Who Decides
What’s Best
when
The End is
Coming?

Version 2 (missing hyperlinks now inserted)

I thank Kathryn Mannix for her book, and Lucy Series for her recent tweets, which prompted me to write this piece.

Kathryn’s book is about the ways in which people die, and Lucy’s tweets were, loosely, on the theme of the connection between law and ethics, and between one law and other laws. My interests in both, for the purposes of this piece, is mainly in the context of the understanding and application within real life (not within court cases – but in guiding behaviour without resort to courts for rulings) of the Mental Capacity Act (MCA).

If I had called this piece ‘Who knows what’s best when the end is coming?’, it would have been a very short piece – the answer is a simple ‘nobody’.

I will be discussing, while answering the question I did ask (who DECIDES), the question ‘Who knows what when the end is coming’.

This piece will investigate the two legal concepts of [Mental Capacity Act] Best Interests and Substituted Judgement, and it will touch on ‘integration of knowledge’ during end-of-life. I will also be discussing some recent developments around Clinically-Assisted Nutrition and Hydration (CANH).
I will also comment on the book by Kathryn Mannix.

1) The Mental Capacity Act – honestly, it is a law, and it exists for a reason!

The tweets from Lucy Series, were in fact about deprivation of liberty, which is ‘part of’ the MCA. The issues of what the MCA is, whether the MCA changed the earlier legal situation, and the connection between law and ethics, and indeed between laws, were the subject of the tweets. Lucy was ‘looking beyond the MCA’, but I pointed out ‘if I were made a Welfare Attorney, with decision-making authority over best interests, I could look at the MCA itself (the Act) reasonably easily, but I could hardly be expected to study the background of case law, or the wider area of Human Rights Law’.

I will not elaborate, beyond pointing to what Mr Justice Charles wrote in ‘Briggs’, which was the court ruling that set in motion the recent developments around CANH (in ‘OVERVIEW’):

(16) 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.

I would point out, that while Mr Justice Charles eventually wrote in the context of CANH the same as I had earlier written in the context of CPR, it seems to me that he unnecessarily spent time discussing the Doctrine of Double Effect, and in answering a question which section 11 of the MCA had ‘already answered’.

Some people, seem to believe that the MCA is about the treatment of mentally-incapable people: actually, the MCA is a description of decision-making both during mental capacity (when it describes Informed Consent) and during mental incapacity (when it requires that the concept of 'best-interests decision-making' should apply). If we consider that best-interests, which is the replacement for consent when the patient cannot consent, is 'part of 'consent law'', then 'the MCA contains all of our 'consent law''.

I will point out, that there is no 'best' in Informed Consent: there is a 'best' in Best Interests, but we cannot be certain of what 'is best in any given situation'; and that I titled this piece 'Who Decides What's Best ...' instead of 'Who Knows What's Best ...' because the MCA allows us to work out 'who decides'.

2) MCA Best Interests – it is NOT Substituted Judgement, but …

The BMA and RCP, in their leaflet 'Clinically-assisted nutrition and hydration: your role in decision-making - A guide for family and friends', states:

A best interests decision is based on the person's past and present wishes, feelings, values and beliefs. It should be the decision the person would make for themselves if they could.

Now, as I point out both often and forcefully, the BMA and RCP are wrong to assert that 'the role of the family and friends is to help the doctor to make the best-interests decision', but here I will point out that the leaflet seems to be describing, with no clear qualification, 'substituted judgement' with the sentence '*It should be the decision the person would make for themselves if they could.*'.

Substituted Judgement is the legal concept of 'working out what the patient would have decided, and doing that'. Best Interests is different, in a way that nobody can clearly explain: Best Interests requires the decision-maker to work out what the patient would have decided, but 'conceptually there are then other considerations as well'. What Mr Justice Charles wrote in Briggs, is close to stating that Best Interests is Substituted Judgement, but he did add 'the caveat':

62. But, in my view when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self-determination which an individual with capacity can lawfully resolve and *determine by giving or refusing consent to available treatment regimes:*

i) 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, and

ii) if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.

In 62 ii) Mr Justice Charles uses the word ‘generally’, which to a scientist means ‘always’ - here, however, I think Mr Justice Charles intends ‘generally’ to mean ‘almost always’.

Whether Mr Justice Charles meant ‘always’ [in this type of situation] or ‘almost always’, the rationale he arrived at - ‘I am persuaded to a sufficient degree of certainty that this patient would have refused the intervention’ - does seem to be the only obvious way to withhold a potentially life-sustaining treatment, while complying with section 4 of the MCA.

PLEASE NOTE: IMPORTANT This is NOT ‘understanding that the patient has made and expressed the decision in advance of incapacity’ - that is a part of the law of self-determination/informed-consent, and in the MCA that is where the provision for Advance Decisions comes from. The point being, that there ‘the patient was the decision-maker’.

What Mr Justice Charles was stating, is that **without the patient having clearly expressed** ‘the decision he would make in this situation’, the person making the best-interests decision should ‘work out the decision which the patient would have made, if the patient had considered the situation’: here the decision-maker, is still the person making a best-interests decision.

In her much-praised book ‘With the end in mind’, Kathryn Mannix wrote something I will quote. We cannot tell exactly when the story happened (a son of the patient says *‘Dad asked me to do one of those attorney documents in case Mum ever needed a hand, and I just said he’d be here forever and to stop being gloomy ...’*. But, that might have been an attorney under the EPA, which was earlier than the MCA – and the law around ‘who decides what’ was very much less clear, before the MCA was enacted).

This story from Kathryn’s book, is ‘Slipping Through My Fingers’ in the section

‘Naming Death’, and Kathryn wrote:

Sometimes, even unconscious people are aware of sounds around them, so he may be able to hear your voices and be glad that you’re here. We have to decide quickly how intensively to treat him, and we want to do what he would want. We can’t ask him, because he is unconscious. That’s why we need you, who know him the best, to tell us what he would say. We’re not asking you to make the decision – doctors have to make the medical decisions. But if you think there are treatments that he wouldn’t want, we will take his views into account as we decide’.

Whenever that was written, it is obviously logically paradoxical.

Doctors never ask relatives to make ‘medical decisions’ - relatives are not asked how deep compression of the sternum should be during CPR, or what should be the intensity of electric shocks during CPR. Nobody asks relatives ‘which drugs do you think we should use if we treat his chest infection?’.

‘What would he want’ is **absolutely NOT** ‘a medical decision’.

And, so far the BMA/RCP have described the objective as being ‘substituted judgement’, Mr Justice Charles almost said the same with ‘*if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail ...’* and Kathryn Mannix has written ‘*we want to do what he would want’.*

Not only is it necessary to ask the family and friends ‘what would he want?’ because the family and friends might be able to work that out, whereas the clinicians haven’t got the faintest idea [because they do not know the patient as an individual – see 62 i) by Mr Justice Charles], **but the answer to ‘what would he want’ IS THE BEST-INTERESTS DECISION**.

And it isn’t even ‘ask the family and friends to tell us, what the patient told them’ - as Mr Justice Hayden pointed out (my added bolds), the family and friends possess a ‘wider understanding’ than simply ‘having listened’:

53 If ever a court heard a holistic account of a man’s character, life, talents and priorities it is this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine *what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment* ***but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation.*** *I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.*

To be blunt: doctors persist in claiming that best-interests decisions, which require an understanding possessed by the family and friends who are 'close to the patient', that being an understanding which the doctors do not possess, 'are made by us' **when all of the logic implies** that 'the family and friends are better-placed [in terms of understanding, if not in terms of 'emotion'] to make the MCA's best-interests decisions'.

3) The connection between Informed Consent and Best Interests is Patient Individuality: and the emphasis on 'patient individuality' is the fundamental legal change for incapacitous patients, introduced by the MCA.

Sometimes, clinicians write 'capacitous patients decide in their own best interests', but that is flawed wording: the law simply says 'capacitous patients decide'. Mr Justice MacDonald explained this very clearly, in the context of a patient who was refusing a life-sustaining intervention:

The decision C has reached to refuse dialysis can be characterised as an unwise one. That C considers that the prospect of growing old, the *fear of living with fewer material possessions and the fear that she has lost, and will not regain, 'her sparkle' outweighs a prognosis that signals continued life will alarm and possibly horrify many, although I am satisfied that the ongoing discomfort of treatment, the fear of chronic illness and the fear of lifelong treatment and lifelong disability are factors that also weigh heavily in the balance for C. 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.*

It is this 'individuality' which the MCA placed firmly at the centre of its concept of Best Interests – as Mr Justice Charles wrote in the context of best-interests decision-making (see page 3):

i) 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, and

I find it hard to understand how, in the light of what I have already presented, anybody could claim that 'normal family and friends, if adequately-informed of clinical options and clinical prognoses, cannot form legally-satisfactory best-interests decisions about medical interventions' - somehow, the BMA, etc, persist in making that claim, so …

4) The authority of best-interests decision-makers

Judges are the decision-makers for best interests, 'because they are judges'.

Welfare Attorneys are the decision-makers for best interests, because the patient decided the attorney should be the decision-maker.

The only other 'authority' over best interests within the MCA, is a very complex ‘pseudo-legal authority’ which comes from section 42: it is, to use my phrase here, ‘the description of a mechanism by which ‘the senior clinician’ can ‘impose’ a best-interests decision on more junior clinicians’. Importantly, it is NOT the case that the senior clinician can ‘impose’ a best-interests decision on family and friends – because section 42 of the MCA does not apply to normal family and friends.

While there is not a ‘best’ in Informed Consent, there is a ‘best’ in Best Interests: there is clearly a concept of ‘the best decision’ within MCA Best Interests, although we cannot be sure whether any particular decision ‘is best’. Which is why the MCA doesn’t require a best-interests decision-maker, to defend the quality of the decision made – the requirement amounts to ‘showing that the decision was made correctly’.

However: what I wrote in one of my earliest BMJ rapid responses, must surely be correct [and – I defy anyone to explain where the Supreme Court’s recent clarification of CANH withdrawal differs from this]:

The trickiest issue with EoL behaviour is the legal aspect, and in practice this means the interpretation of the Mental Capacity Act. Clinicians do not usually agree with me about this, and most believe that ‘best interests decisions ultimately devolve to the senior clinician’ – but the Act does not state that. If there is a suitably-empowered attorney, who almost certainly will be a layman, the attorney is ‘the ranking section 4 decision maker’ because of section 6(6) of the Act. So, it is clear that ‘making a best interests decision’ does not require that one is a trained clinician: this is because the section 4 best interests test can logically only start from the concept of ‘if we could somehow ask the patient, what would he decide ?’ (see section 4(6) of the Act). As an aside, it is often clearer, to think in terms of ‘interventions being accepted or refused’ rather than of ‘treatments being accepted or refused’.

If there is not an attorney – and it is unusual for there to be an attorney – the Act does not define who can be a decision maker, it merely requires anyone who makes a best interests decision, to be able to have legitimately made it (section 4(9)). So, instead of assuming ‘the doctor is the decision maker’, let us simply assume ‘there is a decision to be made’ and look at the mechanism. The mechanism should be, that the clinicians describe the clinical outcomes with and without any offered treatments to ‘everyone who could validly have an opinion (the family and friends) about what the patient would say, if the patient could answer for himself’: then, all of the ‘family and friends’ individually answer. The question put to family and friends is ‘What would the patient want to happen’ – it is not ‘What do you want to happen’. If *they all say ‘Fred would accept the treatment’, or they all say ‘Fred would refuse the treatment’, it seems simple – in such a unanimous situation, behave as if the (incapable) patient has answered directly, record who was involved in the discussions and who said what, record the best interests decision which emerged, but do not claim who ‘made the decision’.*

Diverting from this analysis – which is in any event essentially complete, except for ‘resolution or analysis of ‘why do the doctors dispute my final sentence above?’’ - temporarily, I will point to something I have recently written about decision-making during cardiopulmonary arrest and to my ‘Anne, David and Dr Jones’ scenario, and I will continue here by commenting on Kathryn Mannix’s book. Some of my comments, are relevant to what I have discussed above, and I will return to the analysis after these comments.

5) Some Comments of the book ‘With the end in mind’ by Dr Kathryn Mannix.

I have been reading the hardback version of Kathryn’s book (ISBN 978 – 0 – 00 – 821088 – 5). What follows are a few comments, some relevant to what I have written above, and others ‘more personal to me’.

On page 4, I have already analysed a passage from Kathryn’s book, where I used a common-sense logical-argument to prove that something Kathryn was claiming to be ‘a medical decision’ could not be any such thing. In the context of the MCA, the correct question is actually ‘where does the Act state that it is a decision for the doctors to make?’ and as I have pointed out, the answer is in fact ‘nowhere in the Act does it state that’.

I will start, with a ‘nerdy’ comment. If I define ‘a story’ as the description of a real event – of something that happened to actual people – and ‘a scenario’ as a constructed ‘event’, then there is an aspect of Kathryn’s book which I am somewhat uneasy about. Whenever I write about real events, if I ‘quote’ then I try to use the actual words, verbatim: sometimes possible with spoken conversation, and relatively easy with e-mail discussions. This is, I think, important: so much of end-of-life complexity, rests within the understanding and interpretation of things other people say. So: for a story, ideally we need the ‘from the horses mouth version’ of what the horse said – and, preferably first quoted in Equine and then translated into English. A scenario, is different: the person who constructs the scenario, also constructs the conversations. See, for example, my ‘hypothetical conversations’ where I try to explain the

MCA to readers.

You can learn by thinking about both stories and scenarios – but, while I do not have much of an issue with people thinking of a story as if it were a scenario, I do have a bit of an issue with thinking of a scenario as if it were a story. Kathryn admits that her book is a sort of mixture between story and scenario: but it ‘reads like’ a collection of stories. And I a bit less than sanguine, with the potential for readers to think ‘the son said ‘whatever’ and then the nurse said ‘whatever’’, when those ‘whatevers’ are Kathryn’s words, not the verbatim words of a real-life story.

As it happens, I was recently told a real-life story of a recent death in hospital – see the footnote to this section.

During end-of-life, ‘words carry meaning’. For example, in one of the stories Kathryn writes about the legalisation of euthanasia – whenever I stray onto that topic, I always discuss the legalisation of assisted-suicide.

More interestingly – and I admit this surprised me – Kathryn uses the term ‘order’ in the context of ‘DNACPR Orders’ in her book. I had gained the impression, that most doctors had stopped using the term ‘order’ in the context of those documents: they are not [in the format invariably created by clinicians] ‘orders’ in any true legal sense of the word ‘order’, and I think most authors are now using ‘DNACPR Form’, or simply ‘DNACPR’.

I am often made tearful these days, by ‘things around dying’ - before my mother’s death, I would not have cried in the way that I often do now. The reason I cry, is quite complex in my opinion, and I tried to explain that in my piece here.

So I’ll begin with a comment on a section of Kathryn’s book, which made me cry as I was reading it (so far, the only section of the book which made me cry). In ‘Travel Plans’ (in the ‘Looking Beyond the Now’ section) we are told that a nurse reports that Sanjeev ‘is delirious and disorientated in time and place’ - I think ‘Sanjeev was exhibiting dementia’ is what I would have written. My objection – assuming this is not ‘mere terminology – is to the word ‘delirious’. My mum was ‘doing that’ when she was dying, and I’ve written about how it did not match my pre-conceptions.

In ‘The Sound of Silence’ (in ‘Naming Death’), we have the situation of a wife who knows she is dying but thinks her husband doesn’t know, while the husband knows his wife is dying but thinks his wife doesn’t know. Which – as Kathryn makes clear - ‘is a very ‘unhappy situation’’. But my point is a different one: **Kathryn uses the ‘his wife is my patient’ description, whereas I much prefer ‘you are my wife’s doctor’.**

Much of Kathryn’s book, is a description of the changed breathing which often occurs as death nears: how relatives can misinterpret the associated noises with ‘distress’ or ‘struggle’, how the depth of ‘natural unconsciousness/coma’ by that stage can be assumed to be ‘sedation’ when there is no [administered] sedative, etc. I was surprised – although I have only the experience of my mum’s death to ‘work from’ - by ‘Every Breath You Take (I’ll be Watching You) (in ‘Naming Death). We can read:

Patricia is now surrounded by daughters and sons, partners and spouses, grandchildren. Despite the number of people in the room, it is quiet as everyone listens to her breathing.

We are told the silence had changed to ‘gentle conversation’ by the time that Patricia dies – and we are also told that ‘nobody notices when Patricia dies’. Well – we are told that none of the relatives notice, although a nurse does. That surprised me – my mum died when my back was turned to her, her breathing had not been particularly noisy, but I immediately turned round: ‘I knew something had just happened’ when my mum died. So I’m surprised that a room full of relatives, who had shortly before ‘received the ‘lecture about breathing changes’’, did not notice when Patricia died.

In ‘Tiny Dancer’ (in ‘Patterns’) we are told the story of Holly and her family. We are told that Holly had had hardly walked more than a few steps for weeks, until suddenly Holly had become animated and active, unable to settle. Kathryn is summoned after a night during which no one in the flat has slept, because Holly wanted to walk around and chat to everyone. Holly says ‘I feel GREAT today! I wanna sing and dance and get outta this bloody flat’!’ and Holly has a wonderful trip out: Holly loves meeting and greeting friends and neighbours she has not seen for weeks.

Kathryn works out, that this new behaviour was caused as a side-effect of an anti-nausea drug which Holly has been given – and Kathryn describes the effect as ‘feeling restless’. But Holly, has described it more in terms of ‘feeling great’. And, I have a problem with what happens next: it ‘seems to be a given’ that an anti-dote to the anti-nausea drug, will be given. **Why is that ‘a given’?**

Kathryn describes the situation, as being one in which Holly is rapidly depleting her limited reserves of ‘energy’. Kathryn also spends time in the story, explaining that what is killing Holly is her illness, not any of the drugs she is being given. But – to use an analogy, if we consider Holly's energy reserves as being a battery which is near-to-depletion, and we consider her life as 'being a bulb connected to the battery', then before the anti-nausea drug the bulb was 'glowing weekly' and the battery was draining relatively slowly: and with the anti-nausea drug, the bulb was 'glowing brightly' and the battery was draining relatively rapidly. Nothing in the story, suggests that the option of staying on the anti-nausea drug, and dying sooner but after a day or two of 'being engaged with life again', compared to taking the antidote and 'living for a little longer, but in a 'disengaged from life' state', was given to Holly. Nothing, suggests that the option of staying on the anti-nausea drug, and 'leaving life like a shooting star', was explained to Holly and her family. **Why not?**

Holly seemed pleased to have been able to talk to her friends again, etc. If her family understood the 'options' - Holly's 'restlessness' might mean they didn't get any sleep for a couple of nights, but they would 'have Holly back to talk to her, etc' for a couple of days, before Holly ran out of energy and died, but if the alternative was Holly 'dwindling and dying over a week or two' - would they have been bothered by a couple of sleepless nights?

Why wasn't Holly asked? Why wasn't that a choice for Holly to make?

One of the themes of Kathryn's book, is that the relatives often fail to understand what is happening. But, while true, the point can be over-stated. In 'Never Let Me Go' (in 'My Way') Sally is dying, but she refuses to ever say that. When the family are asked 'what do you think is happening?', they say they think Sally is dying. When asked 'Do you think she realises?' her mum says 'She knows, but she doesn't want to talk about it … She can't bear it … And we have to help her to keep pretending … I think we'll break her if we are honest with her'.

So, it isn't true that 'normal people' can't see when a person 'is dying' - often, the family will know perfectly well, that a loved-one 'is dying'.

Kathryn has a background in CBT, which is clear in 'Take My Breath Away' (in 'My Way'), where what I'll describe as 'a CBT Circle' involving 'breathlessness and panic' features. That 'bit of psychology' I don't have a problem with – but I do have an issue with 'trying to change the patient's 'attitude to dying'' because I would tend to see that as an inappropriate use of the patient's limited remaining time alive [unless the patient requested such an approach].

I found it interesting, when I came across something in 'Acknowledgements' where Kathryn thanks the members of her local Clinical Ethics Advisory Group, for agreeing to examine the ethics 'of the book'. Kathryn's section about that, ends with:

'… with the safeguards I have been able to put in place, publication is ethically justifiable and morally acceptable'.

That caught my eye, because a few months ago a doctor suggested that I should write something on the theme of 'social media' for BMJSPC. I decided to write on the theme of how 'ethics committees' are impeding the engagement of clinicians with social media – my piece included:

So, if the NHS falls behind the curve for social media, these better-informed upset bereaved relatives will surely become increasingly problematic for the NHS. When I read papers written about the uses of social media by clinicians, I was struck by discussion of the 'ethical issues' involved in its use, and the need to satisfy ethics committees: whereas we layfolk 'just ask our questions'. I am not sure exactly how – and it is for clinicians to decide how, anyway – but, to cool down the often 'boiling waters' of social media, I believe that clinicians will need to figure out how to use social media as nimbly as we laymen use it, without clinical 'regulatory frameworks' that may prevent or discourage them from diving into these social media seas.

I will draw these comments to a close, with a discussion of something that crops up at least twice in Kathryn's book, and something that is personally 'relevant' for me.

My mum died at home, and for about the final four days of her life, she was what I usually describe as 'peacefully terminally comatose', although some people would say 'deeply unconscious' instead of comatose. But whatever words you use, my mum never moved, never blinked or opened her eyes, showed no reaction when being turned, washed, etc.

I did not talk to my mum, during those 4 days: I assumed that she wasn't aware of anything at all. A couple of years after my mum's death, I read a book by a war nurse – she told a story of a ward full of comatose patients, and how suddenly the usual silence of the ward was broken when one patient started to sing, and how slowly one-by-one the rest of the patients joined in the singing, until the whole ward of 'comatose' patients were singing. Then, at the end of the song – a return to silence.

Kathryn's book, suggests that 'comatose or deeply unconscious' dying patients, might be aware of people talking. This, for me, raises two issues:

one is ‘unsettling or disturbing’, and the other ‘invites thinking about’.

The unsettling point, is that if my ‘comatose’ mum could hear and perhaps understand, then I should have talked to her, while she was comatose. It also raises the concern that ‘comatose dying people might be in pain and distress which we cannot see’ - which is ‘disturbing’ as a thought.

The ‘invites thinking about’ is this. For me, ‘my mum had ‘really died’ when she became comatose – when she stopped breathing 4 days later, that wasn’t, fundamentally, ‘when my mum ‘left me’’. The ‘emotion’ would have been at the ‘became comatose’ point, not at the ‘end of the coma’ point. So, I ‘wasn’t ‘freaked out’ when my mum finally died’.

If I had been aware of the ‘ward of singing comatose soldiers’, etc, then I would have talked to my mum, during those four days. Even if I doubted that dying comatose people could hear you, I would have talked to my mum. This is ‘the invites thinking about’: if I had been talking to my mum during her 4-day terminal coma, then when she finally died, would my emotions have been ‘engaged’ at that point? Would my mum have ‘died twice, for me’ - once when she became comatose, and again when she eventually died about four days later?

FOOTNOTE

A lady who lived about a minutes walk from my home, moved away to be nearer to her daughter a year or two ago. In the month or two before the lady moved away, I had been doing some shopping for her – she was of my mother’s generation. Just before Christmas, in response to a card I had sent to the lady, her daughter sent me a card telling me that her mum had died during the autumn.

On the Friday after Christmas, I was out browsing the local shops, and I heard ‘Michael! Michael!’ from behind – it was the lady’s daughter trying to catch up with me. The daughter told me about her mum’s death in hospital, and her view of the hospital’s treatment of her mum: which was not a good view.

Mum was in her late nineties, and before admission had ‘seemed in reasonably good health’, and the daughter: had the impression that the hospital was ‘ageist’ and hadn’t really wanted to keep mum alive; the doctors were all uncaring and useless, except for one doctor who the daughter only found after a few days; the hospital wasn't investigating what was wrong with mum, let alone properly trying to treat mum; and, 'how could my mum die in a hospital having been in it for a week or more, and the hospital not know why she died?!'.

I was listening to this, and a mixture of deja-vu and annoyance was coming over me. I tried to explain 'frailty' to the daughter (if we'd been online, I would have pointed her to a short piece I've written about frailty and communication), and to explain to her that it might not have been ageism: how the doctors might have felt that even the 'necessary investigations' might have been 'too much for her mum to stand', how doctors 'try to avoid extending a death', etc. And – crucially – that hospital staff often fail to explain the situation and consequences of 'extreme frailty' **soon enough**: which can leave bereaved relatives, confused and thinking 'they weren't trying to keep my mum alive'. If you explain 'frailty' AFTER the clinical deterioration, it is VERY EASY to see the explanation 'as an excuse for poor care'.

I think the daughter understood what I was explaining – I seem to recall she even said after I'd tried to explain it 'that – is probably what was happening'. I left her with the suggestion, that if she wanted to think about what had happened in the hospital, it might help if she 'googled' 'Extreme frailty in the elderly' or similar terms. I need to either phone her (not sure if I can find her number – I might have it, somewhere) or write to her, with an offer of 'a bit of help' if she does want to keep trying to figure out exactly what was going on in the hospital.

6) How can the MCA's Best Interests be 'taught'?

Many people have wondered how the 'meaning of' the MCA can be better 'communicated or taught' to both professionals and lay people: there is widespread agreement, that currently the MCA is widely misunderstood and widely misapplied.

Some people, have concluded that 'emphasising the **MCA's 5 Principles**' is the way to go – I'm not very happy about that approach, because extracting the meaning from the 5 principles is less-than-straightforward, but these are the principles (within the Act, they are labelled 2 – 6: 1(1) is 'The following principles apply for the purposes of this Act.').

1(2) A person must be assumed to have capacity unless it is established that he lacks capacity.

1(3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

1(4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

1(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

1(6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Some of those are quite difficult to apply in certain situations [and 1(5) is also a little problematic - 'Informed Consent' is enshrined 'in the Act' but, as I've pointed out, the MCA's use of 'best interests' is for incapacity, not during capacitous informed consent).

I decided it would help, if the objective of best-interests decision-making could be described correctly and in one or two sentences, and I 'posed that as a challenge' in a piece on Dignity in Care. My one-sentence description was:

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.

A doctor who is very active in an MCA context, and who is actively promoting the 'use the 5-principles approach to teaching the MCA', commented to me in an e-mail (as an 'aside' during a discussion of the best name for the DoLS replacement):

I like the one sentence too re Best Interests decisions.

One person commented on Twitter, that a problem with my sentence is that it looks a lot like a description of Substituted Judgement – I would argue that it is correct as a description of the MCA's best interests, and as I've pointed out, both the BMA/RCP and Kathryn Mannix have apparently described MCA best interests with words which are even closer to a description of substituted judgement.

There is, so far as I can see, nothing in Kathryn Mannix's book, to suggest that she would disagree with my one-sentence of MCA best-interests.

Where we do seem to disagree, is over this assertion typically made by clinicians that 'the best-interests decision is made by the senior clinician' - it is very obviously absurd, if you focus on

… *which would result in the most satisfactory future when considered from the perspective of the incapacitous person as an individual*

to suggest that clinicians who have had no previous contact at all with a now-unconscious patient, such as 999 paramedics and A&E doctors, can understand that as well as family-carers, spouses, partners, etc can. As I pointed out, posed 'as a question' in a BMJ rapid response:

To Close: (hypothetical)

I have been sharing a home with my now 'dying partner' for 20 years, although my partner has only been 'dying' for about six months. I have talked to my partner a lot during this six months, and during those 20 years. The GP has talked to my partner a little, especially recently. We both talk to the district nurses who have visited a couple of times a week for the last 6 weeks – but they are often different nurses each visit.

My partner has just collapsed. I have called 999 to find out why my partner has collapsed. I am now standing over a 999 paramedic, who is doing something to my unconscious partner. Why on earth, should I accept that this paramedic decides what happens next ?

The other thing – to an extent sensible, but not sensible when 'taken to extremes' as is the case at the moment – is that doctors, who are perfectly aware that clinicians who have had no previous involvement with a patient cannot possibly 'understand the patient as an individual', address that by stressing 'making best-interests decisions in advance' and 'Advance Care Planning'. Well – if you read the 'principles of' MCA, it does seem to describe a 'concept' which I've summed-up in my single-sentence description, and it doesn't say 'the concept doesn't apply during 'an emergency''. *It could be argued, that if you are a family carer of a terminal patient, or a hospice doctor, then the MCA is effectively 'imposing a duty to try and acquire sufficient understanding, as to be able to make best-interests decisions* ***during*** *'emergencies''.*

As a former family-carer of dying parents, I believe that trying to be sure of 'what my dad wants' is always at the front of your mind – and, indeed, 'getting the decision from dad' is also what you want: as in 'I don't need to decide – dad made it very clear what he wanted in this situation'. On one level that means we should all be promoting Advance Decisions and not ‘advance statements’, but on another level it also means that ‘what I’ve just been told by dad, takes precedence over what had previously been written down’ - see my ‘Father and Son’ scenario and my little survey about it.

I have some problems, with ACP – see here and here for short pieces which outline some of my issues with Advance Care Planning.

There is one other excerpt from Kathryn’s book, which I like because I will be able to use it in analysis – but, not this analysis. However, I’ll show you the text from Kathryn’s book, and you might ponder ‘how I’ll ‘use that’’:

On page 307, in ‘Perfect Day’, and in the context of the professionals discussing the ward round that is about to happen:

The meeting takes on a distinctly glum mood. We deal with suffering all day, every day, but our coping mechanism is to help. If our help is declined, we feel disempowered and our helplessness opens the gates to sadness.

@MikeStone2_EoL Written by Mike Stone December 2018

PS Kathryn’s book, is not about the same things which I usually write about for end-of-life.

Where Kathryn comes closer to the things I write about, is probably in the 2-page section ‘Pause for Thought: Naming Death’.

And while Kathryn is writing as a medical doctor, I definitely write ‘as a patient or ‘relative’’. One well-known doctor, suggested to me that I am a ‘narrow detail’ person – he, of course, was ‘a big picture’ person. The assertion, seems to hinge on my emphasis on the Mental Capacity Act. Which, for me, suggests that even some senior doctors ‘have missed the ‘big picture’’.

Because – as I pointed out on page 2:

> If we consider that best-interests, which is the replacement for consent when the patient cannot consent, is ‘part of ‘consent law’’, then ‘the MCA contains all of our ‘consent law’’.

There is, therefore, nothing ‘small picture’ about involving the MCA – unless doctors still believe that they can act without legally-valid consent, then ‘all instances of medical intervention should involve compliance with the MCA’: so, not ‘small picture’ but most definitely ‘big picture’ in my view!

Since I published the original version of this, Kathryn Mannix has posted some comments about my comments, on Twitter – her series of tweets starts at:

https://twitter.com/drkathrynmannix/status/1082289217634476033

Kathryn posted her tweets after my own tweets, such as those at:

https://twitter.com/MikeStone2_EoL/status/1082264920262094849

I must admit, I have ‘issues with’ two of Kathryn’s tweets:

https://twitter.com/drkathrynmannix/status/1082292756666613760

In attempting to simplify yet not patronise, some 'sharp edges' are less distinct, and some of these blurrings have offended Mike's detailed examination. I have no doubt that similar sins of omission or blurring occur about clinical detail, too, that medical readers will spot.

https://twitter.com/drkathrynmannix/status/1082301322152554497

I'm not going to engage in protracted discussion of the way I've written my book. I simply wanted to share stories and get people talking; to share comfort and consolation. I'm delighted that's happened for many. For me, that's enough. Someone else can do the clever stuff. End.

I made it clear why I’m not very happy with those tweets, in my tweet at:

https://twitter.com/MikeStone2_EoL/status/1082627881052839936

That tweet had a ‘text image’ which I’ve put on the next page.

To be clear – I think Kathryn's book IS A GOOD THING.

But, Kathryn's book is about how people die – whereas my own area of interest, is how the decisions are made while people are dying.

I cannot rationalise, why any Palliative Care Consultant, would not consider that patients and relatives need to understand both of those things.

So, I can't understand why Kathryn would object to my 're-purposing' of parts of her book, to enable discussion of the 'who decides what, and how should decisions be made' aspect of end-of-life.

And, it clearly makes no sense to have patients and relatives arguing with their clinicians, about what the law around decision-making is, **while patients are actually dying**. That makes a stressful situation, much worse. Which means, that the discussions must take place either before people are dying, or after a loved-one has died.

So, I must ask: where are laymen and clinicians, going to debate the issues around decision-making during end-of-life? It can't really be at medical conferences, nor within BMJ rapid responses or similar, for the simple reason that the patients and relatives are not present. And, if doctors say 'I'm not willing to debate this on Twitter' – where there are plenty of relatives and patients to debate with – **then where does Kathryn think the decision-making issues I am interested in, should be debated?**

I CANNOT ACCEPT 'the decision-making issues should NOT be debated between patients, relatives and clinicians': so I would 'have a problem', with any Palliative Care Consultant who claimed that the issues around decision-making do not need to be thrashed out. I would also have a problem – because consultants and GPs are expected to understand the Mental Capacity Act – with any consultant or GP who wasn't capable of debating the 'decision-making issues'.