

Mike's Cheeky Blog: We must do better by bereaved families

I was corresponding with an end-of-life doctor a few weeks ago, and the doctor wrote a concise and very clear description of the way that 'do not resuscitate' documents have altered over the years. I show it below, and I will in this piece use it to make a few points, as well as to elaborate on aspects of it.

I should explain, that this was sent to me at the conclusion of a discussion, which had been about the necessity for family-carers and clinicians to be working together if good support for patients who are dying at home is to be provided, and also my dislike of the term 'shared decision making' which is much used by doctors. And, I also need to explain that I became involved in debate about end-of-life care and behaviour in 2009, after my own mother's death. And, for reasons I will not elaborate on here, I read the law [which is mainly the Mental Capacity Act, which became law about 2005] first, and only afterwards did I read about 'medical concepts' [such as 'shared decision making'] and medically-created forms [such as DNACPR forms].

So, before the doctor's longer piece, we had already exchanged:

From the doctor to me:

I think even clinicians often feel uncertain and anxious when they are caring for dying people and talking about dying. Those of us who have been thinking about it for years, like palliative care people and families affected by horrible events are far more aware of what needs to be discussed, and how, than the general public including those who train to become health care professionals. It seems there is a lot of work to do.

From me to the doctor:

I agree with all of that - everyone, lay and professional, seems to 'struggle with' 'talking about dying'. Perversely, as the importance of the conversations has been better-recognised, recent 'guidance' stresses the need for the conversations, and then contemporary protocols seem to assume the conversations will have taken place. The second is very problematic - because it often isn't true, and assuming it is true is very unhelpful [especially re situations of EoL at Home when the 999 Services are involved]. A relative contacted me last year, and he said a nurse [presumably tasked with completing a ReSPECT form] persisted in asking his elderly father about CPR, after the father had become distressed by the conversation: clearly [if we take that as correct] 'bad behaviour', and I can't help wondering if there is a connection with 'we need to have had the conversation' as opposed to the correct 'it is very helpful if we have had the conversation'. I've banged-on about this for years!

This is the longer piece from the doctor:

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Yes: 'we're in this together' is vital. Thinking about all those forms and signatures... I see it a bit like a journey from 'Doctor knows best' to 'all in this together.'

Enlightened practitioners agreed with patients and families that a point is reached when 'doing everything' is no longer the most important thing.

Initially, this led to a form that told would-be resuscitators, usually fellow clinicians in hospital and possibly less enlightened than the person writing the form, not to start CPR. It was, at that time, a 'doctor's order' to enable colleagues to stand down with 'medical permission'. All this, of course, pre-dates the MCA. I suspect that the origin of the 'DNR' form, as it was then, has muddied the waters ever since. First, the existence of a form allowed clinicians to fill it in and sign it without discussion with patient and family (note to readers: as the [Janet] Tracey court case highlighted). This is at odds with the original intention around the form, but already the workforce had forgotten/never been taught how the form originated in conversations before decisions were reached. Secondly, the doctor's signature on the early DNR forms was to take 'medical responsibility' for colleagues following an instruction not to resuscitate, because we require a responsibility trail for medical actions/inactions that result in a death. As more nuanced iterations of the DNR form and associated conversations were developed, including the title change to the more accurate 'Do Not Attempt...' forms, that medical decision-making signature has persisted, and rightly so. However, although newer forms including ReSPECT now acknowledge DNACPR status 'because the patient wishes it,' we haven't progressed to the point that the person wishing it countersigns their wish.

And what of a Best Interests DNACPR? Should all witnesses to the BI process sign? Or a representative of the patient? It's tricky.

Like so many things that are welcome developments in medicine, moving from 'what we used to do' to 'how we'd like to do it' involves a series of changes that each throws up unexpected consequences, potential misunderstanding, and frustrations for those who have a clear vision for a better future yet find their vision gets bogged down in process. No signatures makes it hard to trace who takes responsibility when a DNACPR document (or any other plan for care in a crisis) is put in place. Not necessarily responsibility for making the decision (the old 'Doctor Knows Best' model), but responsibility for ensuring that interested parties have had sufficient information, support and time to reach that decision - patient, Attorneys, clinicians.

I wonder how we will reach the point where a person can collapse at home, amongst their dear people who know their wish 'not to be interfered with,' and it will be a matter of course that an attending ambulance crew accept the family's word that this person does not wish for CPR, IV drugs, etc. Likewise, that we can attend our dear person as they die at home, and not be questioned by the authorities as though we murdered them afterwards. In most of the UK, cot deaths are still investigated by police officers in uniform: another example of inhumane practice. We must do better by bereaved families. I share your frustrations.

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My brief comments on the above. Aside from 'it is brilliant - not telling me anything I didn't already know, but really easy to understand' [which is often not true of my own writing on the same topic]. And it gives me 'a hook' on which to hang the following points.

First: the concept of 'shared decision making' was clearly being developed by 'Enlightened Practitioners' well before the MCA was enacted. And, when SDM was being promoted by those progressive doctors and nurses, it was 'ahead of the law'. So SDM was necessarily

either being presented as a position on 'best practice', or as 'ethically correct'. But SDM was never - and it still isn't - at all clear about how disputes between clinicians and relatives can be resolved: in essence, SDM asserts that 'working together is best' but it doesn't explain 'the actual rules for decision-making'. And obviously if everyone talks, and then everyone agrees about what should happen next, there is a good outcome and no conflict: but SDM simply doesn't adequately cover the situation of everyone talking but then there being disagreement - especially problematic if the patient is lacking in mental capacity when the discussions take place.

Partly, the problem is that there cannot be a single set of 'legal rules' for 'shared decision making', because the 'rules' must comply with whatever a particular country's law states.

Which is where I become 'very vexed'. Because, for England and Wales, the Mental Capacity Act in essence enshrines what looks like a clearer version of 'SDM'. The MCA make it clear that when patients are mentally capable, the rule is Informed Consent (the doctors describe the possible clinical interventions and their likely outcomes - then the patient decides which offered treatments to accept [or to decline them all]): and, the 'rules' described for mentally-capable patients within the MCA, are 'very clear'.

I often see phrases such as 'doctors and patients making decisions together' but I rarely see an equivalent for the situation when the patient lacks mental capacity: the MCA's 'rule' in this situation, is the application of its Best Interests requirements. The MCA describes both who can legitimately make a decision, and also how the decision should be made: being technical [and slightly simplified here] the guidance as to how the decision should be made is in section 4 of the MCA, and the descriptions of the legal authority of the possible various decision-makers are in sections 6 and 42 of the MCA. Being very 'nerdy', the MCA doesn't actually make clear how a best-interests decision-maker gets from the factors which should be considered to the actual decision itself: I wrote 'the guidance as to how the decision should be made is in section 4 of the MCA' when it is a process of decision-making, which if followed provides legal protection for a decision-maker, which is described by the MCA.

The logic of best interests, does imply that 'doctors, nurses and paid-carers have to work together with family-carers and relatives to support a mentally-incapable person' - so 'family and doctors making decisions together when the patient cannot make the decision' is [while technically incorrect - not because the 'working together' part is wrong, but because best interests can lead to a doctor and a relative each legitimately holding opposing best-interests decisions] a phrase we should probably see more often.

The doctor wrote:

And what of a Best Interests DNACPR? Should all witnesses to the BI process sign? Or a representative of the patient? It's tricky.

I think that is misleading: whereas a logical interpretation of the LEGAL DUTY IMPOSED BY section 4 on a best-interests decision-maker does result in 'doctors, nurses, relatives and [sometimes] close-friends NEED TO be 'working together'', I don't like the 'witnesses to' wording. Either an individual understands enough of the factors necessary to make a legally-defensible best-interests decision (the 'factors' are described in MCA 4(6)), or else the individual doesn't: so instead of 'witnesses to the process' I would separate people in terms of 'understanding enough to enable the person to make and express a best-interests

decision' or 'not understanding enough to make a best-interests decision - but, having been informed about the best-interests decisions which others have made'.

And - the phrase '*a representative of the patient*' is very unclear, in legal terms.

So: while progressive doctors developed SDM BEFORE the MCA, I am baffled by why NOW, after we have the MCA as a law, those 'progressive' clinicians have not CHANGED TO simply arguing 'we all should be properly applying the MCA'.

It seems likely, that the doctor does understand the points which I have just inadequately made - because this, further on in the doctor's piece, is much more directly expressive of the MCA:

Not necessarily responsibility for making the decision (the old 'Doctor Knows Best' model), but responsibility for ensuring that interested parties have had sufficient information, support and time to reach that decision - patient, Attorneys, clinicians.

That is indeed the legal change which the MCA made clear - that 'doctor knows best' is no longer the legal situation [and that is true for both capacitous, and incapacitous, patients]. And it is a change in the legal situation, which doctors and 'the NHS' still seem to be struggling to come terms with (and to be honest, our judges - who for several years seemed to sometimes ignore or even contradict the MCA in some rulings - didn't help the doctors, before a flurry of rulings since about 2014 which do seem to apply the MCA correctly).

This, in what the doctor wrote, is 'close to my own heart' and also warrants some discussion:

I wonder how we will reach the point where a person can collapse at home, amongst their dear people who know their wish 'not to be interfered with,' and it will be a matter of course that an attending ambulance crew accept the family's word that this person does not wish for CPR, IV drugs, etc. Likewise, that we can attend our dear person as they die at home, and not be questioned by the authorities as though we murdered them afterwards. In most of the UK, cot deaths are still investigated by police officers in uniform: another example of inhumane practice.

I'll start with cot deaths. By definition, a cot death is unexpected – so, the parents 'will be in shock'. Beyond that, there is a similarity with end-of-life death-at-home: when looking at a dead body, all that can easily be seen is obvious evidence of some unnatural cause of death if such evidence is present. There is NOT 'evidence of a natural death' to see. And while the police necessarily attend cot deaths, it is indeed very insensitive for those police to be in uniform. Furthermore, what the police want to know, is whether the death had a natural cause – which, as I have just pointed out, is NOT DIRECTLY OBSERVABLE.

For EoL deaths, the concept of 'expected death' exists to keep the police away from the death of a person who is expected to die: but, it is in fact impossible to include all natural EoL deaths in the 'expected death' pot – many natural EoL deaths will therefore be attended by police officers. And by police officers, whose experience of 'expected' death is necessarily limited, because by design the police are kept away from 'expected EoL deaths'. Which doesn't necessarily mean that the family will be 'shocked by' what currently falls into the category of 'sudden or unexpected' death – but it does mean, that the police 'are expecting to find 'shocked' relatives'. I have been avoiding inserting URLs into this

piece, but I am so angry at the current state of EoL Home Death Protocols, that I will point to two relevant pieces here.

What happened when my mum died:

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

And my proposal to address the issue of 'expected/unexpected EoL Death' more sensibly, and in a much more perspective-balanced way – the first URL goes to a one-page PDF which describes my proposed solution, and the second URL goes to a longer [and somewhat rambling] thread in which I explained the arguments:

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

<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/>

So, in conclusion, it DEFINITELY IS A CHALLENGE:

We must do better by bereaved families

Written by Mike Stone, with thanks to the doctor I corresponded with, late January 2020.

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