End-of-Life and Perspective part 4: Process

I am not sure that ‘process’ is correctly a matter of perception, but I think that the professional ‘love of process’ does influence how professionals perceive other things, such as the Mental Capacity Act and Advance Care Planning [which I will be writing about in part 5 of this series].

When I look at the material on the internet pertaining to end-of-life, my perception is that the professionals take the law, objectives, and in essence ‘all of the considerations’, and they turn it into ‘a process’. They generate guidance which describes processes to be followed, including sometimes ‘tick-box’ approaches, and for professionals justification of their behaviour is usually ‘I correctly applied with the process’.

From my family-carer perspective, I wasn’t bothered about ‘process’ when my parents were terminally ill: I was more concerned with ‘can you do something to help?’, ‘is what is being done, what my mum would have wanted to happen?’, etc.

Not only did I not think mainly in terms of ‘process’ - **but, even if I had, I would not have been familiar with whatever ‘process(es)’ the various professionals were following**: it simply isn’t possible to create coherent lay+professional behaviour, for end-of-life at home, if the emphasis on ‘process’ becomes dominant. Process is fine, but only as a part of the answer, and only if the limitations of ‘process’ are correctly understood.

This failure to understand the limitations of process, combined with a tendency to turn guidance into ‘tick-box’, is in my opinion why the Liverpool Care Pathway was eventually withdrawn after a media campaign – and I found nothing in the Neuberger Review (I was one of the lucky people who was sent a printed copy of the Neuberger Review by the Department of Health, and I did read it) that surprised me.

I think more in terms of 'principles' than in terms of 'process'.

Interestingly, I have a scenario 'Anne, David and Dr Jones' which seeks to draw attention to a very simple situation, in which 'the process of' best-interests decision-making seems to 'hit the buffers':

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-PDF-contains-my-Anne-David-and-Dr-Jones-scenario-it-poses-the-question-what-is-the-meaning-of-shared-decision-making-for-EoL-at-home/947/

In the original scenario, Anne lacks the mental capacity to decide if she should be taking a tablet which her GP thinks she should take, but Anne's husband isn't willing to give the tablet to her – so there is an impasse.

In my addition at 12/06/18 to the above thread, I changed the scenario: now, I changed from 'Anne isn't mentally-capable' to 'we can't decide if Anne is mentally-capable or not at first sight', and I changed from 'Anne doesn't want to take the tablet' to 'Anne is happy to take the tablet'. Then I did a bit of analysis, of the new situation:

This is the twist. Suppose that we change the situation in 'Anne, David and Dr Jones' to one in which there isn't agreement as to whether or not Anne is mentally-capable with respect to 'should she take the tablet'. And, remove the disagreement between Dr Jones

and David - now, Dr Jones wants to prescribe the tablet, and David is happy to try and arrange that Anne takes the tablet. And, also remove the 'Anne doesn't like taking tablets' issue: instead, change that to 'when the tablet is discussed with Anne, she wants to take the tablet'.

A common-sense approach to that, would be 'if Anne is capacitous, it is her decision and she wants to take the tablet'. If Anne is not capacitous, then both David and Dr Jones think it is in Anne's best interests for her to take the tablet'. So - looked at 'using common sense' - there appears to NOT be a problem: Dr Jones prescribes the tablet, and David does his best to see that Anne takes the tablet.

But - HOW DOES IT WORK IN TERMS OF 'NHS PROTOCOL'?

We have NOT established, whether or not Anne is capacitous for this decision: does 'protocol' REQUIRE that capacity or incapacity is 'established'?

And we have NOT established 'who made the decision' - in my original scenario, I had two people making different decisions with no obvious way of resolving the conflict: in this modified version, I have an agreed course of action but it is impossible to claim that we have established who is the decision-maker [although, we clearly CANNOT assert 'all three of them' because the MCA makes that impossible].

So, HOW WOULD NHS protocol handle that situation: what would be recorded, and is the 'common-sense solution' even 'acceptable' within the constraints of 'NHS process'?

I sent this to a contact, who sent back (I'm paraphrasing) 'I can't see any legal issues, with the common-sense solution – seems very sensible' and I sent back 'I agree – all perfectly reasonable in legal terms, and also clearly very sensible: but, if Dr Jones and David decide to do that, what exactly does Dr Jones write in the patient notes?'.

As I pointed out in my recent piece about 'advance care planning' during end-of-life:

https://www.dignityincare.org.uk/Discuss-and-debate/download/325/

In EoL, sometimes things can happen – clinical deterioration or clinical improvement which wasn't predictable, or a 'clinical development in an unanticipated direction' – which can throw a spanner into 'the best-made plans of mouse or man'.

And I am going **to make an assertion about the way** that decisions are often made during EoL at home:

Often there is no alternative to the decision being made by a group which is a happenstance mixture of patient, family, GP and nurses [depending on who happens to be present] and very often 'common-sense compromises' will be adopted: not 'idealised decision-making' and not 'theoretically-perfect decision-making', but decisions which 'everyone settles for'. It is a case of ‘compromising and ‘muddling through” in many situations.

I am stating 'that is the reality of how it works' – that what happens during EoL at Home is hugely complex, and frequently 'the decisions made are the decisions which 'seem sensible' to the people involved'.