If I only had the chance to tell my family carer, and 999 paramedics don't believe my family carer – then how does that work for me!

On Wednesday 9 January 2019, an episode of 'We Need to Talk About Death' was broadcast at 8 pm. Joan Bakewell presents the series, and my newspaper implies the episode was titled 'Ensuring end-of-life wishes are met'.

To be clear, I really liked the broadcast: it was almost entirely factually correct in terms of what we were told, it was MUCH BETTER than the type of thing you would have found a decade ago, and we definitely DO need to try and resolve these issues around end-of-life and dying. I think the paramedic, Rob Cole, was word-perfect in terms of his description of both the problems from a paramedic's perspective, and also in his description of the current guidance [but whether the current guidance is the only, or most satisfactory, 'expression of our law' is a different question – and I would say 'it isn't' and I'll explain why later in this piece]. Gary Rycroft, the solicitor, was in my opinion very legally precise, and also legally correct, in almost everything he said: but, he did not answer Joan Bakewell's question about 'why can't the paramedics believe the relative?' (Gary gave a technically correct answer – but to a different question from the one I believe Joan was asking). Catherine Baldock, the 'ReSPECT' person, gave answers which reflect ReSPECT's position: it would be wrong for me to not point out, that I dislike the ReSPECT Form in its current iteration, and that unless the ReSPECT Form is fundamentally altered, I will be trying to prevent the adoption of the form (in essence, I want the signatures of non-clinical people – patients, welfare attorneys, court deputies and 'normal relatives and friends' on the form: and, I want the prominence of the ReSPECT Form [which is basically part of best-interests decision-making] to be very-much reduced, with Advance Decisions being promoted much more strongly than the ReSPECT Form).

Also in the interests of honesty: I first discussed the issues which are being talked about in the broadcast with Rob, as far back as about 2009/10 [although I haven't been discussing them with Rob during recent years] – and I hugely value discussions with Rob. We also discussed the situation – which was then, and still is now, very unsatisfactory – of 'expected/sudden' deaths, but that wasn't discussed in the broadcast.

The timings, are from the podcast of the broadcast, which can at the moment be downloaded from the BBC website. I hope I have transcribed what people were saying correctly. So, a few comments.

NOTE: I will not be inserting URLs into this piece, except for one hyperlink to a recent piece where I discussed the concepts of MCA Best Interests and 'Substituted Judgement' in the context of the withholding or withdrawal of life-sustaining treatments such as CPR and CANH. That piece, gets [to use my normal phrase] 'all nerdy MCA'. Here, I will be trying to discuss various problems, without 'getting too MCA nerdy' while, at the same time. I hope 'not straying from legal correctness'. Even though I'm trying to use normal language, and to make this understandable for 'a normal reader', it is quite complex, so 'no guarantees'.

The overall context of the discussion, is decision-making and the communication of decisions 'at the very end of life, when you might not be able to speak for yourself'. The term usually used is Advance Care Planning (ACP), but there isn't complete agreement about what falls within the term ACP at the moment: there are also some people who think we need more than a single term to describe 'ACP'. At 1:20 a WMAS paramedic tells us, that 'we don't know [what the collapsed patient would have wanted]'. Then, at 12:00 we are told '… if not, we're resuscitating the patient'. Translated, into a phrase which uses current NHS terminology [and ignoring certain caveats] 'without ACP in place, 999 paramedics will almost always attempt CPR unless it is very obvious that CPR could not re-start the patient's heart'.

13:24 I found it interesting that Susan, the daughter, was asked by a hospital surgeon to sign a do not resuscitate form by her mum Eileen's surgeon: later, when her mum is out of hospital, Eileen's GP discusses CPR with Eileen and Susan, and 'mum counter-signed a DNACPR form'. THIS IS INTERESTING – and it is interesting because:

I'm not sure that I can remember seeing any DNACPR Forms, which provide for relatives to sign them, and I can't recall any which provide for patients to sign either (I might be wrong – but if I've just missed these forms, I would like people to send them to me so that I can take a look);

It definitely makes sense, to allow people to sign forms, but we need to clear about why people are signing – as I pointed out in a BMJ rapid response when what has now been renamed as ReSPECT was at the time called ECTP:

EXTRACT BEGINS

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.

The complexity of best-interests decision-making, and my mother’s death (see ref 4), convince me that we should be pushing for patient-expressed decisions made in advance: so it is Advance Decisions which need to be promoted. But there seems to be an agenda to encourage patients to create ‘written advance statements’, which – unlike a written advance decision – cannot ‘just be followed in an emergency’. In contrast to this push to promote the essentially ‘very challenging in application’ ‘written advance statement’, nobody seems to be trying to address the problem I mentioned in reference 5 of a patient at home expressing a decision to only a family carer.

I am not reluctant to state, and the perceptive reader might have discerned this, that I am very annoyed by this situation.

EXTRACT ENDS

And I don't think I've ever seen a DNACPR Form, which in my opinion 'is 100% MCA-compliant'.

At 17:30, answering 'why a DNACPR Form didn't work', an NHS Trust person says 'the form existed in her living room – it is completely incredible and unrealistic to expect that in an emergency situation when everybody is fraught and concentrating on getting the patient to hospital that all the attention is focussed on a piece of paper …'.

And at about 19 minutes, Gary says 'it seems beyond the wit of man [to sort out these problems in communicating and implementing decisions which patients can legally make] … 'the system is letting people down''.

At 20:30 Rob points out the problem with disseminated copies of DNACPR Documentation: '[we] could have multiple copies of a DNACPR – and things can change'.

There is a similar problem, especially if a still-capacitous person has made an

Advance Decision (ADRT) refusing CPR, with the placing of DNACPR decisions within online electronic databases: the decision can be changed whenever the patient decides to do that, which is easy if the decision is recorded on a written ADRT which 'lives with the patient', but it is much more problematic if the ADRT is 'mentioned or embedded within an online system' [which the patient might not have access to 'immediately' or easily]. This involves a 'conflict' between the legal right of a mentally capable patient to make, alter or retract decisions in real-time, whenever the patient wishes to – and the 'desire of the system' to have decisions 'embedded within clinically-controlled records'.

I found it very interesting, when at 34:38 Rob said '… an ADRT (refusing CPR) [is] slightly more complicated, just presenting that to us'. I am interpreting that, as meaning that Rob is saying that 999 paramedics find it 'easier to' accept a DNACPR Form with the signature of a GP on it, than to accept an ADRT refusing CPR which only carries the signature of the patient and a lay witness. I know that paramedics find it 'easier to respect' the DNACPR than the ADRT, for the reason I've just explained (the DNACPR Form should be 'embedded within NHS records', whereas an ADRT is a legally-binding 'stand alone' document under patient control) – but, that is LEGALLY PERVERSE because the ADRT is legally-binding because of the presence of the patient's signature: and, unless the DNACPR carries the patient's signature and is in fact an ADRT refusing CPR, the DNACPR is NOT legally binding. The doctor's signature, while many things, does NOT 'carry legal authority over best-interests decision-making'. The signature of a Welfare Attorney is 'very close to' the signature of the patient, in terms of 'legal authority', but the signature of the senior doctor is a different thing altogether.

I am VERY PLEASED THAT Rob said at 33:50 'we train our clinicians to 'understand what was the purpose of the call'' because some years ago, a paramedic sent a comment to me in an e-mail: it is the central section of this, which I have extracted from a more recent BMJ rapid response of mine from November 2016 (I show the e-mail as I received it: the exclamation marks were in the e-mail, and .. does not indicate that I have removed sections of text – the e-mail was sent to me in that form, with phrases separated from each other by ..):

EXTRACT BEGINS

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.

EXTRACT ENDS

I am pleased that Rob tells us that paramedics are now being trained to ask why they were called, instead of simply assuming that it is because the patient needs to be treated and taken to hospital: the issue is present in Bridget and Mel's story, which we will discuss later.

At this point, I will give the URL to my recent piece which discussed best-interests decision-making which results in the withholding of potentially life-sustaining treatments:

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

When the treatment of an incapacitous patient is being considered, then as Dr Katryn Mannix wrote in her acclaimed book 'With the end in mind':

'… we want to do what he (the patient who at the time cannot tell us) would want'.

Quick note for other 'MCA nerds' who are reading this – before you say 'Mike isn't describing Best Interests', read the piece I've given the hyperlink to.

Bridget is the daughter of her mum, Mel, and before I discuss the story, I want to discuss a question from Joan Bakewell and an answer from Gary. At 35:08 Joan asks Gary '[why] couldn't [the paramedics] take Bridget's word for it'. I INTERPRETED Joan's question as amounting to 'the family-carer or relative sometimes does understand what the patient would want to happen – why can't 999 paramedics ask the relative who called them, and believe what the relative tells them?'. Gary did NOT answer that question – Gary answered a different question, about the possession of legal authority during best-interests decision-making: it seems to me, that Joan's question was a different one. I think Joan's question, was in essence the same question that I put to some of the senior ReSPECT people in a BMJ rapid response:

a) it is clear from section 4 of the ReSPECT form (‘Clinical recommendations for emergency care and treatment’), and also from other material on the RC(UK) and ReSPECT websites, and my e-mail communications with various clinicians, that there is a prevailing ‘medical opinion’ that ‘CPR is a clinical decision’. It is not: the method of performing CPR is ‘a clinical decision’, but whether CPR should be attempted is not a ‘clinical decision’. It might be a decision a clinician is forced to make – but it is either a normal ‘consent’ decision or else it is a best-interests decision, assuming there is any prospect of CPR restoring life. And best-interests decisions require an understanding of the factors in section 4(6) of the MCA, which are not things an emergency clinician can possibly possess an understanding of. So as Pitcher and Spiller agree on that point, logically they should agree with me (4, 5) that 999 paramedics should provide family carers with clinical information, and then defer to the family carers for best-interests decision-making. Please note: I am not saying the MCA requires such deference – I am saying, that it would follow from the logic of ‘we should be making the best decision’ if it is accepted that the family carer has a superior ‘holistic understanding of the situation’ (6).

I will now describe the essentials of the Bridget and Mel story.

At 31-15 into the broadcast, we get the story of daughter Bridget, and her mother Mel. Mel becomes poorly at home, Bridget calls 999, and by the time 999 arrive Mel is in cardiopulmonary arrest. The paramedics are intending to attempt CPR, and only withhold CPR when Bridget produces her LPA/Welfare Attorney documentation and says 'don't attempt CPR'.

Now – the broadcast, made it perfectly clear that if Bridget HAD NOT BEEN a welfare attorney, the paramedics would have attempted CPR.

This is the 'nerdy conceptual problem'. Bridget's 'don't attempt CPR' is supposed to be a best-interests decision, made in line with MCA section 4. And the best-interests decision which Bridget would arrive at, IS NOT AFFECTED by the fact that she is her mum's welfare attorney [provided we assume that Bridget has read and understood the MCA whether she is an attorney or not – for example, she might have read the MCA because she was in the process of being appointed under the LPA: better still, let us postulate a world within which everyone is adequately familiar with the MCA]. Bridget is 'against CPR' because her in-depth understanding of the situation – and especially of the factors in MCA 4(6) – allow her to arrive at 'CPR is not in my mum's best interests' on a legally-defensible basis. In fact – it seems that the MCA REQUIRES 'normal family carers' to make decisions in line with the MCA's best-interests requirements. So not 'Bridget's 'feelings about'' what would be best for her mum – but 'if I apply the MCA, then this is the appropriate best-interests decision'. And that DECISION does NOT depend on whether or not Bridget is a welfare attorney – it stems from Bridget's understanding, and correct consideration of the MCA.

So: if Bridget ISN'T a welfare attorney, AND if she understands that 'if I involve 999, to find out why mum has collapsed (which she would understand – if she had listened to your broadcast), then even if I say it wouldn't be in my mum's best interests for CPR to be attempted, THE PARAMEDICS WILL ATTEMPT CPR' then what is Bridget supposed to do: not phone 999? Risk that her mum hasn't collapsed with a non-fatal stroke? Or phone 999 and let paramedics 'apply 'ignorance' (default to preservation of life) instead of her decision, which is based on 'understanding'? Technically I believe 'should I call 999?' is a best-interests decision for the family carer to make – but I suspect the police would disagree with me. So when Rob said at 34:50 'they could have cancelled the ambulance' then in my opinion 'yes, the relative could indeed not phone, or cancel the ambulance – but it often gets very messy, and pretty horrible for the relative, after that has happened'.

The less 'nerdy' problem, if Bridget isn't a welfare attorney and if the paramedics do attempt CPR, is that it leaves relatives (often just-bereaved relatives) with horrible memories of 999 paramedics attempting CPR when the relatives 'know that made no sense'. WE SHOULD BE WORKING TOGETHER TO SUPPORT DYING PATIENTS – we SHOULD NOT 'have relatives and clinicians 'at war with each other'' BECAUSE OF PROFESSIONAL GUIDANCE.

Viewing this as a relative or family-carer, who has been 'listening to my 'dying' loved-one for months', it seems that 'the clinicians don't trust me' – which is DEEPLY OFFENSIVE.

Viewed from the perspective of the patient, you can get to my title for this piece:

'If I [a patient] only had the chance to tell my family carer, and if 999 paramedics don't believe my family carer – then how does that work for me!'

Before I continue with further analysis of CPR decision-making, which will be from a legal and logical perspective, I will mention something which while true, in my opinion doesn't lead anywhere useful. Many doctors who work with dying patients, are promoting the idea that 'CPR isn't a treatment for dying people'. In essence, these doctors write:

'CPR is NOT a treatment for Normal Dying – in Normal Dying, the body dies first and subsequently the heart stops beating. CPR is a treatment for situations in which the heart stops beating first, and subsequently the body dies'.

Which is true – and which can also be expressed by an angry relative, who says to clinicians 'I've been watching my dad dying for a month – why the hell did you attempt CPR, when he finally died!?'.

BUT – that doesn't help to sort out the interface between long-term family-carers and 999 paramedics, which I believe is the most problematic of all end-of-life interactions.

Since 2014 I have been publishing the DNACPR Justification Hierarchy, which seems to result from consideration of the MCA and the 'only potentially-successful treatments need to be offered' principle – and consideration of this hierarchy, helps to clarify thinking, because it makes the nature of the problem very clear. This is the hierarchy I publish:

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 issue – IF YOU DEFAULT TO TRUSTING FAMILY CARERS – is that the hierarchy is top-to-bottom (so 'reason 1 comes first – then reason 2, etc') and the family-carer fits in at no 4, but a 999 paramedic can only logically fit in at no 5.

Often clinicians like to put no 6 at the top of the list, but the legal justification for no 6 is separate from the other justifications [which all come from the MCA] and it doesn't matter where you place no 6, provided it is above no 7. If you emphasise the patient's decision-making and the MCA, then you would put no 6 where I've put it – if your thinking 'is more clinical' then you might put no 6 at the top of the list instead.

YOU CANNOT 'move' a 999 paramedic, from no 5 into no 4, by means of any documentation: it simply isn't logically possible to do that, if you read section 4 of the MCA, and think about 4(6) and 4(9).

And please note: I do not fully discuss 'disagreements' in that hierarchy. Basically, the 'rule for' a 999 paramedic, even if people would agree to fall-in-line-with my position of 'accepting the best-interests decision of someone 'higher up the list than you are', would STILL BE attempt CPR in the following situations:

1) the 'relative/s' who called 999 'are distraught and incoherent', or are saying 'do something!!!';

2) if several relatives or family-carers are present, then even if most of them say 'I'm sure mum wouldn't want to be resuscitated' then even if ONLY ONE says 'I'm sure mum would want you to try CPR' the paramedics must attempt CPR.

BUT – if the relatives ALL say 'dad wouldn't want CPR', or if the only relative present says 'I'm sure dad wouldn't want you to attempt CPR', then WHY are 999 paramedics 'attempting CPR based on no understanding of the patient, against a relative who has an in-depth understanding of the patient and says 'don't try to bring him back'?

Which is where I am fundamentally at odds with 'ReSPECT'.

The Main ReSPECT Form, contains only the signatures of clinicians – and I'm sure that Rob, with his comment to the effect that he thought the ReSPECT form would work well IN A HOSPITAL SETTING, understands that the ReSPECT Form 'isn't an instruction'. Section 4 of the ReSPECT Form pertains to no 6 in my DNACPR Justification Hierarchy [and therefore is correctly signed by a clinician]. But a clinician's signature, simply isn't enough in terms of the rest of the hierarchy, and MCA best-interests decision-making. As I have pointed out in my materials which critique ReSPECT:

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

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

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

SIGNED BY EVERYONE – family and clinicians.'

So far as I can see, that resolves the problem that whatever a 999 paramedic reads at a cardiopulmonary arrest, the paramedic could never logically claim to have 'considered the factors in MCA section 4' – it 'satisfies no 5 in my hierarchy' correctly.

Which no document, with only clinical signatures on it, can do.

If I were a 999 paramedic, with Rob's understanding of the law around CPR, then I would be willing to accept my version of 'being steered away from CPR' by means of signatures from the clinicians and the family that amount to 'we have all agreed that CPR would NOT be in the patient's best interests, we are ALL signing to confirm that, and by signing we are also confirming that to the best of our knowledge, there isn't anyone who could reasonably challenge this best-interests decision in court'.

But I wouldn't accept the ReSPECT Form – which by its own admission, is about information to guide decision-making by clinicians during emergencies: whereas my version, allows those clinicians to 'reasonably follow a decision made by people who were better-informed than we could possibly be'.

Which gets me back to Gary's answer, to Joan's question, and to my earlier comment:

'I think the paramedic, Rob Cole, was word-perfect in terms of his description of both the problems from a paramedic's perspective, and also in his description of the current guidance [but whether the current guidance is the only, or most satisfactory, 'expression of our law' is a different question – and I would say 'it isn't' and I'll explain why later in this piece].'

I hope I have now explained, and coherently argued why 'the guidance' should be changed – and this piece is getting very lengthy, so I'm going to post it, and see if others care to comment on it.

Any typos or proof-reading errors are all my own work.