

‘Not much point in me going on Twitter saying something that isn't the law!’

The title of this piece, is the [text of a tweet](#) made last week by Tor Butler-Cole, a barrister, during a discussion about the Mental Capacity Act (MCA). It raises the interesting question of ‘what is the law’, and a second question: do I understand the law?

INTRODUCTION

The MCA is now a decade old – and there are still reports, every year or two, pointing out that the MCA is still being implemented partially or incorrectly.

I will ask ‘why is that?’ during this piece, but I’ll first say that this is not a satisfactory situation: 10 years is long enough for professionals to have understood a law, and in particular for them to have understood the MCA’s sections 1- 6 (which cover ‘Best Interests’) and 24 – 26 (which cover Advance Decisions) – there is not much in those to read, and the language is normal [not the sort of ‘legalise’ that afflicts some older court rulings].

It is clear – even without a deep analysis of the Act – that it is part of a wider shift in law and society, away from ‘paternalism and prescription’ towards ‘individual autonomy’. In fact, as I will argue in this piece, that very shift is probably one reason why the MCA has not been correctly implemented within healthcare: the Act itself, runs contrary to the desire of the NHS to have structure, hierarchy and protocol. As [I recently pointed out](#) in a BMJ piece:

‘... the NHS still clings to ‘paternalism’: for example, the recently-developed [‘ReSPECT’](#) persists in placing the clinician ‘front-and-centre for the decision-making’ (1). I have pointed out more than once, the issue which Fiona Godlee describes as ‘most challenging of all, shared accountability (replacing medical authority with mutual trust)’ (2).

This is a deeply difficult transition for ‘the NHS’ to come to terms with: because to a significant extent, ‘shared’ equals ‘diffuse’, and ‘diffuse’ means that things such as clarity of decision-maker, hierarchy and ‘easy descriptions of decisions’ are no longer available. Which means, of course, that they cannot be easily recorded on those ‘electronic databases’ so beloved of NHS policy creators.’

In [the 2015 Montgomery court case](#), Lady Hale {116} explains this shift: ‘Gone are the days when it was thought that, on becoming pregnant, a woman lost, not only her capacity, but also her right to act as a genuinely autonomous human being.’

The MCA introduced ‘new autonomies’ for patients: legally-binding Advance Decisions (ADRTs) and ‘Welfare Attorneys’, which are both means by which a person might seek to take control of future medical interventions, should the person lose mental capacity in the future – neither ADRTs nor Attorneys (often incorrectly called ‘LPAs’) currently achieve the level of control which, as a patient ‘using either’, I would hope to achieve.

WHAT 'IS THE LAW' - and WHY IS THE LAW TRICKY?

I have been accused, during a discussion a few years ago with Claud Regnard, of 'clearly having read the MCA - so why are you ignoring the law!'. More recently David Oliver, another consultant doctor who works with elderly patients, suggested that I seem to believe that I understand the law better than our judges. I will return to those, later - first, I'll discuss the problem with 'so what is the law?'.

The Montgomery ruling effectively made clear one thing: that our law is now what I describe as 'genuine Informed Consent' - a legal concept called Bolam was discarded for issues of 'consent'.

But, Montgomery told us that this had BEEN our legal situation, since before the year 2000 - and that was revealed in a 2015 ruling. Lady Hale also 'explained why this is true' using a method, which some doctors are less-than-happy with for understandable reasons - for example, Lady Hale {107} wrote:

'In the third (2010) edition of their leading work on *Principles of Medical Law*, Andrew Grubb, Judith Laing and Jean McHale confidently announced that a detailed analysis of the different speeches of the House of Lords in *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871 was no longer necessary. A combination of the 2008 Guidance provided by the General Medical Council, the decision of the Court of Appeal in *Pearce v United Bristol Healthcare NHS Trust* [1999] PIQR P 53 and the decision of the House of Lords in *Chester v Afshar* [2005] 1 AC 134 meant that it could now be stated "with a reasonable degree of confidence" that the need for informed consent was firmly part of English law (para 8.70). This case has provided us with the opportunity, not only to confirm that confident statement, but also to make it clear that the same principles apply in Scotland.'

What bothered the doctors, was not that the law had changed: their point can be summed-up as 'we are doctors - we can't be expected to work out what the law is, by reading legal textbooks with 'confident assertions'!'.

In the more recent [Briggs](#) case, Mr Justice Charles wrote {81}:

'As appears above I prefer the approach taken by both Pauffley J and Hayden J to the assessment of P's past wishes and feelings, beliefs and values in the application of s. 4(6) of the MCA.'

OBSERVATION and COMMENT

Judges and lawyers probably do (certainly should) better-understand the law than clinicians and family carers. But it is clinicians and family, who are involved when end-of-life patients are dying in their own homes; it is family and clinicians who are involved, when loved-ones have lost their mental capacity to make their own decisions because they are living with severe dementia.

So we need clinicians and family carers and relatives, to understand the MCA – they are the people who must apply the law correctly day-to-day.

DO I HAVE A REASONABLE UNDERSTANDING OF THE MCA?

Setting aside the ‘who knows’ answer, I’ll throw in a few things. After pointing out that I STARTED IN 2009 WITH THE ADVANTAGE OF NO KNOWLEDGE – I WAS NOT HAMPERED BY ANY EXISTING UNDERSTANDING OF ANY LAW pre-MCA. So I read the MCA and thought about what it must logically mean. To be 100% clear: by ‘logically mean’ I do not mean what I think the law should be – I mean, if you read the Act, what interpretation is internally consistent IF YOU DO NOT LOOK OUTSIDE THE ACT ITSELF.

I was debating the MCA by e-mail with Claud Regnard, I think during the autumn of 2012 (it might have been autumn 2013). Claud insisted that section 4(6) of the MCA, was some sort of ‘objective process’ and that it only covered things which clinicians who did not know the patient as an individual could consider [such as written documents]: I insisted that wasn’t correct, and that a person ‘close to the patient’ (close family and close friends) could use his/her ‘life-experience of the patient’ when considering section 4(6). If my position was correct, it did – of course – imply that family and friends could consider section 4(6), and by clear implication the entire concept of best-interests, BETTER THAN the clinicians: which might be why Claud insisted I was wrong. It is also possible that Claud had been influenced by a court ruling which I had not read – as I’ve said, ‘I worked directly from the Act’.

This is section 4(6) – what do you think it is saying?:

4(6) He [the person making the best-interests decision] must consider, so far as is reasonably ascertainable—

- (a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.

Some time after this disagreement between Claud and myself, Mr Justice Hayden {53} [released a consideration of one of his cases](#), in which he clearly agreed with me about the extra knowledge of family and friends, compared to clinicians – the phrase used by Mr Justice Hayden was:

‘He [the now-incapacitous patient] 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.’

The point is - 'he has in so many oblique and tangential ways over so many years communicated his views' - can clearly ONLY APPLY to the close family and close friends of the patient (unless we are considering, for example, a person who has lived in a care/nursing home for a lengthy period).

COMPARING THE BRIGGS RULING TO MY EARLIER WRITING

I will now show things that [Mr Justice Charles wrote in his Briggs ruling](#), and some of the things which I had published BEFORE that ruling: I will give the 'online dates' for the quotes from my own pieces, and the Briggs ruling was 20/12/2016. I will show my own words first, followed by extracts from Briggs.

And I will first, summarise the Briggs case. Paul Briggs was in a minimally-conscious state, and the question was could clinically assisted nutrition and hydration (CANH) be withdrawn as a consequence of a best-interests decision. Mr Justice Charles approached this in two stages: he asked could he make such a best-interests ruling, and then he made and justified or rationalised a best-interests ruling that withdrawal of CANH would be in the best interests of Paul Briggs.

I will point out, that it strikes me that Mr Justice Charles took far too long to argue that CANH could be withdrawn: a shorter version would simply be:

'All best-interests decision-makers are following the guidance of section 4(6) of the MCA, and the Act is clear in that attorneys appointed under the LPA can be given decision-making authority over the application or non-application of life-sustaining treatments: hence it must follow from section 4(9) of the Act that any person who is not 'the court' could legitimately conclude that withdrawal of CANH would be in the patient's best interests. It would, therefore, be 'perverse' if a case reached court, and the judge could not arrive at a similar conclusion.'

I was not, in my own writing, analysing the withdrawal of CANH. I was analysing how a best-interests decision could legitimately arrive at 'although attempted cardiopulmonary resuscitation (CPR) might keep the patient alive, in the patient's best interests CPR should not be attempted'.

A moment's thought, will convince the reader that these are identical questions, in legal terms.

[I wrote](#) (BMJ March 2015):

The Mental Capacity Act, is an unusual piece of legislation: not only does it state that anybody caring for a mentally-incapable person must make decisions 'in the person's best interests', without any clear explanation of what 'best interests' means, but the Act also allows a person to appoint a person as his/her attorney (for decisions about treatment, this would be a 'welfare attorney') for best-interests decision making. Section 6(6) of the MCA, very clearly places a welfare attorney in charge of best-interests decision making - and most welfare attorneys, will be laymen, and therefore not 'expert' in either medical ethics or in law. It logically follows, that whatever 'best interests'

means, it must be possible to deduce that, from the MCA itself - the law contained in the MCA applies to all decision-makers, and it is unreasonable to expect lay decision makers to read beyond the Act itself, while lawyers tend to argue from 'historical case law' (logically, all 'case law' prior to the MCA, would be incorporated within the Act itself when it was written). So 'read the Act' and 'understand the case law from which the Act developed' are equivalent [except for any new law an Act introduced: for the MCA, Advance Decisions were new law]. It also follows from the ability to appoint a layman to control best-interests decision making, that for the purposes of the MCA 'laymen must be able to understand the law satisfactorily'.

Mr Justice Charles wrote {OVERVIEW: 16, page 4}:

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 wrote as an explanation of the differences within a DNACPR Justification Hierarchy – I did not in my piece question whether a best-interests DNACPR could be legitimate [see above – the answer is very obviously 'yes' if you work ONLY from the MCA/LPA]: instead I asked 'what makes the decision defensible?' - [in a PDF](#) (Dignity in Care 18/08/14):

A genuine section 4 best interests decision, involves 'working out the patient's likely wishes' - there must be some degree of uncertainty about those wishes (a degree of uncertainty entirely absent for 1). Whoever is considering the best interests test, the fundamental struggle is in persuading oneself that this uncertainty is small enough, to believe that the patient would have refused CPR for the particular CPA in question.

Mr Justice Charles wrote {REASONING 62}:

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.

So it seems to me, that Mr Justice Charles has used identical arguments, to arguments which I had already published online.

Before moving on to why this all matters – and what matters is CARE: not the law, but how application of the law impinges on care – I will point to something else Mr Justice Charles wrote {REASONING 48}:

A court can if necessary make binding findings of fact and it carries out the weighing exercise required by the MCA with the benefit of hearing evidence that is tested and argument. As a consequence, it is likely to be in a better position to determine the existence of, and the weight to be given to, the matters set out in s. 4(6) of the MCA that are based on the past when P had capacity than, for example, treating doctors are. So, if P's family are asserting that they favour a different conclusion to that reached by the medical team, it is likely that in many cases to be reasonable if not inevitable for doctors to give great and probably determinative weight to medical and ethical issues in their exercise of the MCA best interests test pending the resolution of the existence of the matters in s. 4(6) and the weight to be given to them by a court.

Put at its simplest, this is a suggestion that there might be factors which inevitably mean that clinical teams and families, will tend towards forming different conclusions about what is in the patient's best interests. I have written about this more than once, because the following is necessarily true (it assumes that there is a unique 'best decision' and it ignores the possibility of there being several 'equally good 'best decisions'' - that does not affect the argument: if the question is 'what is the fastest way for me to get from here to Newcastle?' the facts might be train (202 minutes), air (310 minutes), car (241 minutes), walking (about 12 days) or it might include 'train and car both the same time'):

'Although we CANNOT KNOW FOR CERTAIN what the BEST best-interests decision is, the MCA's concept of best-interests depends ONLY on the individuality of the patient and on the circumstances of the decision: so the decision arrived at should in principle BE INDEPENDENT OF THE DECISION-MAKER if all decision-makers are equally-informed and are applying section 4 correctly'.

That is a bit nerdy (and, as I keep pointing out, nobody is in reality 'equally-informed' and that is true of best-interests decision-makers: also, over time 'societal expectations' might affect things, but decisions are made at a specific time) but there is a simple truth: if 'on average' relatives as a group, and clinicians as a group, tend to disagree about what is in the best-interests of patients, at least one of the groups (it could be both) must be wrong about best interests.

MOVING ON – BEYOND THE LAW (and whether or not I understand the law)

Although it might not be obvious, I am not very interested in writing about the law: my interest is in improving end-of-life behaviour, and it is only in pursuit of that objective, that I write about the MCA.

In particular, I am bothered by end-of-life when patients are in their own homes – and it is an objective of the NHS to facilitate an increase in the number of people who die at home, because surveys suggest that far fewer people currently die at home than would like to.

[I sometimes swap e-mails with Bee Wee](#), the end-of-life lead for NHS England, and two excerpts from those e-mails are very relevant here.

Commenting on a very lengthy PDF which I had sent to her in 2013, within which I developed arguments in support of my [Core Care Team](#) model/approach for end-of-life at home, Bee supplied quite lengthy feedback, and with regard to my assertion that death at home is more complex than death in hospital/hospice, Bee wrote:

'I particularly agree with the point you make about the most complex situation being that of patients who are at home. As somebody who started off my professional career in GP training, and who has much experience of doing domiciliary assessments as a consultant in palliative medicine, I am very much au fait with what caring at home entails, for the patient, his 'live-with' relatives and the professionals and systems who are trying to support that arrangement.

This also cropped up in our e-mails (March 2015):

Bee to me:

I agree with you that we need to break down the 'inappropriate separations' between the lay person and 'lived-with' person at home and professionals involved in the person's care - but along with that, there is a need to recognise that not everybody has live-with relatives that they trust. Obviously, in the many situations where they do, professionals do need to work with them as a team. In my own clinical experience, that happens a great deal, especially where staff have had a chance to get to know the person and those close to him/her.

My reply to Bee:

'but along with that, there is a need to recognise that not everybody has live-with relatives that they trust. Obviously, in the many situations where they do, professionals do need to work with them as a team. In my own clinical experience, that happens a great deal, especially where staff have had a chance to get to know the person and those close to him/her.'

I agree with you - but the problem for EoL at home, is that in complicated and confused situations (an 'early patient death' for example, or an ADRT which 999 Paramedics do not already know about) the family and the paramedics/police 'do not know each other' and, logically, would never be able to 'know each other'. My issue has never been the way interactions with senior

professionals tend to go (i.e. with GPs for EoL at home) but with what happens if family are interacting with only junior HCPs, and/or with police officers. I can assure you that arguing the toss around EoL issues with professors 'at leisure', is not the same as trying to get on the same wavelength with paramedics and police officers 'in stressful situations'.

Bee's reply:

Absolutely agree with you Mike - no easy answers, sorry.

During a recent Twitter discussion, [Celia Kitzinger](#) tweeted:

'When my mother was dying, carers challenged her ADRT because I was the witness. Horrible argument (even tho' I was right + they were wrong).'

and also:

'In the end (after showing them the MCA and being told about their 'company policy) my mother resigned her ADRT in presence of new witness.'

Celia and I both know that the MCA does not say that relatives cannot witness ADRTs - and [Tor Butler-Cole](#), a barrister, helpfully chipped-in with:

'Well they shouldn't be the Act doesn't exclude them as witnesses'

Bridget Johnson recently [tweeted](#):

'... cannot necessarily be protocolled'

Some years ago, when we were discussing whether the Deciding Right guidance series was legally correct, Tessa Ing (at the time head of an end-of-life care section at the Department of Health) expressed the opinion that 'the detail of the law will not matter so much once patients, clinicians and relatives start to talk to each other properly' and to an extent, Tessa was right.

Celia Kitzinger adopts a 'pragmatic' approach - to an extent, Celia is advising people about what they need to do to improve the chance of their legal rights being respected WITHIN THE CURRENT SITUATION of many professionals not correctly following the MCA.

However, I am sticking to my own approach: we need to change behaviour so that the MCA is being correctly implemented by professionals, and not 'distorted so as to make their own working lives easier': THE MCA IS ABOUT

THE RIGHTS OF PATIENTS – IT IS NOT ABOUT MAKING LIFE EASY FOR CLINICIANS.

It isn't as if those of us engaged in this debate, are unaware of the problems:

Tessa Ing to me (May 2014 – HoL SC means House of Lords Select Committee report into the understanding and implementation of the MCA):

'The HoL SC should help, if only by highlighting the fact that there are serious shortfalls in understanding of the MCA. Details of interpretation won't be surfaced and thrashed out until people realise that they're there to be worried about!'

A consultant doctor who is one of the leading-forces developing ReSPECT (and I will state again – and anyone who reads my BMJ rapid responses will already know this – that I dislike ReSPECT!) included in an e-mail to me February 2017:

'You know only too well the huge culture shift that is required in many, many areas to make something like this [i.e. ReSPECT] work for patients and families but that needs to come from the public as much as from healthcare professionals. This is a significant step in the right direction but no one is under any illusions that it is the entire solution.'

[My problem with ReSPECT](#), is that it isn't the correct starting step: ReSPECT 'has a clear [attitude](#) of the retention of clinical control of decision-making for 'consent decisions''. By 'consent decisions' I mean the decision-making covered by the MCA for England – Informed Consent and Best Interests. The whole point of the MCA, [is to REMOVE that decision-making from clinical control](#): it has been moved to patients, people chosen by patients, or failing either of those, to a best-interests process which REQUIRES DEEP COLLABORATION between clinicians and relatives and friends of the incapacitous person, within a framework which describes not clinical authority over best-interests decision-making, but the justification for acceptable best-interests decision-making.

Furthermore, for many situations which call for best-interests decision-making, it isn't even possible to separate clinicians from family carers in terms of 'who is providing treatment' - as my 'Anne, David and Dr Jones' [scenario](#) was designed to prove

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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 ?

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To the best of my knowledge, there is NO GUIDANCE which clearly explains what should happen next, in 'Anne, David ...'.

But THERE WILL BE 'protocols & 'training'' for nurses, etc, which 'seems to apply' to such situations. We SERVICE USERS interact with those nurses, etc - see the tweets by Celia Kitzinger which I reproduced earlier. See my e-mail with Bee Wee.

If you ask 'an expert' for the 'answer' to 'Anne ...' then you get rather 'sophisticated' answers - for example, Rachel Griffiths, who at the time was the MCA Lead for the Care Quality Commission, posted:

'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!’

And Hugh Constant, who does the MCA for SCIE, then posted:

‘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 sent an e-mail to Professor Brendan McCormack (Head of the Division of Nursing/ Head of QMU Graduate School, Associate Director Centre for Person-centred Practice Research, School of Health Sciences, Queen Margaret University) asking if he was willing to express a view, and Brendan replied (and I've got his permission to publish):

Hi Mike

Good to hear from you again and yes I am still here!

Hope you are well

Thanks for this and we could have a long and lengthy discussion about the various ethical and moral and legal perspectives in this case. However, as a person-centred practitioner/researcher/academic and a humanist, it is more simple in my head, but with a few caveats, i.e. I don't know what these new tablets are for; I assume Anne is not able to make a decision for herself. David's decision is the only one that matters – he knows her best, he (I assume) loves her and spends most of his days with her and is thus able to know by her emotional and behavioural responses if she does or does not want something to happen (process consent). Nothing in the case detail says she is ‘suffering’ other than when David is trying to administer this medication. Clearly she does not want this tablet and so that has to be respected.

PS: I ‘hate’ the language of ‘suffering with dementia’ as we have no idea if people suffer or not. I only use the term ‘living with dementia’ and use the word ‘suffering’ in specific cases, e.g. when we know someone is in pain, discomfort etc

Best Regards
BRENDAN

CONCLUDING REMARKS

Operational – especially junior, or ‘working outside my area of expertise’ - clinicians and other professionals, follow ‘guidance and protocols’.

In my opinion, relatives and family carers usually adopt a quite different approach: in most situations, it amounts to ‘we should be doing what the patient wants or ‘would have wanted’ us to be doing – and we definitely should NOT be doing things I feel sure my loved-one would not want!’.

Those nurses and HCAs are taught about the MCA – and often the teaching involves scenarios. But NOT scenarios such as ‘[Anne, David and Dr Jones](#)’ which I create to illustrate both ‘user perspective’ and also ‘complexity’. NOT the scenario which I’ve titled ‘[Father and Son](#)’: NOT the scenario which I call ‘[Alan and Liz](#)’.

Somehow – deeply challenging to work out how – we need to bring together those different understandings, mindsets and approaches, so that clinicians and family can effectively WORK TOGETHER because unless they are working together, PATIENT CARE SUFFERS.

I will finish, by briefly describing the nature of this challenge, starting with a couple of things I’ve written, moving on to a very brief description of how we should, if those issues are to be resolved, ‘be thinking from a different starting point’, and ending with a short discussion of a recent BMJ article.

I [wrote](#):

‘I come across many clinical authors who describe the same problems that I write about, and to an extent suggest similar solutions: but I then read operational protocols for ‘front-line clinicians’ and these are often ‘going in the wrong direction’, as I discussed in my previous rapid response.’

And in the summary of a survey of hospital DNACPR forms. I wrote:

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‘I get very angry, and perplexed, when I read a lot of clinically-authored material about end-of-life and the Mental Capacity Act, but I have no doubt that most of these clinicians are well-intentioned: the problems I see in their writings, seem to stem from other issues, quite often ‘perspective’.

But good intentions, are not enough: good, and fairly balanced, outcomes, should be the objective for end-of-life – and the current guidance, does not achieve that, especially for EoL home deaths. And as allowing more patients to die at home is an objective of the healthcare system at present, this isn’t satisfactory.

...

It seems to me, that there is a significant difference between the way I look at the Mental Capacity Act, and the [apparent] way that many clinicians look at it. In essence, to me the Act is about the definition of, and duties and powers of, decision-makers, and about the principles these decision-makers must follow: it is clear that the Act is not describing clinical things, such as the best way to apply a treatment, or how best to arrive at a prognosis - the Act is about a wider, less well-defined and much more complex, question of should an intervention take place at all. I also see what I consider to be a lack of terminological clarity, around the phrase 'best interests': I reserve 'best interests' for decisions which involve the decision-maker being able to claim to have legitimately complied with section 4(9) of the MCA - effectively, this places the non-offer of a medical intervention because it could not be clinically successful, and any decision made by a person who does not understand at least a substantial portion of the things described in section 4 of the MCA, as 'not best interests decisions' (although, that does not automatically equate to not legitimate decisions).

By contrast, many clinical authors devote much more time to descriptions of the clinical situations in which decisions are made, with much less discussion of the origin of the 'legal authority or legal justification' of the person making a decision.

Very bluntly, and somewhat over-simplified, I analyse the 'rules' by defining the decision-making process and this leads to less involvement of precise clinical situations in my analyses: most clinical authors are much more precise in their categorisations of clinical situations, but then they tend to make unproven assertions about who can legitimately be a decision-maker.

In its most concise form, this difference comes down to sentences which I often see, such as 'ultimately DNACPR is a clinical decision': unless 'a clinical decision' need not be a decision which requires a clinician to make it, that sentence is clearly wrong, because of sections 6(6) and 6(7) of the MCA, taken in logical combination with the absence of any requirement that welfare attorneys and court deputies need to be clinically qualified.'

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If you think from my perspective - if you start from 'SHOULD THERE BE a clinical intervention or not' instead of from 'WHO COULD PERFORM the intervention' - then the major differences for end-of-life are not clinical issues, but are instead these:

There is a fundamental difference between a patient who is at home, and a patient who is in hospital or hospice;

There is a fundamental difference between a patient who is mentally capable, and a patient who is mentally incapable.

I will not elaborate - I'm considering doing that in a separate piece.

There is a recent BMJ paper, '[The cult of CPR](#)', by Dr Margaret McCartney. Various people have responded to the article, including Kate Masters, Claud Regnard and Juliet Spiller, Margaret McCartney and myself. Margaret responded to the responses of Kate and me.

Kate ended her response with:

'I am flummoxed as to why I keep reading articles such as this that explain the barriers, but offer few ideas for solutions, especially as I have seen so much good practice in the process of attending DNACPR focus events. How about articles in the future sharing all the ideas and great practice I know is out there aimed at getting the dialogue right?'

Margaret replied to that with:

'I have to disagree that discussing problems without easy solutions in contemporary medical practice is a bad thing. ... It's only by talking about the problems we have that we have a hope of getting them better. Currently the harms of the current nature of the legal, cultural and regulatory view of CPR is going largely uncounted but is noted in, for example, the NMC judgement against a nurse who did not provide CPR on an 'almost cold' resident of a nursing home (<http://www.bmj.com/content/356/bmj.j1548>). I don't think it's possible to improve without the wider landscape acting in support of the evidence.'

And I replied to Margaret's reply with:

'The problem is that guidance - things such as EoL Home Death protocols, and the 'Joint CPR Guidance' - implies that there are much clearer solutions than those learned academic debates arrive at. For example, Home EoL operational protocols, imply that the conversations which Dr McCartney has pointed out are difficult, will have taken place - when often they will not have taken place. And those protocols are read by people such as police officers, who have no idea of the real-world complexity of EoL at home.'

It is, in fact, very difficult to get professionals to debate the correctness of their published positions: the process is usually 'consult the public - then the professionals think amongst themselves, and publish 'a solution': what isn't published and stressed to the same extent, are the counter-arguments which were discarded when the chosen solution was settled on.

I myself was so vexed by ReSPECT, that during my online critiques of ReSPECT I resorted to an approach which is very close to 'brawling' in terms of 'academic debate' - an approach which I suspect I only got away with, because the BMJ is committed to debate open to patients as well as to clinicians. I was so frustrated with the difficulty of getting the ReSPECT team to explain their defence to my objections, that I sent an e-mail to Juliet Spiller and David Pitcher with an explanatory - and 'provocative' - title: 'An open e-mail to David Pitcher, Juliet Spiller and doctors who are BMJ readers: how exactly can a person such as Beverly Tempest, involve 999 paramedics and also successfully

forbid CPR for a 'sudden' arrest which occurs at home ?'. [My e-mail/BMJ response](#) started with:

'Dear Drs Pitcher and Spiller,

Immediately after sending this e-mail to you I will be submitting its text as a rapid response, under the title 'An open e-mail to David Pitcher, Juliet Spiller and doctors who are BMJ readers: how exactly can a person such as Beverly Tempest, involve 999 paramedics and also successfully forbid CPR for a 'sudden' arrest which occurs at home ?', to your article describing ReSPECT at:

<http://www.bmj.com/content/356/bmj.j876>'

And I ended the e-mail/response with:

'If this e-mail is published as a response to your paper, then if you respond to me, please do so by means of one or more rapid responses to your paper, in the hope that some discussion of these issues can be achieved,

Best wishes, Mike Stone

PS Juliet Spiller ended an e-mail to me on February 10 with '... but I would ask that you wait for the launch and I know you will carefully look at all the documents, guidance and resources. Feedback will be possible via the website at that point'. If this appears as a BMJ response, please view it as feedback – I believe that 'feedback' is less useful than discussion, and I hope that posting this on the BMJ might achieve the more useful discussion.

I did get a BMJ response from Juliet and David – and also a separate response from Alex Ruck Keene (a barrister who advised the ReSPECT team).

I received a very honest (very honest: in other words, the e-mail forcefully described the level of frustration, exasperation and anger which we 'very upset service users' feel in a way which would get us 'dismissed as nutters' by many doctors and nurses) e-mail from someone else who has been trying to get the NHS to change its behaviour, and there is part of it which although 'over-cynical', is something I '100% get':

'Most places that say they have Patient Collaboration actually have carefully chosen yes-men and women who tick the box on the patient collaboration form. I call it pseudo patient collaboration and it's alive and kicking. I will never be on a panel because of this - they just won't have me. Probably the same for you! We know too much, and are not yes-men and women.'