

Some Points from the BBC Radio 4 'Inside the Ethics Committee' broadcast about treatment of a dementia patient

In the radio programme, Penney Lewis said:

'In this case the family would really have benefited from knowing more about what sort of a death Jean wanted, what sort of care she wanted at the end of life, what sort of interventions she might have wanted.'

And Liz Sampson said:

'I think it is quite a complex process, there are so many different forms around and I think we can get very hung up on having a signed bit of paper. Actually it's the discussion that can be really useful and I don't think we should undervalue the importance of having a discussion with your family, with your friends.'

I have repeatedly written about this, in connection with refusals of treatment expressed in advance:

'Put simply, a written Advance Decision, is merely an elaboration of a refusal in writing: and if the refusal lacks clarity, you cannot ask the document 'to explain the refusal more clearly'. But if the patient can talk to you, he or she can explain to you his or her intended instruction, as recorded on the document - so, however you look at it, a verbal discussion with a person, is better than just reading something they have written.'

See 11/04/1313:32 in the posts at:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=665&forumID=45

I have listened to a few of your really interesting programmes. I may have missed this, but I think a much more in depth discussion of the law around people without capacity would be interesting and helpful. My Mum is now in a vegetative state, following herpes encephalitis. I was astonished to discover the legal position that in the absence of a power of attorney I have no decision making capacity on my Mum's behalf. As an ex-lawyer, I had no idea that this was the position and a straw poll amongst my friends demonstrates the same lack of awareness. We all assume that as next of kin we have rights - but we don't. We only have the right to be consulted; the decision is actually that of the medical team. **There is guidance around the 'best interests' concept - but not really unpicking what this means. In my view, the medical team's role should be to give advice; the people best placed to decide on a person's 'best interests' are surely the family, taking into account the medical advice.** The current law seems to me to enshrine an outdated paternalistic attitude that we lay people are not capable of making decisions or taking responsibility. Indeed I have been patronised by a range of doctors during discussions of 'escalations of care' who have told me that it's best for me to have the 'burden of responsibility' taken off my shoulders. I actually think that the medical team should have the burden of responsibility taken away from them. In retrospect I wish so much that we had done a power of attorney; your recent discussion of advance directives did not mention powers of attorney - the latter are far more useful. Advance decisions require a level of specificity while a power of attorney simply would have put me in my Mum's place for all decision making.

(Sarah Morpeth)

The above is a comment about a BBC radio programme, and a transcript of the programme, and the comments, can be found at:

<http://www.bbc.co.uk/programmes/b04brpdk>

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?forumID=45&obj=viewThread&threadID=732

I wrote in the above piece:

There is a lot of current debate around many aspects of the MCA, including around 'best interests': the argument above, does imply that whatever 'best interests' is, it must be defined within the MCA itself, and in practice this means by section 4 of the Act. Within the overall context of the fact that the MCA, where it is clearest and most obvious, attempts to strengthen patient self-determination: it seeks to 'get the decision from the patient' if at all possible. **But it isn't entirely clear, exactly what section 4 says about how a best interests decision should be reached: the Act tells decision-makers what they need to be thinking about, which isn't the same thing at all.**

<http://www.bmj.com/content/347/bmj.f4085/rr/654490>

I wrote in that one (see below):

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 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'. It is more complicated, if all of the 'proxy minds' are not unanimous (there is not the space to elaborate, here) - but the current interpretation, by most clinicians, of the Act's best interests requirement, isn't logical and isn't coherent.