who is raising the issue/concern. And I think that my own personal qualities, in combination with sheer luck, are the reason why those professionals are willing to exchange e-mails with me: but I don't claim any credit for my personal qualities, any more than a horse could 'claim credit' for being a horse and not an elephant.

It was recently suggested – more as an aside, than as a considered analysis – to me by one of my contacts, that clinicians will discuss things with me 'because unlike some, you are willing to listen'. As it happens – and this is purely my personal opinion, after a few years of 'campaigning' - I think those interactions between Lay NHS Campaigners and doctors, nurses, etc, start from this situation:

We campaigners, who want to alter some aspect of ‘NHS systemic behaviour’, are interested in discussing things with the professionals because we want to understand ‘what they believe, and how they think’;

The doctors and nurses who do engage with us, are initially interested in understanding what it is we see as problematic, and they want to help.

But from then on, I think the reason if continued long-term interactions do subsequently occur, is that there is a mutual interest in learning from the other person’s different perspective as it impinges on a shared interest of both parties to the conversations. It also helps, if every so often the other person tells you about something ‘you didn’t know about, but feel you should have known about’ [for example, details of a relevant court ruling might be passed to the other person, who had not already picked up on it].

In my experience, quite often I will be offered at the start of an interaction with a new person, ‘a phone call’. I usually turn down phone calls, for my discussions of EoL issues: at least, I have little use for phone calls **before** ‘we each have a reasonable grasp of what the other person already understands’. I had an hour-long phone conversation with one of the people I discuss EoL with recently, and the e-mail to me afterwards explains the problem with those phone calls:

*Dear Mike,*

*Good to talk this afternoon.*

*I suspect we could have talked all afternoon....about all things end of life/palliative care/mental capacity act/the challenges of data collection and context of care and services models ... I’m not sure if we came up with any fixed solutions!*

That neatly leads to my next topic:

## **The Burden of Decision-Making ‘if relatives make decisions’**

Celia Kitzinger and Jenny Kitzinger, research and write about what I will here describe as ‘coma and coma-related’ situations. They have a particular interest in the withdrawal of clinically-assisted nutrition and hydration (CANH) from patients who are ‘long-term-comatose’ and because I analyse the legal justifications for withholding attempted CPR while CPR might be clinically

successful, we discuss very similar legal issues. The Kitzingers have described some of the ‘burdens on’ and ‘feelings of’ the families of patients who are comatose, or close-to-comatose, in their papers.

In my piece ‘The Burden of Best-Interests Decision-Making’ at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/302/>

I opened with the e-mail shown on page 22, and I went on:

*The nurse threw in a comment, that family members who are ‘welfare attorneys’ [who have been given decision-making authority over best-interests decisions via the LPA and section 6(6) of the MCA] ‘often find it a great burden to make those best-interests decisions’.*

*Not only is that true, and also often-stated by doctors and nurses, but it is only part of the necessary analysis of ‘best-interests and burden’: I have recently written about this issue, but in a ‘scattered about’ way. So our discussion, has prompted me to write this piece, which will use things I had already published.*

I then explain the problem – which put concisely is:

The Kitzinger paper states – and while I disagree with this in legal terms, as is clear from the above I agree about the ‘burden’ issue:

*... healthcare teams making best interests decisions not to continue ANH-treatment would need to ensure (as they should do currently<sup>22</sup>) that family members know that the decision is not theirs to make, that the burden of responsibility lies with the clinical team and that everyone involved recognises the immense gravity of the decision to allow death.*

Because the clinicians will usually not understand ‘what the patient would have wanted’, **if you let the clinicians make best-interests decisions, then inevitably the clinicians tend towards ‘preservation of life and ‘best clinical outcomes’**” – but, while the legal concept of ‘best interests’ is incredibly difficult to express in clear and simple terms, it is much closer to ‘doing what the patient would have wanted’.

As I pointed out at the end of my PDF:

*That is the point, and the current analyses of these situations by most authors is almost correct: where it is incorrect, is in its 'effective assertion' that the clinical team 'makes the best-interests decision', after discussion with family and friends. What would be a correct description of the wording of the MCA, is that the clinical team and the patient's close family and close friends need to talk together, in some depth, with an objective that after those discussions some individuals would then be sufficiently well-informed about the things described by section 4 of the MCA, as to be able to individually claim to have arrived at a best-interests decision which can be 'defended' by compliance with section 4(9).*

*Those 'sufficiently-well-informed individuals' are not defined by clinical or lay status – they are solely defined by their ability to defensibly claim compliance with section 4(9) of the MCA: 4(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.*

## **CONCLUSION**

*Provided that there is no exclusion of anyone who wants to be involved in the discussions – for an example, provided no close family or close friends who it is suspected might 'form a contrary [but defensible] opinion about best interests' are excluded from the discussions – then if everyone agrees about the nature of the best-interests decision (here, for example, that CANH should be withdrawn in the patient's best interests) that is the best-interests decision which should guide subsequent actions. Which is NOT 'the clinicians made the decision'.*

*And, of course, the larger the number of individuals who can each claim compliance with 4(9), the 'stronger' is the best-interests decision which each of those individuals had arrived at.*

Personally, I have described some of the things 'which I learnt' when my own mother died, in '**My Own Story by Mike Stone**' (a link to it is on page 16) and I wanted to avoid any such burden of 'making life-or-death decisions', even though it wasn't actually such a decision (in reality - 'life wasn't an option'), and crucially '**despite my being virtually certain I still 'needed to ask'**'.

As I explained in 'My Own Story' (the whole of the next page, is extracted from My Own Story):

Dr Smith, the GP, prescribed some antibiotics and energy drinks, but my mum wouldn't take them. While Dr Smith had been trying to examine her, my mum had been pushing Dr Smith away and saying 'don't want no more'.

Some time later (i.e. a couple of hours later the same evening) it struck me that 'don't want no more' might mean LIFE, instead of 'being examined/messed about', **something I needed to be sure of**. So when I was sure my mum was 'with me' I asked twice. That evening I said 'Do you know that you won't get better unless you take the drinks and medicines' and the following morning I said 'If you don't take the drinks and medicine you will go to sleep and not wake up again. Is that what you want ?'

My mum wasn't speaking by then - she was nodding and mumbling. But I was bending down in front of her, and having nodded 'yes' to that final question she looked me in the eyes, smiled, and SAID 'you know I love you'.

That was the last thing she ever said to me.

To explain 'when I was sure my mum was 'with me' I asked ': my mum was having episodes of dementia by then. The nature of these 'episodes' still puzzles me – it didn't seem to be what I had assumed ('in the present but with gaps in memory'), instead it was if at various times she thought she was a teenager still living at her parent's home, or that she was 70 and my dad was still alive. As if 'when her mind awoke, it searched its memories, and 'booted into the past". So, before asking I made sure that 'the mum I was talking to' was the mum aged 86 – I needed to get answers from 'a mum in the present' and not from a mum who was living in a past world. COMMENT: I could see this 'sometimes it is the mum of now – but at other times, my mum isn't in the now': **I can't see how a nurse, or GP, could have** 'seen that in the way that it was obvious to me [because I knew my own mother]'

The conversation with my mum, was I think on a Friday night and Saturday morning – the GP and the DNs had at that stage each visited once, and they did not visit during the weekend: by the next time the DNs visited, my mum had stopped communicating and certainly by the Tuesday she was comatose (well, I'll describe it as comatose: on a bed, no signs of any interaction, even when being turned, etc). **So the GP and DNs could not have asked my mum, the question I had asked her – but I can assure you that 'having asked and been told, you damn well know!'**



As an aside – I will point out here, that despite at the time never having heard of the Mental Capacity Act, because I ‘believed in ‘informed consent’” my behaviour was **instinctively** exactly what the MCA requires.

Because of these two factors – it is horrible to make a life-ending decision if you are ‘close to the patient’, but if you are a clinician who doesn’t understand the patient ‘as a person’ you will naturally tend towards ‘preservation of life’ instead of towards a genuine application of the MCAs concept of best-interests – I am firm in stating that **‘we should be trying to avoid anyone having to make best-interests decisions – so we should be strongly promoting the making and following of Advance Decisions’**.

See:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-believe-that-Advance-Decisions-should-be-encouraged-but-that-advance-statements-should-be-discouraged/814/>

It makes sense to move on, from here, to one of the issues which has annoyed me ever since I became aware of it ca 2011/12:

## **The Verbal Refusal of Life-Sustaining Interventions**

I became involved in ‘EoL debate’ after my mum’s death late in 2008, and the first thing I did was to look into the meaning of the terms ‘expected/unexpected death’, and during 2009 I read both the MCA and the then current version (the October 2007 version) of ‘Decisions relating to cardiopulmonary resuscitation [A joint statement from the British Medical Association, the Resuscitation Council \(UK\) and the Royal College of Nursing](#)’. In the ‘Main messages’ section of that CPR guidance, it was correctly stated:

- *If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable advance decision refusing CPR, this should be respected.*

That says ‘or a valid and applicable ADRT’ - somehow, once clinicians started to read the MCA, some of them then managed to completely misunderstand sections 24-26 of the MCA. The first ‘major’ NHS policy about CPR, was the March 2010 South Central ‘[Unified Do Not Attempt Cardiopulmonary Resuscitation \(DNACPR\) Adult Policy](#)’: unfortunately – partly because several other regions seem to have ‘cloned’ their own policies from this one – that contains the incorrect sentence (in 10.1):

*A verbal request to decline resuscitation is not legally binding; however it should not be ignored and does need to be taken into account when making a best interest decision.*

That obviously absurd belief – that the MCA ‘made verbal refusals of CPR not-legally-binding’ – seems to have become widespread within the clinical community: despite the BMA/RCN/RC(UK) previously having described the situation both correctly and concisely, in the main messages section of its CPR guidance shortly after the MCA came into force.

I have been attempting to point out the insanity of believing that ‘a verbal refusal of CPR cannot be legally-binding’ for years. One explanation of why, can be found in ‘There is a problem with Advance Decisions’ which is part of the composite PDF at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/264/>

A more recent explanation, can be found online as the 26/08/17 addition to my post at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-the-BBC-Radio-4-broadcasts-about-Mr-C./958/>

I will show the piece here, in green text – and if this doesn’t prove that verbal refusals of CPR can be **more** legally-binding than a written ADRT, and also explain why the MCA contains section 25(6), then it is beyond me to explain it any more clearly!

mike stone 26/08/17

‘... AND WATER IS WET, AS WELL!’

A Twitter conversation, on one of my old ‘favourites’, cropped up yesterday: does the MCA’s requirement that a valid ADRT refusing a life-sustaining treatment must be in writing, mean that a verbal refusal of a life-sustaining treatment cannot be legally binding?

The answer is clearly ‘no, it doesn’t mean that’ - I find that most of the rest of the world say ‘yes, it does mean that’, and to be frank ‘it almost makes my brain hurt’ that I need to keep arguing about this one.

I’ll have yet another go – using a ‘general point about the MCA’, and then using 3 ‘collapsed into a cardiopulmonary arrest scenarios’.

## GENERAL POINT

The MCA, is clearly about strengthening patient control: about increasing patient autonomy. It would surely be contrary, to introduce legally-binding written ADRTs and to introduce 'this now means that your expressed refusals are not legally binding on the people you tell, until you also write them down and get them witnessed'. That would be 'absurd and bonkers' so such an interpretation, simply must be 'missing something'.

Here goes – yet another way of arguing this, to add to my earlier versions.

## SCENARIO 1

You are a 999 paramedic. You arrive at a house, there is a man lying on the floor next to a table. He is holding in his hand what seems to be a valid written and witnessed advance decision (ADRT), refusing CPR, and he is in arrest. The woman who lives next door is in the house, and she explains to you that he had fallen the week before, she had minutes ago heard a thudding noise so came round to his house, and found him on the floor, so she called 999.

You might be pondering 'why is he holding his ADRT'. You might think 'was he about to write 'I retract this decision' across the written ADRT because he had changed his mind – is that why he was at the table, with his ADRT?'. Or you might think 'did he feel unwell, and was he reading his written ADRT because he somehow felt he was going to arrest, and he wanted to check that if he arrested with the ADRT next to him, its wording would prevent a 999 paramedic such as myself from attempting CPR?'

You **COULD NOT ANSWER THOSE QUESTIONS**. There is no possible way, for you to know the answers.

## SCENARIO 2

You are a GP visiting a patient, about his bad knee. At the end of this visit, he asks you about his ADRT refusing CPR, which you already knew about, because he consulted you when he created it 2 years ago. He gets out his written ADRT, puts it down on a table, and questions you about its wording, because he is not convinced that it will definitely prevent attempted CPR. You tell him that the wording on the ADRT should prevent 999 staff, or A&E staff, from attempting CPR. You (GP) are walking to the front door to leave when

you hear a thud, and you turn round to discover that he has collapsed and arrested, and he is on the floor next to a table with the ADRT in his hand.

### SCENARIO 3

You are a GP visiting a patient, because he is going to write a written ADRT refusing CPR, and he wants to consult you about its wording. You have spent 20 minutes discussing what he should write in the 'instruction section' of his written ADRT, you have both agreed about what it is best for him to write in that section to convey his instruction, and OF COURSE YOU UNDERSTAND HIS REFUSAL BECAUSE YOU HAVE BEEN DISCUSSING IT WITH HIM. The patient has just picked up his pen, to complete his ADRT. But before he writes anything, while he is making a final check of what is already written on this ADRT-in-preparation, he suffers a sudden cardiopulmonary arrest, and falls to the floor next to the table, with the paper in his hand.

Three situations, but there is no 'reasonable doubt about the patient's instruction' in 2 and 3, despite there being a valid ADRT in 2 but not in 3. By contrast, there is much more 'uncertainty' in 1 than in 2, despite there being a valid ADRT in each.

The only logical way, to make sense of this, is to assume that the thrust of the MCA – its shift away from 'paternalism' towards 'patient self-determination' - means that the ADRT must be written, precisely because the paramedic might ponder those questions, with no possible way of answering them: which means that the paramedic should withhold CPR if the ADRT is prima facie valid, and if it is apparently applicable. If the risk of a written ADRT refusing CPR being followed, has not been transferred to the ADRT's author when the ADRT was created, then the ADRT is pointless! 'I was told verbally by the patient 3 months ago that he was refusing - but I have not seen him since then' is the reason the refusal of a life-sustaining treatment AS AN ADRT must be written: you cannot know, whether he has changed his mind. But it says ADVANCE decision - if you are in ongoing contact with a patient, and he verbally expresses a refusal to you, you know he has not retracted it if he has not told you that he has changed his mind. Perhaps we need a new term about these refusals: an ADVANCE decision to refuse life-sustaining treatment must be in writing, but a verbal 'PSEUDO-CONTEMPORANEOUS' decision to refuse life-sustaining treatment is also legally binding.

But it is BLINDINGLY OBVIOUS that in both 2 and 3 the understanding of the GP, that his patient has INSTRUCTED HIM TO NOT ATTEMPT CPR, is identical.

Advance Decisions are INSTRUCTIONS – if you have no doubt about the instruction, then as Mr Justice MacDonald explained:

'C has capacity to decide whether or not to accept treatment [so] C is entitled to make her own decision ... As a capacitous individual C is, in respect of her own body and mind, sovereign.'

If you keep that firmly in mind – a verbal discussion explaining a decision is always better than merely reading a document describing a decision – then the justifications for withholding CPR logically come out as I described in a PDF you can download from:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/261/>

## The DNACPR Justification Hierarchy

- 1 A face-to-face discussion with a mentally capable patient, which takes place during the clinical events which lead to his CPA, the outcome of which is that the patient issues a DNACPR Instruction which those who were involved in the discussion can interpret correctly
- 2 An apparently valid and applicable Advance Decision refusing CPR which has not been discussed with the patient
- 3 A DNACPR decision made and communicated by either a single Welfare Attorney (where only one has been appointed), or agreed and communicated by all Welfare Attorneys  
(Note: for non life-sustaining treatments, a Court Deputy can fit here between 3 and 4 – see section 20(5) of the Act)
- 4 A DNACPR decision made by any person who is sufficiently informed of the patient's clinical situation and likely wishes, to enable that person to defensibly consider section 4 of the MCA.

5 A DNACPR action, which is based upon information supporting the reasonable belief that something within categories 1 to 4 makes DNACPR the best available behaviour

6 If none of the above apply, but it is clear that attempted CPR would be clinically futile, then DNACPR

### **7 If none of 1 to 6 apply, CPR should be attempted**

The PDF I extracted that from, also contains explanatory notes, and quite a lot more besides.

I have observed, that when clinicians write about CPR they often seem to start from 6 [that CPR could not be clinically successful] whereas when I write about CPR, I start from 'we know the patient has refused CPR, whether or not it might be clinically successful': this might be because I had that conversation with my dying mother, which I described on page 25, with my closing observation of I can assure you that '**having asked and been told, you damn well know!**'.

There is also a problem with 6. The NMC seems to have a tendency to 'sanction/discipline' nurses who consider that CPR would be clinically pointless, and decide to not attempt CPR 'in the absence of a 'DNACPR Order''. Hospitals and regions often have very similar policies, and sometimes have policies which amount to 'junior clinicians should leave discussions of life-sustaining treatments such as CPR to their senior colleagues'. Ditto the guidance for 999 paramedics – it tends to effectively be 'look for a DNACPR signed by a GP'.

I was recently discussing with a doctor, the situation of a patient in hospital, who explains that 'I definitely refuse attempted CPR from now onwards' to a nurse. The nurse/s are unable to involve a doctor during the next 30 minutes, and then the patient has a cardiopulmonary arrest – the doctor believes that most nurses, would attempt CPR and call the crash team.

See my tweet at:

[https://twitter.com/MikeStone2\\_EoL/status/976091426277740547](https://twitter.com/MikeStone2_EoL/status/976091426277740547)

The doctor and I, both believe that 'the nurses are assaulting the patient if they attempt CPR' after the patient has told them not to do that.

See also:

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

When the doctor explains to nurses '... but you are assaulting the patient!' the nurses tell him '... its all right for you – but we know what has happened to other nurses who withheld CPR in that situation, we need our jobs and we aren't willing to take the risk of withholding CPR'.

The fact that nurses would attempt CPR, makes my own Thinking Clearly No 6 (green text here) something of a 'moot point':

# Thinking Clearly for End-of-Life Care at Home

## Part Six: Symmetry and Balance

Imagine that my father were in hospital, I knew he was 'dying' but not necessarily within the next few days or even the next few weeks, and I could see he was suffering a lot.

**It is for my father to judge his own suffering - not me, nor his clinicians.**

So if he called over a nurse and said to her "I've had enough of this. If I arrest, you must not attempt resuscitation. Please call my son, so that he can come in and I can explain this to him", and then he arrested before I had been able to go to the hospital and hear this from him directly, I would not expect the staff to attempt CPR - that was my dad's decision, and if he had made it, they should follow it.



If he had been at home, and had made the same decision but he had explained it to me as “I’ve had enough of this, and if my heart stops I want to be allowed to die in peace. We’ll sort this out with the GP tomorrow, but if you think I’ve stopped breathing before then, let me die in peace and don’t call anyone” then this is still his decision, so if I do not call anyone professionals should not expect me to have called someone.

I might have doubts about the nurse, but I would have no sensible option except to believe her - ‘the system’ might have doubts about me, but likewise it logically has to believe me. The NHS has many ways of upsetting relatives - implying that they are lying without any proof, is definitely one of these ways !

Having witnessed 10 weeks of sub standard care in regard to my grandfather , I was then introduced to the LCP . I was consulted , and I fully understood the implications, However what I found difficult to stomach was the fact that poor NHS care and support had already taken his independent active life. The most devastating part of my life was being a NHS member of staff, complaining via the complaints system & the CEO to ensure care was appropriate I failed. I more than anyone knew the system, the organisation , how to complain, yet despite my complaints in writing via the correct process and to a CEO . The organisation failed him . The Liverpool care pathway may well promote death with dignity, but it lacks meaning when there is poor quality negligent care.

I ‘surveyed the question’ a few years ago, when I was using a ‘Father and Son’ scenario, and the survey can be found at:

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

The survey did not get many replies, but they are supportive of my understanding of the likely situation: that both family-carers and doctors follow the ‘respect the patient’s decision’ principle, that nurses are split between respecting patient autonomy and looking for some sort of ‘back-up’ within the records, and it does seem to me that those 999 paramedics who have thought about this situation ‘would prefer to not be involved in the first place’.

## Returning to the RCP EoLC Podcast

In the RCP end-of-life care podcast which I mentioned (with a URL to it) on page 16, Professor Bee Wee makes the point that not many people who do not die suddenly, die at home these days: I consider this to have been a hugely significant complicating factor, after my mum's death. I was present when both of my parents died at home, and I found a cousin who had died in his home: all 'end-of-life deaths' but, I 'felt differently' on the three occasions. Even I myself, cannot entirely rationalise 'my own feelings when a relative died' - **and my conclusion, is that nobody should even attempt to 'get inside the mind of a just-bereaved family-carer'.**

It was clear to me, that 'my 999 staff' - both the paramedic and the police - 'wanted to understand 'my mind''.

Even if they had their own experience of a loved-one dying at home, my inability to understand even my own 'just-bereaved mind' suggests to me that these professionals should be trained: a major difference between professionals and family-carers is that the professionals **could be** trained, although I think the police in particular would resist the necessary training, which is '**Do NOT EVEN TRY to understand** 'the mindset and thinking' of just-bereaved family carers who have been involved with end-of-life patients'.

Professor Wee, as her latest addition (I suspect) to the recent attempts to promote conversations during end-of-life, argues that 'the discussions themselves have therapeutic value' in the podcast. I tend to argue 'without the discussions, you can't get the decisions right' - so as usual I am using an argument based on 'consent and best-interests decision-making' whereas Bee is introducing 'therapeutic benefit'. Everyone agrees that somehow we need to promote the discussions: and whether or not the discussions do have a therapeutic benefit, it is definitely the case that 'without the discussions, the decisions being made are going to be the poorer for the lack of discussion'.

My problem with ReSPECT, is not about the necessity of promoting the discussions: it amounts to 'ReSPECT is implying or asserting 'that relatives and family carers **cannot listen**' - as I wrote in my comments on the podcast:

*Bee's emphasis on the discussions – although she introduces a 'the conversations have therapeutic value' while I write that the conversations are necessary to inform decision-making – is of course completely correct: but when I was discussing EoL with Tessa Ing at the Department of Health*

*between 2009 and 2013, it was already well understood that 'we need the conversations – but they all-too-often don't happen'. Telling terminal patients 'to talk to your clinicians and your family' while at the same time not telling the 999 Services to believe family carers isn't a satisfactory situation: and most relatives are likely to discover 'we are not being believed' **too late**.*

I would also point out, that if the conversation takes place – for example the 'I'm now refusing CPR' or the conversation I had with my mum (page 25) then I think a family-carer 'on the receiving end' **will not have** 'I need to document this' foremost [or, perhaps, anywhere] in mind: when my mum made it clear to me 'that I want to die now', even though I had been 'almost sure beforehand', my first action was to make an excuse to temporarily leave the room so that I could cry, and 'so, I need to stop any attempt to keep mum alive' is the 'instruction foremost in mind'.

**While it is obvious that 'you have to document the conversation' is both a correct and also necessary instruction for healthcare professionals, such as nurses – it is 'a perversion of the point' if nurses somehow get from 'you need to get it documented' to 'so until it has been documented, you have not received the patient's instruction to you'.**

## **MCA Myths, Muddles and Misunderstandings**

What I am about to write, is 'my perception based on what I come across – in 'guidance', protocols, Tweets, etc'. So if anyone can definitely prove that I've drawn incorrect conclusions, I stand to be corrected.

There seems to be 'some confusion' about what the MCA was and did: did it 'consolidate earlier laws and concepts' or did it 'create a new legal situation'? The former cannot be what the MCA 'did' - because it doesn't mention those earlier laws: the MCA has to be viewed as 'defining our legal situation', as explained by Mr Justice Charles (see page 9).

And while the MCA describes two distinct situations – decision-making during capacity, and decision-making during incapacity – the decisions it covers are '**not** clinical decisions'. There seems to be a misunderstanding that MCA best-interests is 'somehow a clinical decision', and an associated implication that clinical decisions are made by clinicians: this is no more true than any claim that decision-making during capacity 'is a clinical decision'. Nobody has ever claimed that 'you cannot consent to brain surgery because you could not perform brain surgery'.

The Montgomery ruling, seems to have made clear to doctors, something that should have been clear from sections 3 and 25(4)(c) of the MCA: that the MCA describes **genuine** Informed Consent during capacity, not the peculiar pseudo-informed consent which existed in the earlier ‘world of Bolam’. And if you read Montgomery, we are told that ‘genuine informed consent’ was the legal situation at the end of the 20<sup>th</sup> century – so it was already the case when the MCA was enacted.

Despite Montgomery, it is far from clear exactly how its point – which I would express as ‘the amount of information which the doctor must disclose during the consultation and consent discussion, is defined by how much information a reasonable patient selected from the patient’s peer group would consider sufficient’ - ‘works in practice’.

Logically, because different patients will attach different weightings to different factors, it looks as if Montgomery could mean ‘doctors need to explain **everything** to the patient’ which isn’t practicable. And compared to the best-interests requirement of incapacity, ‘informed consent’ during capacity should be ‘much simpler to describe’. I was thinking about what has to be explained to the patient, and it seems to me that the following are probably correct – so even informed consent isn’t all that simple:

\* Suppose the patient says ‘I’ve got a pain in my knee. What could be done about the pain, so that I can walk with less pain?’. It looks as if the doctor must describe all of the possible treatments, for ‘knee pain’

\* Suppose a patient says ‘I’ve got a pain in my knee. What could be done about the pain, so that when I participate in a Charity Walk in three weeks time, I’ll be able to walk with less pain?’. In this situation, the qualification of the patient’s objective, legitimately allows – indeed, requires – the doctor to use medical expertise to restrict the information he supplies to the patient.

\* Montgomery hinged on incomplete disclosure by the doctor to the patient, of the clinical situation, clinical options and outcomes, and the conclusion that if more information had been given, the patient would perhaps have chosen a different intervention with potentially a different outcome. The initial ‘thought’ is likely to be that ‘informed consent **requires** disclosure’, but if you think about section 25(4)(c) of the MCA, it seems that a patient can say ‘Just get on with it – nothing you tell me, is going to change my mind’, if we extrapolate from ‘refusals’ to ‘acceptance’. But that isn’t ‘the defence of necessity’ - it amounts to ‘what you say will not alter my decision’ whereas ‘necessity’ amounts to ‘we had no opportunity to ask’.

There is also a widespread belief that Informed Consent requires an explanation from the patient of ‘the reasons for the refusal’ - that isn’t logically true. The only mind making the decision about consent or refusal during Informed Consent is the patient’s mind: the doctor needs to be sure that the patient understood and had been ‘informed’, for the consent to be valid, but the patient is not logically required to explain ‘the reasons why I decided as I did’. However – best-interests decision-making does require ‘an understanding of the patient’s ‘mind’’: **so something which a capacitous patient need not explain, becomes a requirement of decision-making if the patient loses capacity.**

Probably the most fundamental ‘MCA misunderstanding’ is a failure to understand what I explained concisely in three linked tweets:

[https://twitter.com/MikeStone2\\_EoL/status/906073527236907009](https://twitter.com/MikeStone2_EoL/status/906073527236907009)

As much of this entire piece relates to ‘MCA muddles’ I will stop this section here, and move on to ‘Advance Care Planning’:

## Advance Care Planning

The ‘system’s’ ‘solution to’ many of the well-understood problems which afflict end-of-life, involves an emphasis on ‘advance care planning’ (ACP). I am much less keen on stressing the centrality of ACP, than clinicians seem to be. Three of my pieces relating to ACP can be found at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/293/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/That-dying-Sontaran-in-Dr-Who/934/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Here-is-a-little-thought-experiment-which-can-be-transferred-to-decision-making-during-healthcare/916/>

My basic issue, is that ‘the plan can become something rigid which the patient is ‘fitted into’ - which was one of the problems with the Liverpool Care Pathway.

My other issue, is that if ACP ‘is the solution’, then when we remove any legal complexity about ‘who should be the decision-maker when the plan is made’ and if ‘ACP is effective’, then it should be possible for Alan to achieve his objective in my ‘Alan and Liz’ scenario. **But he cannot!**

## Alan and Liz

Alan (73) and his wife Liz (71) turn up at their GP's Surgery. Alan is believed to be in good health, but he explains that his mum had a severely incapacitating stroke 6 years before she died, and he is averse to such an outcome for himself.

So he asks his GP "How do I refuse any attempt at CPR, if I am in CPA - if my heart has stopped, I prefer to be left alone to die, rather than to face the highly uncertain outcomes of 'successful' CPR.

Also, nobody could certify that death at the time, but it is my decision and not Liz's - how do I make sure that Liz, who knows I don't want CPR but would presumably be shocked and should not therefore be 'unnecessarily harassed' just after my death, isn't messed about by the police: I think messing Liz about, would inevitably strengthen her long-term memories of the actual death, and that is a very bad thing.

But I want Liz to be able to call 999 if I collapse, because if I'm not in CPA I would probably want treatment - for example, if I've collapsed with a stroke, and it wouldn't kill me, I would want as much active treatment as possible, to avoid living on with avoidable clinical damage.

How do I achieve this ?"

I surveyed CCGs - 'What would GPs in your CCG, say in answer to Alan's question(s) ? - a few years ago, and no satisfactory answer emerged.

I also asked a GP, and I think this reply from the GP is both correct and unsatisfactory from Alan's perspective:

*Difficult situation.*

*Personally I think that it should be an individual's right to make this type of decision (and the recent hospital case stated that CPR decisions should not be made without involvement of the patient [putting aside capacity issues for the moment]) and why should health professionals think that they should be making decisions of this nature without discussion with the individual?*

*the process is more difficult...*

*there appears to be no way of facilitating this with an advance directive and non-doctor health professionals seem to be increasingly reluctant to make decisions using 'clinical judgement'*

*AND forms locally (which I do not like) seem to be de-professionalising nurses and paramedics when it comes to end of life decision making. I think better training and them being prepared to take more responsibility could be a better way forward*

*Not sure if this answers your question*

It seems to be 'legally clear' - Alan **should be able to** achieve his objective, by means of a written Advance Decision. But in reality – because of the way that 999 paramedics behave – it turns out that even a valid and applicable ADRT would not prevent paramedics from attempting CPR:

<http://www.bmj.com/content/356/bmj.j1216/rr-1>

In summary, I have no objection to 'thinking ahead' but I feel that an over-emphasis on ACP is dangerous, because it potentially conflicts with 'make the right decision, at the right time, as required by the situation'. And the type of ACP I come across, isn't a good fit with my own analysis of EoL - which is closer to something I opened a Thinking Clearly about ACP with:

The interesting issue is the validity of conversations within the family compared to those with healthcare professionals - and this is something of interest to you and me!

If informal carers are really the new healthcare professionals, to support the dying at home agenda, then we need to trust family members, have confidence in their caring and communication skills and see them as co-partners in the team as you suggest - I think Canada is way ahead in their thinking. In the UK we are more mistrustful of motivation and sadly this leads to increased suffering.

(E-mail from a hospice doctor, December 2012)



## CPR and DNACPR

I decided to see what a 'DNACPR Form' would look like, if it were genuinely MCA-compliant, a few years ago. The rather lengthy resulting PDF is at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/265/>

There is an enormous amount of angst and also confusion around CPR – and I started that PDF with:

*The place where all of the 'misunderstandings and unbalanced beliefs' around end-of-life, tend to come together, is in the DNACPR Form (sometimes called a DNACPR Order). There are enough problems with Advance Decisions (ADRTs), but a written ADRT is a legally-defined document: by contrast, a DNACPR Form is an 'operational document' and beyond its obvious objective, of preventing inappropriate attempted CPR, the answer to 'what exactly is a DNACPR Form?' is complex.*

I have already covered the legal justifications for the withholding of CPR on page 30. That did not cover other aspects of the current situation: that EoL Doctors created DNACPR forms because of the 'futility of' many of the CPR attempts they are aware of, which far from 'helping patients' in fact seriously damage patients and increase suffering; that many people and often the press equate even 'asking patients about CPR/DNACPR' with 'the NHS wants elderly people to die'; that media representations of CPR have unrealistic outcomes, and as one doctor tweeted 'and don't have that 'crunchy sound-effect' as ribs crack'. Etc.

Sometimes, when I read clinically-authored material about CPR, 'it looks as if patients can forbid it – but preferably only once it would not be clinically successful'.

I also see implications that 'you refuse CPR because of the clinical cause of the arrest': you can legally do that, but logically you are more likely to be refusing CPR because you prefer death to the outcome of attempted CPR [not the cause of the CPA, which might be of no significance at all].

A Palliative Consultant suggested that ADRTs refusing CPR might stand more chance of being followed, if they mentioned the cause of the CPA: but a paramedic was very clear about 'if the patient is in arrest when we arrive, we cannot tell why the patient arrested'.

I was discussing DNACPR Forms and ADRTs refusing CPR with a Palliative Care Consultant, in the context of 'when patients tell me they don't want CPR, I write a DNACPR'. I asked 'why don't you tell them to complete an ADRT refusing CPR instead' and he said 'sometimes they do – but often my dying patients 'don't feel up to' completing an ADRT: they say 'I've told you – will you sort it out for me". I can 100% see that – after all, 'dying patients are often very ill'. What I can't see – is why similarly-ill patients wouldn't do the same thing with a family-carer at home: make it clear 'if I'm dying, I want to be allowed to die from now on' and also say to the family-carer '... will you sort that out, for me – I don't feel up to sorting that out, but I've told you'. See my 'Father and Son' scenario and a survey at:

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

The latest 'line of thinking' seems to be that DNACPR Forms while to an extent preventing CPR, also lead to less-good treatment overall of dying patients: the response – **which I deeply dislike** – seems to be to 'muddle together things the patient is definitely refusing, with interventions the patient would, or might, want':

[http://www.dignityincare.org.uk/Discuss\\_and\\_debate/Discussion\\_forum/?obj=viewThread&threadID=814&forumID=45](http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=814&forumID=45)

That conflates different legal situations – and clinicians should be clear to not conflate the word 'decision' with the words 'wish' and 'preference':

<http://www.bmj.com/content/354/bmj.i3888/rr/927045>

### ***Yes: End of life care everywhere is everyone's business***

*I am pleased to see that Dr Oliver writes in his article 'These included patients or loved ones discussing their own concerns and choices'. Because a lot of end-of-life guidance written by clinicians, seems to avoid describing patients expressing their clear choices - which I think should be more clearly worded as decisions or instructions - and instead typically mentions 'the patient's wishes and preferences'. The word 'wishes' is not appropriate when describing a decision: I can decide to take an umbrella with me in case it rains, and I can wish it doesn't rain'. And 'preferences' is better used in connection with things which are less clear than decisions: 'I never eat oranges, and I often have a preference for pears over apples'.*

*The thing that really bothers me about this, is the contemporary promotion of 'advance statements' from patients, instead of the promotion of the much*

*more helpful Advance Decisions (I discuss this in ref 1). The point being that if the patient loses mental capacity, and there is a decision to be made, a clear decision previously expressed by the patient should be followed, but 'patient preferences' are merely things which a best-interests decision-maker would need to be considering: and best-interests decision-making is a fraught and complex process, best avoided if at all possible.*

*There might be something going on with the way people use words, which further clouds this issue. I recently asked on a Facebook page 'Are – and I'm not being sexist, nor am I trying to start a discussion of 'why this might be true, if it is true' – women, when describing their definite refusal of something, more likely than men to say 'I wish to' or 'I would prefer' instead of 'I've decided to' ?'.*

*Fundamentally (ref 2) you need to get the words right, or else you risk confusing informed consent with best-interests decision-making.*

Ref 1

[http://www.dignityincare.org.uk/Discuss\\_and\\_debate/Discussion\\_forum/?obj...](http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj...)

Ref 2

[http://www.dignityincare.org.uk/Discuss\\_and\\_debate/Discussion\\_forum/?obj...](http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj...)

In any event – I knew that my mother would have refused CPR because of the conversation I had when she wouldn't take some prescriptions: see page 25. I did not ask 'are you forbidding CPR' but 'that was obvious' - and, again, 'I had asked – I had been told – so I knew'.

## **The Things which Guide My Thinking for End-of-Life**

We should all – relatives, friends, nurses, doctors and others – be trying to work together to make end-of-life better for the dying person;

We have different things to contribute: in particular [usually] 'expertise' is held about two different things, by two different groups – the family and friends are the experts 'about the patient as an individual' (unless, of course, 'you can ask the patient'), and the clinicians are the experts about 'clinical options and prognoses';

The correct differentiation is very often not between 'who is a healthcare professional and who is not' - instead for many things, the most appropriate differentiation is between 'who has been involved long-term with the patient and who has not';

We urgently need to sort out 'expected/unexpected death' and I have explained how we should sort that out:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Markers-and-Timelines-for-End-of-Life-Reconsidered-an-attempt-to-bring-order-to-chaos/785/>

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

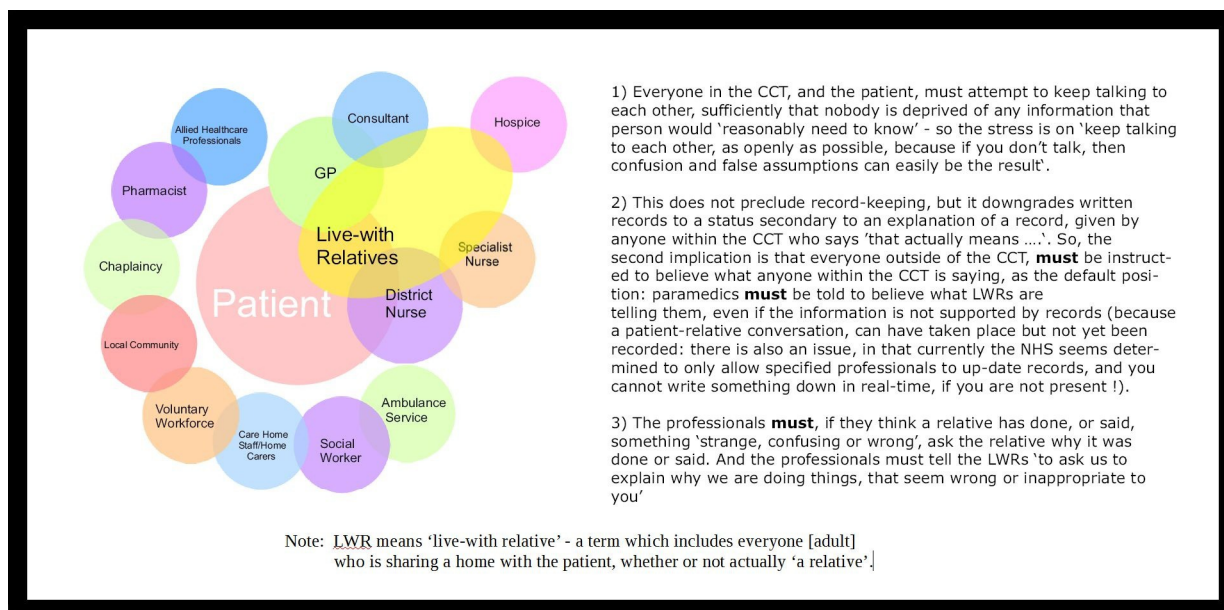
We are **not** at present, in the situation of the MCA being well-understood, nor do the majority of people, lay or professional, have personal experience of caring for a dying loved-one through-to-the-death in their own home. Those two things alone are sufficient to make any 'process and records-based' solution for the problems of EoL very unlikely to be satisfactory: and even if we lived in a time when those two things were not problematic, it will always be true that family-carers during EoL are unfamiliar with the protocols and guidance which professionals are subject to. So unless the professional 'methodology' reflects an acceptance that 'family-carers are always going to be guided by 'instinct'', decent joined-up-and-cooperative EoL behaviour is impossible to achieve.

My own 'solution' for improved EoL behaviour, based on thoughts such as those I have just outlined, is something I call the 'Core Care Team'. The Core Care Team is described in a PDF at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/258/>

More concisely, I described its basics in an image attached to a Tweet, and I show the image at the top of the next page.

I also show some other images which I have attached to my tweets, on the following page.



**'End-of-Life journeys' are rarely 'shared' - we do not 'journey together'.**

**The patient's journey ends with death: the relative's journey ends with bereavement: wherever the clinician's journey ends, it is somewhere such that the clinician can embark on the journey many times. No normal person could repeatedly experience the death of loved-ones, without becoming deeply altered.**

**Professionals work within 'hierarchies' - families have a much less formalised structure: live with that and STOP 'trying to IMPOSE 'hierarchy' onto families'.**



The relationships within families (and I include friends) cannot be 'neatly defined' - **so stop trying!**



## ReSPECT and why I Firmly Object to ReSPECT

At the time of writing – early April 2018 – I cannot write about end-of-life, without also writing about something called ‘ReSPECT’.

I intensely dislike ReSPECT: it ‘has an attitude’ of ‘retention of clinical ‘control’ over end-of-life which conflicts with my own ‘the patient decides – not the doctor – and we can all, relatives and clinicians, listen to the patient’s decisions’ position. Also, ReSPECT is legally flawed: it insufficiently stresses the differences in relevant law which apply in different countries within the UK, and ReSPECT also continues a long-standing RC(UK) tradition of misrepresenting the Mental Capacity Act.

Notably, ReSPECT describes the legal situation for MCA best-interests decision-making incorrectly – put concisely in three linked tweets:

[https://twitter.com/MikeStone2\\_EoL/status/906073527236907009](https://twitter.com/MikeStone2_EoL/status/906073527236907009)

My issues with ReSPECT can be found online, notably within this set of BMJ rapid responses (which also contain some responses from the ReSPECT team):

<http://www.bmj.com/content/356/bmj.j876/rapid-responses>

and in my thread on Dignity in Care at:

<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/>

Some PDFs can be downloaded from that thread, discussing various aspects of ReSPECT and my reasons why I dislike the main ReSPECT Form in particular, including:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/283/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/294/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/296/>

It is probably fair to say, that at the moment ReSPECT and I share a mutual lack-of-comprehension of the other's position, 'which could be described as mutual exasperation'. From my perspective, I am firm in my opinion that the type of experience I suffered from after my own mother's death – described in



'My Own Story' to which there is a link on page 16 – **would be made more likely to happen, not less likely**, by ReSPECT in its current form.

An e-mail to me early 2017 from one of the 'leading lights in' ReSPECT, included this:

*We cannot change the law and it is a fact that an ADRT is the only advance decision that is a “legal document” because it sits within a legislative framework, as you know, but that is only in England and Wales. A DNACPR form or a ReSPECT form cannot therefore be a legal document any more than any clinical record is a legal document however much we might or might not want that to be different. However the guidance is that all relevant documented advance decisions should be respected in common law and any clinician making an alternate decision must be able to justify that clearly and robustly. What you also need to realise is that the ReSPECT process is simply a summary of recommendations which reflect patient preferences about what might be clinically realistic in a future emergency situation. If the patient lacks capacity to engage with that conversation then the guidance is very clear that those close to the patient must be consulted about what the patient’s preferences might have been. The clinician signs to say that they have followed correct capacity process and that means discussing with those who know the patient best, of course it does.*

*The clinician who attends the patient during the emergency situation is the one who takes responsibility for the treatment and care decisions at that time so whatever information can be provided to rapidly inform them about realistic patient preferences is going to be helpful. This ReSPECT process is all about helping patients and families understand what is relevant and realistic for them and trying to give them more control over actions taken at a future time when a patient will be too unwell to make their wishes known.*

Again, with my own added comments in plain blue text.

*We cannot change the law and it is a fact that an ADRT is the only advance decision that is a “legal document” because it sits within a legislative framework, as you know, but that is only in England and Wales. True. So why a common form across the UK? A DNACPR form or a ReSPECT form cannot therefore be a legal document any more than any clinical record is a legal document however much we might or might not want that to be different. Not true. You designed your own form. If it recorded the patient's decisions, then if signed by the patient and witnessed it could be an ADRT. But so long as it only records 'preferences' then even if signed and witnessed*



it wouldn't be a valid ADRT. However the guidance is that all relevant documented advance decisions should be respected in common law and any clinician making an alternate decision must be able to justify that clearly and robustly. What you also need to realise is that the ReSPECT process is simply a summary of recommendations which reflect patient preferences about what might be clinically realistic in a future emergency situation. In other words – the main ReSPECT Form is information relevant to the making of best-interests decisions during 'emergencies': we should be trying to avoid making best-interests decisions during emergencies, not promoting that! And in any event – the clinicians reading that form, understand less of relevance to best-interests decision-making than many family-carers understand: so you are promoting the wrong thing, and you are asserting that the wrong people should be making best-interests decisions. If the patient lacks capacity to engage with that conversation then the guidance is very clear that those close to the patient must be consulted about what the patient's preferences might have been. As I have pointed out – **logically it should be the other way around**: logically, the clinician should inform the person 'close to the patient' of the clinical situation and the clinical options, and ask the person who 'understands the patient as a person' 'do you know what we should do?'. See note 1. The clinician signs to say that they have followed correct capacity process and that means discussing with those who know the patient best, of course it does. Nobody should self-certify 'compliance with the MCA': you might record what you have done to demonstrate compliance, but that should NOT be present on a form intended to guide decision-making during an emergency. And your form asserts that 'the clinician signs to confirm that a Welfare Attorney or Court Deputy has complied with the MCA – that is not only logically flawed, but it is 'not only legally flawed but also incredibly arrogant'. See note 2.

The clinician who attends the patient during the emergency situation is the one who takes responsibility for the treatment and care decisions at that time so whatever information can be provided to rapidly inform them about realistic patient preferences is going to be helpful. If anyone takes an action, or a decision, they are responsible for that under the MCA. **An entirely different thing from legal authority** – the MCA only imparts legal authority via its section 6(6). This ReSPECT process is all about helping patients and families understand what is relevant and realistic for them and trying to give them more control over actions taken at a future time when a patient will be too unwell to make their wishes known. Not while ReSPECT 'clings to the assertion of legally-obsolete 'clinical authority' – change ReSPECT and stop making that assertion, and it might!

Note 1.

See <http://www.bmj.com/content/355/bmj.i5705/rr-15>

*GPs have been making it clear of late, that they are very time-pressed: so the people best-placed to listen to, and understand, decisions expressed by end-of-life patients, will often be their families. But the 999 Services are currently working to guidelines and protocols which tell them to 'look at the records made by the GP' instead of asking the family carer who called 999 to explain the situation. The 'healthcare system' seems set on 'distrusting by default' family carers – where is the 'compassion' in that ?*

*Some years ago, I was discussing EoL behaviour with a senior paramedic, over a lengthy period. It struck him, during the discussions, that he had an elderly and very frail relative, and that if this relative collapsed and arrested at home, any 999 team summoned would almost certainly attempt CPR. The paramedic told me that he and his family would be horrified, by such a CPR attempt. The NHS is still adopting the wrong approach for EoL at home: it is determined to 'follow a records trail [which has been 'audited' by the GP or by a senior nurse]'. The paramedic sent an e-mail to me, about 5 or 6 years ago, and he wrote:*

*'We are a long way from doing this (although I would!!) But at least we are beginning to agree .. Resus in my opinion is just a clinical intervention like any other skill and should not be seen as a mandated right by health care professionals .. After all if we were not called it would not have been done!! The simple answer is to ask why were we called and how can we help!'*

*The paramedic was wrong, unfortunately: if anything, the role of 'the records' has been strengthened, and 'listen to family carers – who have been involved long-term and who understand everything except narrow clinical issues better than you as a newly-involved 999 paramedic can understand the situation – and be guided by what they tell you' - has not been enshrined within guidance.*

*I repeat: I am perplexed that highly-intelligent doctors, endlessly discuss some very profound issues such as those raised by Iona Heath's video and article, but have not yet applied their considerable brain-power to the resolution of many significant problems which face patients and especially family carers, when patients are dying at home – and this is even more baffling, in the context of an NHS objective to allow more patients to die at home if they wish to, and when people have been dying since the NHS was established [so GPs cannot claim to have not had enough 'thinking time'].*

## Note 2.

The MCA contains the phrase 'while a decision as respects any relevant issue is sought from the court' and I see that as an important protection of the decision-making authority transferred away from clinicians, by the MCA. See my piece at:

<http://www.bmj.com/content/352/bmj.i26/rr-16>

The MCA explains the legal authority of welfare attorneys and court deputies in its section 6(6), and when and how that decision-making authority can be challenged in section 6(7). The Code of Practice, does describe those sections correctly in its section 7.29 – my own added bolds here:

*7.29 Attorneys must always follow the Act's principles and make decisions in the donor's best interests. If healthcare staff disagree with the attorney's assessment of best interests, they should discuss the case with other medical experts and/or get a formal second opinion. Then they should discuss the matter further with the attorney. 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, the clinicians of ReSPECT do not seem to believe that, clear though it appears to be. I have commented on this in my piece at:

[http://www.dignityincare.org.uk/Discuss\\_and\\_debate/Discussion\\_forum/?obj=viewThread&threadID=924&forumID=45](http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=924&forumID=45)

In their major paper promoting ReSPECT and its benefits, some of the leading clinicians involved with ReSPECT write something very different from the Code's very clear description above:

<http://www.bmj.com/content/356/bmj.j876>

*'In the UK, the exception to this is if someone has been appointed as legal proxy with powers to make decisions about life sustaining treatment: that person's decisions must be viewed as binding, as long as they clearly serve the patient's best interests.'*

I read the following in a recent e-mail to me from some of the senior ReSPECT clinicians – I'm not sure that I have ever asserted what this implies, but this:

*To read that the ReSPECT "team" are only interested in increasing clinicians' power and taking power away from patients and carers questions the competence, motivation & integrity of all those involved,*

is a comment which should be read in the knowledge that the MCA states

***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 [against the expressed decision of a legal proxy]***

while ReSPECT had altered that to

***[the legal proxy's] decisions must be viewed as binding, as long as they clearly serve the patient's best interests.'***

What I definitely have written – at the start of my DiC thread of criticisms of ReSPECT – is:

[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/](https://www.dignityin care.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-issue-with-ReSPECT-which-I-will-be-pointing-out-to-the-Public-Guardian/960/)

*I'll be sending the PDF to Alan Eccles, the Public Guardian for the Mental Capacity Act, later today: no need to go into details, you can read the PDF. But in brief - any recommendations on a ReSPECT form which are made on 'best-interests grounds' should not be 'signed off' by the senior clinician.*

*The form does that - only has clinical signatures on it - which seems to me to indicate that those learned clinicians who developed ReSPECT, do not accept that the MCA has moved 'decision-making' to patients, people chosen by patients, and other lay people involved in caring for mentally-incapable patients, and that 'clinical paternalism is supposed to be dead now'.*

If I have written that ReSPECT is trying to increase the decision-making authority of clinicians beyond that present in the MCA, then it was 'a slip of the brain' and I apologise: but I stand by my assertion that 'ReSPECT is **clinging on to** authority which the MCA **has removed from** clinicians'.

I had this argument with Tessa Ing, when she was head of an EoLC unit at the Department of Health until the NHS re-organisation of 2013. Tessa asked me 'why is it so important to you, to prove that relatives can make best-interests decisions about medical interventions?'

I had two reasons. The first one, is that it logically follows from the imposition of the MCA onto family-carers, and the fact that section 4(9) clearly describes a legal duty.

**But also:** Tessa and I agreed that ‘the conversations for best-interests decision-making, do not always take place’ - and my assertion was, and is, that ‘if the HCPs believe that they themselves make the best-interests decisions after discussions with the relatives and friends, then if the conversations ‘would be difficult’ it gives HCPs more ‘wriggle-room to avoid the conversations’ than would be the case if HCPs accepted ‘best-interests decisions should not be for us to make’.

Before I depart from ReSPECT, I will mention something in some Care Quality Commission guidance about ReSPECT for its own inspectors.

The Care Quality Commission issued an Inspector Briefing/Guidance for the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in February 2017 (20170301 900798 v1.0 Respect guidance for inspections).

Extracted from the guidance:

*‘It [the ReSPECT Form] will also save the need for relatives to have to make hard decisions at a time of crisis’*

**In the context of RC(UK) and ReSPECT incorrectly asserting that ‘relatives cannot make best-interests decisions’ I must ask – which ‘hard decisions’ is the ReSPECT Form/process saving relatives from ‘having to make’?**

Anyway – if you read ‘My Own Story’ you should, I hope, be better-able to understand why ‘collaboration’ in my view **must involve** the presence of the signatures of patients and family carers, relatives and close friends **on the ReSPECT documents**.

When ReSPECT tells me in an e-mail:

*We are, in truth, somewhat bewildered by your repeated negative attitude, which contrasts sharply with the spirit of collaboration that will be crucial to achieving change to promote the level of high-quality care that both we and you wish to see ...*

I would ask 'where was the spirit of 'collaboration' from the 999 Services I encountered immediately after my mother's death?

**I would prefer it if ReSPECT and other Clinically-Authored 'Guidance' became genuinely 'collaborative' and Inclusive of Family-Carers, Relatives and Friends – HOWEVER ...**

I might not persuade ReSPECT to alter its publications – but I will adopt and promote a fall-back position, until such guidance is changed to be genuinely inclusive of family and friends.

This clearly-discernible 'attitude' of 'relatives and family-carers are not to be trusted' is offensive to family carers – it definitely offends me [and I was harassed for 7 hours after my mother's death in 2008] - and until 'you' change to an inclusive and perspective-balanced mindset (that it is everyone working together to help the dying person) I will keep explaining to laymen 'there is only one thing to do, if the professionals refuse to change their attitudes':

As I explained at the end of my PDF

<https://www.dignityincare.org.uk/Discuss-and-debate/download/289/>

### **Something which 'rather gives me hope'**

I'll finish off now – I could go on (and on, and on, and ...) but by now anybody who isn't already very familiar with the MCA will probably have lost interest, and the people who are deeply interested in the MCA and who are reading this will be few, I suspect.

This is 'the ray of hope'.

The problem, for most family carers, is a combination of two things: one is that the MCA is very difficult to apply if you are a working professional, and the second is that the professionals [incorrectly in my opinion] assert that THEY 'make the decisions'.

**If many more people appoint Welfare Attorneys, then this unsatisfactory situation – which amounts to 'we professionals are the experts, and our views are the ones which count' - will be swept away:** because it is 100% clear that welfare attorneys are the people 'whose decisions/views count'.



And those welfare attorneys will almost certainly be largely laymen – if I were my father’s welfare attorney, why would I ‘downplay or disregard’ the opinions of my brothers and sisters, etc, and why would I prefer the views of doctors and nurses ?

## Closing

I feel that I should bring this to a close – it is getting somewhat lengthy for its title of '**Mike’s Little Book of Thoughts about End-of-Life**'. So I will close, with a pointer to a thread of mine at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mike-Stones-PDFs-I-hope-to-post-various-PDFs-about-EoLMCACPR-in-this-thread/944/>

It is a thread, to which I periodically add PDFs and links to pieces on Twitter, so pieces on many EoL issues can be downloaded from that thread (and, more generally, from my many posts in the Dignity in Care discussion forum).

For example, it contains PDFs with these titles, among others:

### **Comments about ACP etc by Mike Stone Nov 2017**

### **Advance Directives Advance Decisions Concept or Law**

### **Can an Advance Decision forbid transport[at]ion from home to hospital**

PS: congratulations to any reader who has got this far – and I half-apologise for the absence of indexation, but it would have taken me longer to index it, than it took me to write it. I will try to keep track of the ‘raw file’ for this piece, so if any of the links do not work, tell me and I will try to correct the problem if I create a version-2-update of this piece in the future.

You can e-mail me at [mhsatstokelib@yahoo.co.uk](mailto:mhsatstokelib@yahoo.co.uk)

Twitter [@MikeStone2\\_EoL](https://twitter.com/MikeStone2_EoL)

The above was version 1, but it had some typos which I have tried to correct, and I have decided to add a little extra as well to this version 2.



In the *Fifth Report of Session 2014–15, House of Commons Health Committee, End of Life Care* there is some evidence from the AACE, and these sections are relevant to my EoL 'issues' – my own added bolds:

*106. The Association of Ambulance Chief Executives in their written evidence state that a unified approach to DNACPR documentation is crucial for paramedics and other ambulance clinicians when a swift and difficult decision needs to be taken to allow a person to have a dignified death. They comment:*

*Without a DNACPR form or information that establishes that a person is at the end of life, **resuscitation may be the course of action decided upon by the clinician that may be later seen as unethical, inappropriate and most importantly not what the patient would have wished for.***

*As ambulance services we would strongly support, recommend and offer to assist with work to develop a universally recognised DNACPR form that can be electronically integrated into record systems across England and Wales. 103*

*72. The Association of Ambulance Chief Executives, in their written evidence, highlight the role of ambulance staff in end of life care. They call for more specific education on end of life care that focuses on issues such as identifying the dying stage, the implications of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders and communication skills, and stress that it is not only front line staff who need additional training but also call centre and patient transfer staff. They suggest that higher education institutes should be encouraged to increase the amount of time dedicated to end of life care in programmed leading to paramedic registration. 78*

The AACE were clearly aware of the problems – and I exchanged some e-mails with the AACE during 2015 – but the AACE's solution is 'better records, and better dissemination of and access to recorded information'.

As is obvious: **that cannot be a** solution for my Father and Son scenario – because, to be blunt, 'things can happen so quickly during EoL at Home, that 'the records cannot keep up'. Nor can the typical 'NHS approach ' of 'arrange

a meeting' work well during EoL at home – during EoL at Home, conversations are often between whoever happens to be present: it could be patient and a relative, nurse and patient, relatives and nurses, GP and nurses and relatives, patient and GP, GP and family-carer, etc. I would stress, that family-carers [who have had 'EoL thrust upon them'] 'pick up stuff from all of those conversations' (and not necessarily completely consistent information, either).

I added something I titled 'Tina's Story' to one of my DiC pieces, and Tina's Story was within an addition I titled 'WHAT CAN BE KNOWN ?'. Even 'with the best will in the world' it is unreasonable to 'expect to know' things which you could not logically know – the piece makes it clear. Here in green text.

The person I'm calling Tina isn't fictional – it is a real person, who told me her story.

#### WHAT CAN BE KNOWN ?

Things which have happened, might be 'knowable'. But even some of these, are not 'knowable' 'universally'. If two people talk together, then one becomes unconscious before any record or dissemination of the conversation has been made, the only person who 'knows' about the conversation is the remaining conscious participant.

Records of past events, can exist and be read, but how does a reader 'know' the record is accurate ?

Things like 'the meaning of a multi-party discussion' can be disputed after the event by the participants: if there is a dispute about 'what the words meant', does anybody know what the words meant ?

Some present things, can also be 'unknowable' - in my end-of-life debates, police officers clearly 'want to know why a deceased person died', but often that simply isn't 'knowable' at the time.

Future events, are typically significantly 'unknowable'. Things such as the outcome of a cardiopulmonary resuscitation attempt, are so vague, that the term 'unknowable' fits them well. If you are aged 80, then the answer to 'will I be alive in 5 years time ?' isn't quite the same as if you are a healthy 20 yr old, and you ask yourself the same question.

There is also a problem, in that 'you can only know about, what you can see',

where I'm using 'know' more in the sense of 'properly understand'. And people are 'perspective blind' to quite a lot, of 'what is in front of them'.

Why does any of this matter ?

In terms of my own 'stuff', mainly because the guidance currently being published, downplays 'uncertainty', and as a consequence would lead 'inexpert professionals' to fail to understand how complicated the real-world situations which other professionals are involved in, really are. For example, police officers are not routinely involved in end-of-life at home, but are involved sometimes: the 'theoretical situations and behaviour implied by current EoL guidance' which might be read by a [diligent] police officer, are nothing like as complicated as the real-world interactions between patients, GP, family and nurses.

I will recount a story I was told by someone, who I will call 'Tina' here.

#### TINA'S STORY

Tina's mum, who was in her 90s but 'fairly healthy', was rushed into hospital - the problem was both sudden and acute, and it would probably be fatal if left untreated. The doctor - I'll call him 'Dr Jones' - told Tina's mum (Tina was present), that there were two options. They could try to operate, but the surgeon thought she would not survive the operation - mum didn't fancy that. Or, he could do nothing - an option which he presented as 'Or we could just do nothing, and make you comfortable - but if you chose that, you will never leave this hospital'.

Mum went for the 'no active intervention' option, and died a week or two later.

One of Tina's sisters, who lived in a different part of the country, turned up at the hospital the next day. The sister wasn't happy, and wanted her mum to be actively treated - Dr Jones said 'it is now too late to attempt active treatment'. The sister then accused Tina - who, because she lived closest to her mum, was the sibling 'supporting her mum day-to-day' - of 'selfishly wanting our mum to die, because you are fed up of caring for her' (my phrase - but 'makes the point' here). Tina and the sister are no longer on speaking terms - and Tina has not explained this row to various other relatives, so she doesn't really like 'talking about her mum's death 'openly'.

Tina also has - looking back - another issue. At the time, Tina knew that the doctor's 'but if you choose that, you will never leave the hospital' meant 'if you choose no active treatment, you will die': and AT THE TIME, Tina felt sure that her mum also understood that. But WITH HINDSIGHT, Tina 'isn't 100% certain' - so with hindsight, Tina thinks the doctor should have made it clear that 'no active treatment means you will die' to her mum, so that her mum definitely understood the choice she was making. What Tina sent to me (words copied

directly from the e-mail) was:

'I found it quite a comforting at the time that those words were used, but only because I knew that my mum had capacity and understood the implicit message, in the same way that I did.

However, since her death I have wondered whether she should actually have been specifically told that by not providing any active treatment she would die in hospital, because I would not want this approach to be used with someone who would not understand the nuances of the 'nice words'. My feelings of guilt were based on the fact that perhaps my mother hadn't realised the implications of what the doctor said and I should have asked for a more honest statement - what if she had in fact wanted to be treated or risk the operation, that would have been her choice.'

So what seemed like 'soft and 'kind' vague words from the doctor to her mum' at the time, now WITH HINDSIGHT 'leave Tina with an ongoing slight concern, that perhaps her mum didn't understand what the doctor meant'.

Mum was put on the Liverpool Care Pathway, which wasn't realised by Tina, until a family friend (who was a GP) worked that out, and told Tina.

This type of thing, is really problematic for end-of-life [especially for patients who are in their own homes]: almost nobody is keen to discuss the more 'emotive' things [such as the actual death itself] and consequently it is really easy to make false assumptions 'about why people are doing things'. You simply cannot have good joined-up patient support, if the situation is 'very information poor' - and making assumptions in information-poor situations, is a recipe for really bad behavior.

So, 'who knows what' in Tina's Story ?

Mum: mum might have understood that by not having the operation, she was in effect choosing 'to die as comfortably as the hospital was willing to arrange' - but we don't know for certain. I suspect - but I can't be sure - that the medics didn't really want to operate not because (as some people would be suspicious of) of 'age discrimination', but because of what doctors call 'frailty' (a reduced ability to withstand stress, which is often found in very elderly people [even if 'they just outwardly look old, not ill']).

Tina: the interesting thing re Tina, is this 'with hindsight was I wrong to not make Dr Jones spell it out to mum' thing - that 'hindsight guilt' clearly affects Tina, but because (as is fairly typical of this type of 'around a death' thing) Tina 'doesn't really talk about it', I think it is almost certain that Dr Jones doesn't understand how his 'kind words at the time' approach, caused issues for Tina much later on, after mum had died.

Tina's sister: I don't for a minute, believe that Tina wanted her mum to die 'because the day-to-day support had become too burdensome' as her sister 'claimed'. I think Tina just wanted her mum to make her own [informed] decisions. Tina's sister couldn't have been at the discussion between Dr Jones and mum, because that discussion would have been very soon after admission, and Tina's sister lived too far away - so the fact that the sister cannot be sure of who exactly said what, is not the fault of Tina or Dr Jones. This isn't the same as when people could be present, but are 'excluded from being present' - deliberately excluding people, is very often a bad idea.

There is something, that this 'people like to be involved and to understand what is happening' point, raises about 'NHS behaviour'. The NHS, still seems to somehow want 'a single named relative as a contact point': it is as if the NHS, which has internally got 'hierarchical structures' which it builds into its 'behaviour', cannot really cope with the less formal and more ambiguous 'relationships' within family groups. That really does need to change - attempting to impose 'structure and hierarchy' onto family and friends, however convenient it would be for clinicians if such hierarchies existed, isn't a helpful thing to try and do. Asking (can we contact the family through one person) is one thing - but imposing (we [clinicians] are only going to talk to the family through 'Fred'), is quite another.

The RCP End of Life care Survey 2011 included this comment from a doctor:

*'Having lost both parents and other friends/relatives in different ways wrt EOLC I have learnt the most from this. I also believe that time and maturity at the job make a huge difference and hence my reticence to learn from colleagues who are too junior.'*

A nurse was discussing the death at home of her mother, in the comments to a Nursing Times (online) article a few years ago – very interesting, in the context of 'nurse-to-relative'. There was a bit of 'contributor-bashing' going on in the discussion, which is probably why the nurse ended her comments as she did.

The nurse first posted:

*'I am a Registered Nurse working as a Ward Manager caring for patients at the End of Life. Having looked after my own mum at home, at the end of her life, I can honestly say the process was exhausting and lonely. We had alot of support from our local hospice and macmillan support too but we didn't get night care every night and care in the day was very limited. Here in lies the problem. For*

*those patients who wish to die at home the support needed for those who are caring for that person is immense. The stress and worry it brings can be immense and there just isn't enough support out there to achieve it well all the time. When we receive a patient onto my Ward for end of life care from home it is very often the relatives who can no longer cope at home. This is a very telling reflection on the commitment caring for someone at home at the end of their life requires for these families and is very hard to achieve. Having done it and succeeded, if you like, in giving my mum her death at home, I feel there needs to be much, much more support and resources made available if this ideal is to become a reality and its needed now not tomorrow. For time limited people now is all you have !!!!!!!!!!!!!!!!!!!!!'*

She was then asked 'I think your mum had made it clear to you that she wanted to die at home (as mine did) and you managed to facilitate her wish. I am interested in how you think you would have felt, if you had failed and your mum had actually died in hospital ?' and the nurse posted:

*Thank you for query via your post and also just noticed my spelling is not great today-apologies to all  
In answer to what you said I really would have felt like I betrayed her as it was her only request to me and my sister(Radiographer in the NHS) and we knew we just had to give her what she wanted.  
Having said that we were very much the daughters and not a Nurse or a Radiographer if that makes any sense. It was just about us as a family doing what we could to give her what she so desperately wanted.  
We were not better at it than anyone else and my heart goes out to those who don't manage to avoid going into hospital when it isn't what is wanted. Bereavement is bad enough without the added burden of guilt too.'*

Then another poster took up a point I had raised, which was basically 'did things seem different when you went from a nurse, to the relative of your mum at home ?' and she posted:

*It was very different being the daughter as opposed to the Ward Manager and although a cliché it definitely had an impact thereafter on my professional role.  
I think the greatest difference was the sense of vulnerability we felt looking after mum at home and we spent a lot of time waiting for people to come (ie) Staff to administer anticipatory med's, night Hospice sitters and the relief when they did arrive was immense. As a Ward Manager and Ward Team member we aim to provide a sense of belonging, safety, security to all our patients and their families etc. It is so important that they feel 'wanted' and if*

*we achieve that then I hope they will automatically feel less vulnerable and relieved that we are there, sharing that role of caring with them round the clock.*

*I have nothing but positive comments about those who helped us with my mum. But no matter how much they supported us when there they obviously didn't stay and we were there for great parts of the day and sometimes all night alone- one of us would usually sleep whilst the other looked after mum and dad.*

*Its like anything else in life- you don't know what its like until you do it yourself and experience it for yourself.*

*All my years of experience went out the window because it was my mum in front of me and my experience couldn't pre-empt what that journey would be like. I had an idea but not the full extent of the reality of letting go, saying bye and praying that wherever mum was at the end she knew we had given her what she wanted.*

*I just want add that the beauty of these discussions are that evryone has a right to voice there own thoughts and opinions. No-one's contribution is better or less wanted than the other surely????? Isn't that what its all about???*

*As Nurses we surely meet people with different views to ours everyday????? Everyone has a contribution to make surely????????????????????????????????????'*

I suspect that when doctors and nurses read that, their eyes probably settle on the 'how much support is being provided' issue – but when I read it, my eye settles on:

***I really would have felt like I betrayed her as it [to die at home] was her only request to me and my sister(Radiographer in the NHS) and we knew we just had to give her what she wanted.***