

The Burden of Best-Interests Decision-Making

I had an hour-long phone call with a nurse yesterday, which was very interesting – afterwards the nurse sent me an e-mail:

Dear Mike,

Good to talk this afternoon.

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

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

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

Personal

I have explained how I myself 'found the 'making' of a life-or-death type decision' so burdensome, that **I really wanted to avoid it:**

<https://www.dignityincare.org.uk/Discuss-and-debate/download/299/>

*Dr Smith, the GP, prescribed some antibiotics and energy drinks, but my mum wouldn't take them. While Dr Smith had been trying to examine her, my mum had been pushing Dr Smith away and saying 'don't want no more'. **Some time later (i.e. a couple of hours later the same evening) it struck me that 'don't want no more' might mean LIFE, instead of 'being examined/messed about', something I needed to be sure of.** So when I was sure my mum was 'with me' I asked twice. That evening I said 'Do you know that you won't get better unless you take the drinks and medicines' and the following morning I said 'If you don't take the drinks and medicine you will go to sleep and not wake up again. Is that what you want?' My mum wasn't speaking by then - she was nodding and mumbling. But I was bending down in front of her, and having nodded 'yes' to that final question she looked me in the eyes, smiled, and SAID 'you know I love you'. That was the last thing she ever said to me. My brain cannot cope easily with 'recalling' that : you want to 'file and forget' the answer to the question, but not the 'you know I love you' part - that is a tricky thing for your brain to handle. Unfortunately a problem with the medical notes,*

and a useless subsequent PCT investigation, forced my brain to keep 'running past' that event a few months later - that really damaged my brain, as it happens.

In my piece here:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/297/>

I outlined my own approach when my parents were dying – it hinges in large part on 'get the decisions from them':

My Own Position when I was a Family Carer for my Dying Parents

1 I would push for any interventions my loved-one wanted

2 I had a deep aversion to 'arguing with my dying loved-one'

3 If my loved-one had lost the capacity to make and express his or her own decisions, I desperately did not want 'the burden' of making life-or-death decisions which would affect my loved-one, so:

3a I tried to make sure that I got the decision from my loved-one if possible, so

3b I spent a lot of time listening, 'enquiring', and 'picking-up-on' the 'wants' of my loved-one

4 Horrible though the burden of making decisions is – see 3 – one thing would have been even worse: *if I had allowed clinicians to impose on my incapable loved-one, treatments and interventions which I felt sure my loved-one would have refused.*

A recent Twitter Poll I posted, seems to back this up:

https://twitter.com/MikeStone2_EoL/status/931819196207509504

I asked this question in my poll, and offered 3 answers: 60 people voted, and I show the results:

A mentally-capable adult is 'dying' ['end-of-life' = 'sometime within predicted final year of life'] at home. Who should the family-carers living with their dying loved-one be taking instructions from? Please retweet - an analysis of answers would be 'interesting'.

From the dying patient 92%

From the GP and nurses 2%

From nobody 6%

Total votes cast 60

However – the Problem if the Family and Friends do not 'make' the Best-Interests Decisions

There is a paper by the Kitzingers, which I have commented on:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/286/>

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

... healthcare teams making best interests decisions not to continue ANH-treatment would need to ensure (as they should do currently²²) that family members know that the decision is not theirs to make, that the burden of responsibility lies with the clinical team and that everyone involved recognises the immense gravity of the decision to allow death.

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

As I pointed out at the end of my PDF:

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

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

CONCLUSION

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

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

It isn't acceptable, if we want to preserve the 'individuality of the patient' during best-interests decision-making (and, **one of the things which is clear, is that 'patient individuality' is central to genuine best-interests decision-making**), to argue that 'relatives cannot make best-interests decisions' because 'it is too burdensome', nor is it acceptable to argue that 'the clinicians make the best-interests decisions after discussion with family and friends': not only is it unacceptable because those assertions undermine the MCA's description of best-interests, it is also an indication that the people who make those claims, fundamentally misunderstand that section 4 of the MCA describes a legal **duty**:

https://twitter.com/MikeStone2_EoL/status/906073527236907009

Mike Stone

February 2018

@MikeStone2_EoL