Further comments on the ‘My Dying Wishes’ episode from series 3 of ‘We need to talk about death’

FORENOTE: I made some comments soon after originally listening to the broadcast, and they can be found at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/354/

I was drawn back to this radio broadcast, which can be listened to via the BBC’s website and can be found on the webpage at:

https://www.bbc.co.uk/programmes/b09kgksn/episodes/player

when during a phone call with a doctor, it was suggested that I had concluded something from the broadcast that isn’t true. I had concluded, to put it simply, that West Midlands Ambulance Service was telling its paramedics ‘do not argue with welfare attorneys – if a welfare attorney says ‘don’t attempt CPR – it wouldn’t be in his best interests’, that WMAS was telling its paramedics to obey the instruction’.

It turns out that the doctor and I both ‘know’ the WMAS paramedic who was part of the expert panel on the broadcast, so I said ‘I’ll e-mail Rob – he can tell us’.

Now, I’m not quite sure exactly what WMAS paramedics are being told about the legal authority of welfare attorneys, and it is possible (again, I’m not sure) that Rob said something which was edited out of the broadcast.

Also, I’m not going to listen again to the entire broadcast – I listened to it at least twice back in January, and when I listened to what was broadcast, I drew my conclusion. But, I have listened again to a section of the broadcast, because I wanted to transcribe it [and if anyone cares to listen to the entire broadcast, and decide if ‘what I heard isn’t what they can hear’ then by all means post comments on that]. This is the bit I’ve transcribed:

It turns out on re-listening to the appropriate section of the broadcast, that we don’t directly ‘listen to the paramedics’ and we only get Bridget’s ‘words’. Mel is Bridget’s mother, and Bridget calls 999 because her mum ‘[suddenly] seems poorly’ - by the time 999 actually arrive, mum has gone from ‘being poorly’ to being ‘dead’ (not a term I like – to ‘her heart having stopped beating’ is my preference).

However (from 31:00 for a couple of minutes):

Joan Bakewell says:

Paramedics confirmed that Mel had no pulse.

As we’ve heard, paramedics are meant to treat patients and save life.

But Bridget had simply called in the hope that they would check her mother over, and help get her into bed.

Now that her mother had died, she wasn’t prepared for what happened next.

Bridget now talks:

One of them set off to get the emergency resuscitation equipment from the ambulance, and I said to the other one ‘Are you planning to try to resuscitate her, because I really don’t want you to do that’.

And their response was ‘Well, that’s what we have to do’.

My feeling was very strongly, she has had a beautiful, peaceful death, I do not want anybody to assault her [because] that’s what it would have felt like, to me, an attempt to resuscitate her.

And so I then said ‘Well I have power of attorney’ which fortunately I was able to lay my hands on ‘and I believe that gives me the authority to stop you doing that’ and subsequently they said to me ‘You’re absolutely right – we could have broken ribs, we could have caused her harm, even if she’d come back, probably she would have been a vegetable’.

Then the programme went to the panel, and Robert Cole, who was the paramedic on the expert panel, said, after Joan Bakewell had asked if the situation was unusual:

This is an absolute common problem, and one of the things we train our clinicians to do is to understand what was the purpose of the call.

So Bridget called for help, but obviously her mother deteriorated [short pause] but by the point that the ambulance crew get there they’re not aware of what’s happened so they’ve walked into what is essentially a cardiac arrest situation.

And this is where we need information and help, and we need it quickly.

So had the lady been end-of-life and we could have been assured very very quickly that resuscitation was futile – when I say end-of-life an end-stage dementia, a known heart-failure, a terminal cancer – we could have not resuscitated quite quite lawfully and well within the guidelines.

Had there been the DNR that we all talked about earlier, and had that been presented, that would have been another reason to have not resuscitated, and as Gary said had we have had an Advance Decision to refuse treatment, although its slightly more complicated just presenting that to us, that may have prevented us – but in the absence of all of that, the normal case is we would initiate resuscitation.

Joan Bakewell then talks:

So what can you tell the listeners to help them decide when they should not call an ambulance, and when they should?

Robert Cole answers:

They could have cancelled the ambulance, they could have called a doctor, they could have waited [a word I couldn’t make out – it sounded like ‘til’] not call us at all – I don’t want people to not call us and allow someone to suffer but I want people just to think [very *short pause] I think the answer here goes back to your conversation earlier Joan about advance care planning.*

Joan Bakewell then asked Gary Rycroft (the lawyer):

Yes, you see, we've heard, Gary, these paramedics couldn't take Bridget's word for it about what her mother wanted. Why not at that stage?

Gary replies:

They could take Bridget's word for it once she produced the lasting power of attorney – that was the crucial document

Joan: *no but if she hadn't had that*

Gary: *there is no such thing in law as next-of-kin, its a common misconception*

Joan: *husband, partner (?)*

Gary: *no one has the legal authority to speak for you apart from someone you have appointed under a legal document called a lasting power of attorney, so thank goodness she had that in place.*

Unless something was edited out – which seems unlikely to me [although if Rob can recall that he did say something relevant and it was edited out, then okay: **but in that case, what was broadcast was deeply misleading**] – you can't logically interpret what Bridget said in any way other than the paramedics agreed with her 'I have power of attorney and I believe that gives me the authority to stop you doing that'.

I definitely didn't notice Rob saying *'the power of attorney doesn't give Bridget the authority to stop the paramedics from attempting CPR' when I originally listened to the broadcast - if I had heard Rob stating that, then 'Rob would have got an e-mail!'.*

I am deeply vexed by the idea that 999 paramedics, think they can legitimately dispute the decisions made and expressed by Bridget in such a situation [unless Bridget seems to be 'incoherent' - and clearly Bridget wasn't incoherent as things were described] because of two things:

1) As Bridget says, so far as she understands '*I have power of attorney and I believe that gives me the authority to stop you doing that',*

and

2) Sections 6(6) and 6(7) of the Mental Capacity Act, as explained by section 7.29 of the MCA Code of Practice, explicitly state that the decision of an attorney that a life-sustaining treatment should not be applied, can be ignored '**while** a decision as respects any relevant issue is sought from the court.'

And logically, we know that Bridget was given the legal authority of a welfare attorney by a 'legally approved' process, we know that Bridget was appointed while Mel was mentally-capable, **so Mel wanted Bridget to make the decisions**.

We also now have a judge – Mr Justice Charles in the Briggs ruling – who has belatedly explained in the context of CANH, what a couple of years earlier I had argued for CPR: basically, that if CPR could be clinically successful, then because of MCA 4(5) the only logical justification for withholding CPR is 'being acceptably certain, that if Mel had been able to make the decision, Mel would have said 'don't attempt CPR''. Quite why a 999 paramedic would feel justified in arguing with Bridget, as to 'whether her mum would have wanted CPR or not', is mystifying – the paramedics know absolutely nothing about Mel, whereas Bridget knows a lot about her own mum.

Gary Rycroft did not in my opinion answer Joan's question: she didn't ask 'could Bridget make (being technical, in my view 'impose' not 'make') the decision if she hadn't been an attorney' - **when I was listening, I took it as Joan was asking 'why can't the paramedics believe Bridget?'**.

As I pointed out in section a) of my BMJ rapid response:

http://www.bmj.com/content/356/bmj.j876/rr-7

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).

That has subsequently been 'elaborated to' my suggestion at:

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

I also consider that Gary was unhelpful elsewhere in the broadcast, as I have previously pointed out online:

Gary Rycroft says at about 27 minutes, a couple of things which are flawed [and therefore unhelpful, in the context of the existing very poor understanding of the MCA].

First, Gary says that an LPA enables the person you've chosen (your welfare attorney) to 'advocate on your behalf'. No – you've appointed and empowered the attorney to make the best-interests decisions, so 'other people might be 'advocating' to the attorney': the attorney doesn't need to 'advocate' to anybody, in the context of interventions 'which are being offered' (and most of the broadcast, is discussing CPR, which 'is attempted by *default'). You 'advocate to' the person who will be making the decision – and the welfare attorney IS the person who would be making the best-interests decision.*

Gary then states that Advance Decisions and 'advance statements' are 'telling attorneys what to say on your behalf'. Well – the wording is between wrong and confusing. An Advance Decision, isn't 'directed at your attorney': an ADRT is 'an instruction for EVERYONE to follow'. Your attorney is in exactly the same situation as everyone else, with respect to an ADRT: the ADRT amounts to a DIRECT ORDER from the patient. As for 'advance statements': Gary had previously discussed those in the context of things which are not treatments – such as the music you might prefer to be playing in your room. But the term 'advance statement' can also be applied to any written expression about a treatment which is less absolute than 'I refuse': an Advance Decision is 'My DECISION is [to refuse] …' and if you are instead writing the equivalent of 'My PREFERENCE is …' then that is an 'advance statement'. So 'I never drink coffee – I only drink tea' is the sort of information (but for medical interventions) which an ADRT is conveying, whereas 'I usually prefer tea, given the choice between tea and coffee' would be 'an advance statement'. In the context of treatments, an 'advance statement' IS something the attorney would need to consider during best-interests decision-making.

Expressed differently [and this is how I prefer to express it]:

An Advance Decision removes the need for any best-interests decision-making to take place: in fact, the Advance Decision legally REQUIRES that no best-interests decision-making should take place, if the ADRT is applicable.

While I'm posting this: I think it WOULD BE HELPFUL, if 'the NHS' developed and employed the 'MCA 4(7) Form' that I've rough-drafted at:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Has-anyone-come-across-any-MCA-section-47a-statement-forms-online/956/

Gary's observation that 'next-of-kin' doesn't directly 'count' in MCA terms, is of course correct – but he conflates the legal authority to impose on others best-interests decisions which is given to attorneys by MCA 6(6), with the ability to make a legally-defensible best-interests decision, and he didn't draw out the logic of the different understandings of family-carers and paramedics [which I have discussed above, in 'a)']. As for the next-of-kin point, I wrote concisely about that in 2016 within this piece:

https://www.bmj.com/content/352/bmj.i26/rr

There is a fundamental difference, it seems to me, between working clinicians on one hand, and patients and families on the other hand, around CPR decision-making.

Patients are all individuals within a clinical situation, and the family and friends understand the patient as an 'individual person' [something the clinicians rarely do] while the clinicians understand the clinical situation [but the patient and the laymen 'close to the patient' rarely do]. How much of this is down to 'the operational difficulties of discussions around death' I am unsure about, but it does seem that clinicians are 'most relaxed' when it seems almost certain that attempted CPR would fail, whereas I believe that family and friends are often *'most reconciled to' a refusal of CPR from the patient [irrespective, to an extent, of clinical predictions about the probable 'success' of attempted CPR].*

The situation is even worse, if the patient has lost mental capacity: because 'not really knowing the patient' does of course mean that clinicians are unsure about which individuals do 'really know the patient' [and the Mental Capacity Act's section 4, does not mention 'next-of-kin' – the thing clinicians can easily discover, this 'next-of-kin' concept, is not appropriate for MCA best-interests decision-making]. Which is another way of saying, that clinicians seem to see potential conflicts between 'patient confidentiality' and the logical requirements imposed by section 4(6) of the Mental Capacity Act, rather differently from how I would view that, if I were a welfare attorney (with powers over life-sustaining treatments) considering whether DNACPR was 'in the patient's best interests'.

I have written extensively about CPR decision-making within my analyses of end-of-life behaviour, and I will not inflict a list of references on readers here, but the problems highlighted by court cases and complaints to the NHS, do often seem to stem from the 'it looks different from where I am standing' factor.

Somehow, we need to sort this one out: if more people die at home (and surveys suggest about twice as many people would prefer to die at home as currently do die at home), and if current attempts to increase the numbers of welfare attorneys who are appointed (as part of a drive to improve public understanding of, and use of, the MCA) are successful, then it seems to me that current guidance for 999 paramedics will lead to head-on clashes between attorneys, and normal family-carers, and attending 999 paramedics. **That isn't going to be helpful for anyone – we need to try and keep 'conflict' out of end-of-life**.

As someone has just said, at the end of an e-mail to me:

Discussion like this is healthy .. we will solve the issue together

I hope we do – we aren't likely to solve it, without discussion!

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