

Separations, Similarities and 'Blends': badly described at present.

There is a lot of muddle and lack of clarity – and also legal inaccuracy – within things which are currently written about end-of-life in the context of 'role and decision-making'.

There is also a belief – to my mind an absurd belief – that better record-keeping [and things such as online electronic databases] will successfully address the problems which currently afflict end-of-life when patients are in their own homes.

I'll start, by describing two things which are – legally – clearly 'separations':

a) for a particular decision, at a particular time, a patient is either mentally capable [in which case the patient decides whether to consent to or refuse the offered treatment - 'Informed Consent'] OR ELSE the patient is mentally incapable and a decision is made by someone other than the patient: the concept of 'partial capacity' does not exist, as such, in English law (which amounts to that concept is not present in the Mental Capacity Act (MCA));

b) when the patient is not mentally capable, and if there is a need for a best-interests decision to be made, there either IS, or there ISN'T, an individual [or perhaps several individuals] who has been given legal authority over best-interests decision-making (such authority is **imparted by section 6(6)** of the MCA).

I will now move on to something which many professionals and their protocols assume to be a 'separation', but which I dispute:

c) the idea that only clinicians treat patients, and that only clinicians therefore make best-interests decisions about treatments (please note: **'how the treatment is applied' is NOT in my view a best-interests decision**).

I posted a scenario on the National Mental Capacity Forum, to illustrate precisely how this separation between 'clinician' and 'family carer' makes no sense in many situations (you can also apply the same logic to a family carer who can perform CPR as first aid). The NMCF requires you to join, and on the NMCF there are more responses to the scenario – here I will show the scenario and the first two responses, from Rachel Griffiths who at the time was the Care Quality Commission's MCA expert, and from Hugh Constant who was something similar at SCIE.

The Anne, David and Dr Jones scenario – who is deciding what in this scenario ?

Posted by [Michael H Stone](#) on January 19, 2017 at 10:56am

Anne is married to David, and they share a home together. David is Anne's 'sole [or at the very least, 'main'] carer'. Anne has been suffering from dementia for several years, and her dementia is now quite advanced. Anne's GP is Dr Jones, and Dr Jones believes that Anne should start to take a tablet every morning, and the tablet must be taken 30 minutes before breakfast. The clinical consequences of taking this tablet, and of not taking it, have been explained to David by Dr Jones.

Anne already takes two different tablets after her evening meal, and she isn't always happy to take the tablets: David sometimes has to coax her to take the tablets, and perhaps once or twice a week Anne becomes very angry with David when he tries to persuade her to take the tablets, and Anne will then be very unsettled for, sometimes, an hour or more. Dr Jones is aware of this.

Both David and Dr Jones agree that Anne is not able to understand the clinical advantages of taking the new tablet every morning, but when David and Dr Jones mention it to her, she immediately says 'I don't want any more tablets !'.

David believes Anne should not take this new tablet, and he tells Dr Jones that he is not going to give the tablet to his wife: as they live alone, and if Anne is to take medication it falls to David to administer it, this means that we are in a situation where Dr Jones believes that Anne should start taking this new tablet, but David is refusing to administer it.

Discussion Points:

Who is making decisions here ? Do both Dr Jones and David have decisions to make, and if so, are they the same decision or are they different decisions ?

What can, and should, happen next, if Dr Jones and David cannot see eye to eye however much they discuss this new tablet, and they continue to hold opposing views about whether Anne should be taking this new tablet ?

Rachel Griffiths replied: January 20, 2017 at 10:01am

Thank you Mike for this scenario: not an uncommon one, I would guess. In answering them, I'm giving my own responses, and 'thinking aloud' as I do so. Hence this may not be either well-written or even consider all the aspects of it. I would be interested, as would Mike, in knowing what other people think.

My starting-point is that any discussion of the best interests of a person lacking the capacity to make a decision for herself must be as collaborative as possible, and that the wishes and the feelings of the person have great weight. Also, a decision made today may not reflect the views of the people involved for ever. Another aspect of best interests thinking, not as far as I know laid out formally anywhere, is the recognition that situations change over time and our opinions and wishes may change with them - so we need in making a decision to be aware that this is the best we can come up with now, but the decision can be revisited if circumstances change. Anne here is clear that she does not want any more tablets. I presume the obvious suggestion of finding ways to give her all her medication in liquid form has been explored and found to be impossible.

So then the question arises: even if David was willing to try to get them into her (not just once, but every day, and then she'd have to wait half an hour before breakfast, which might be very trying for her), is the distress involved proportionate to the benefit? David at this time thinks not. Nobody can make him change his mind. Nor should they be quick to try: he knows his wife far better than any professionals can, and loves her more. In the absence of strong evidence to the contrary (which is absent here) there is no reason to assume he is acting other than in her best interests: and in placing her wishes and feelings at the heart of his decision-making, he is acting within the spirit and the letter of the MCA s.4.

So Dr Jones needs to decide whether it is necessary and proportionate to consider other ways to get these tablets into Anne. The concept of necessity and proportionality is linked, in the MCA, specifically with restraint, but must also apply to any intervention in the life of a person lacking capacity: this concept is at the heart of Articles 5 and 8 of the European Convention of Human Rights. And there is no suggestion here that the new tablet is a magic dementia-curing bullet of a kind yet to be invented.

If s/he could justify the costs to the practice of sending a district nurse every morning to give Anne the tablet, would this nurse be any more likely to be successful in persuading Anne to take it? It's possible that she would - many of us tend to fall in line with 'the nurse' - but it's equally possible that Anne would be even more suspicious of this uniformed stranger than she is when David asks her to take tablets.

Eminent judges have warned us to consider very carefully whether any force or deception to achieve a perceived 'good' for someone is justifiable: we should, then, reconsider how necessary any intervention, in this case the extra tablet, is. My hope is that Dr Jones might decide that no extra tablet is worth risking Anne's relationship with David, and making her feel unhappy and disempowered and bullied (by the person she loves and is reliant on) into doing something she hates, on a daily basis. This is I guess how David sees it. The GP must give weight to this view. After all, Anne is completely dependent on David's care of her, and behind that lie all the imponderables of love, companionship, mutual trust, and a long marriage. These could not be bettered or even equalled by any public intervention, such as a care home bed: they are to be supported and valued - even cherished - by professionals. Dr Jones may continue to believe that Anne would benefit from the new tablet. But s/he may also decide that being 'right' is, in this situation, outweighed by these imponderables and that s/he must recognise and accept the situation as it is. By doing so, and doing it gracefully, Dr Jones makes it possible that, if David changes his mind, or if the progress of Anne's dementia is such that she forgets her antipathy to taking tablets, the situation can be revisited in the necessary collaborative way. I have wondered, fleetingly, whether Mike is hoping to lure us into suggesting either a safeguarding alert or an application to the court of protection. I would strongly resist either of these escalations in this situation!

Hugh Constant replied: January 20, 2017 at 4:13pm

Coming to this a little later than planned, I see Rachel has said everything I could possibly think of saying, and more, and put it much more eloquently, too. It would seem like an overly-simplistic take on Anne's best interests to say that the tablet, and its benefits, necessarily outweigh the daily distress of its administration. Like Rachel, I think that distress would be all the more damaging for being caused by her husband, and I would want to explore the option of a district nurse, to see if Anne would more willingly accept the tablet from a professional.

The question, Mike, about what decisions are being made is an interesting one. It could easily be thought that if it's in someone's best interests to be prescribed a medication, then it is inherently also in their best interests that the medication is then actually administered. But your scenario highlights the perils in that assumption.

I would point out, that I deliberately did not explain exactly how David and Dr Jones arrived at their different views about what would be in Anne's best interests: people assume that David's decision hinges on the difficulty of administering the tablet, but all I wanted to highlight was that they each appear to be capable of defensibly claiming that their own decision-making is in line with the requirements of the MCA, and the inherent complexity of 'Dr Jones prescribes the tablet but David would administer it'.

Of course, if Dr Jones and David both believed that the tablet was in Anne's best interests, and if Anne didn't object to taking tablets, there wouldn't be a problem here – **nor, would there be a decision-maker about Anne's best interests** (many authors would write that Dr Jones made the best-interests decision and that David agreed to administer the tablet – that wouldn't be true if David had formed a defensible best-interests decision).

The above scenario is not about 'is Anne incapacitous' because she almost certainly isn't if both her husband and her GP believe she isn't: it is about 'who decides when Anne cannot decide'. And as such, it is 'on a theme' with other questions which I pose but find that clinicians will usually not provide clear answers to:

Jane and Jim have been married for 50 years. Jim has now become 'end-of-life' and Jim and Jane have invited the clinicians to help while Jim dies.

Is there anything in that invitation of itself, which implies that 'Jim wanted the clinicians, and not his wife, to make the important decisions if Jim could no longer make them himself' ?

The question I posed at the end of [this](#) BMJ piece:

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 ?

As well as these fundamental issues around decision-making, there is an awful lot of conflation between CPR decision-making and post-mortem certification/verification of death behaviour (put concisely, ‘stop using DNACPR forms as a proxy for ‘expected death status’’) and there is a deeply unacceptable resistance to non-clinical signatures on documents such as ‘DNACPR forms’ (which makes those forms ‘legally flawed’ and not just ‘legally complex’: I dislike contemporary DNACPR forms, and I also dislike the ReSPECT form and its ilk for two basic reasons – these forms have often got the wrong signatures on them, and they also muddle patient-controlled decisions (refusals of possible future treatment – an absolute legal right) and patient wishes (future treatments which the patient would want – but cannot insist on being provided).

The Resuscitation Council UK [RC(UK)] is – unfortunately – at the forefront of this misrepresentation of English law, for example in this section of its ‘specimen’ DNACPR form:

1	Does the patient have capacity to make and communicate decisions about CPR?	<input type="checkbox"/> YES / <input type="checkbox"/> NO
	If “YES” go to box 2	
	If “NO”, are you aware of a valid advance decision refusing CPR which is relevant to the current condition?” If “YES” go to box 6	<input type="checkbox"/> YES / <input type="checkbox"/> NO
	If “NO”, has the patient appointed a Welfare Attorney to make decisions on their behalf? If “YES” they must be consulted.	<input type="checkbox"/> YES / <input type="checkbox"/> NO
	All other decisions must be made in the patient’s best interests and comply with current law. Go to box 2	

There is a fundamental issue in there about the role of Welfare Attorneys: they are appointed to MAKE best-interests decisions. So if the attorney’s authority extends over CPR, and CPR might be clinically successful, the Welfare Attorney would be consulting the clinicians: not, as this says, ‘the attorney must be consulted’. The attorney – and not the

senior clinician – should also be the person who signed that DNACPR form [instead of the senior clinician] if the form is a record of the attorney’s best-interests decision that CPR should not be attempted: the form does not allow for the welfare attorney to sign instead of the senior clinician.

As it happens, not only are the forms the RC(UK) produces not in my opinion properly compliant with the MCA, but DNACPR forms become very lengthy if you do design them to fit the MCA. You can download a draft version of a DNACPR form which in my view does fit the MCA from my DiC piece [here](#) – but it is a very long, and ‘intricate’, PDF.

It would be much easier in many respects, if instead of ‘DNACPR forms’ we could encourage many more patients to create Advance Decisions refusing CPR, **AND ALSO** to get ‘emergency clinicians’ (999 paramedics, A&E clinicians) to follow ADRTs refusing CPR: there are challenges with both parts of that, but in my opinion that is ‘the way to go’, so we need to figure out how to overcome those challenges.