

Decision-Making and Other Problems at End-of-Life: a personal, and probably 'challenging', perspective

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INTRODUCTION

When I use 'challenging' in this piece's title, I mean 'challenging to the professionals'. I seem to spend much of my time 'challenging professionals about their beliefs re end-of-life'.

The problem I see everywhere, is something Niall Fry quoted from a piece of mine, when he wrote a 'summary note' of a 'listening event' which had been organised to harvest feedback about how well or badly the Mental Capacity Act is being implemented: in fact, we all know (many reports) that implementation of the MCA is unsatisfactory, so the event was more about 'categorising the problems and issues in a clear way'. Niall's description of the problems can be downloaded from the SCIE website at:

<http://www.scie.org.uk/mca-directory/forum/files/national-mental-capacity-forum-listening-event-8-feb-16.pdf>

Niall quoted this from my piece on Dignity in Care:

'I really do think it is important for patients, family and friends to get their experiences and perspectives to Baroness Finlay's group, because otherwise the professionals end up discussing the problems which seem the more important to them: and the most important problems, can seem different depending on whether you are a patient, a GP, a nurse, a family member supporting a patient, etc.'

I have expressed this problem in various different ways, one of which is:

The professionals typically canvass views from the laymen, and then a group composed of only the professionals gets together and creates the actual professional guidance/protocols – during the subsequent 'horse trading' the needs of the laymen tend to be downplayed, and the objectives of the professionals over-emphasised, and it is as if 'the professionals all fight to get under the umbrella, and the laymen are pushed out into the rain'.

Working nurses, doctors and 999 paramedics are bombarded with a mountain of 'guidance': some of this guidance is to try and introduce coherent, joined-up, behaviour [I tend to approve of that], and some of it is an attempt to explain things which most clinicians 'are not very expert in' [sometimes clinical techniques, and sometimes law]. This guidance tends to expand, rather than to shrink: [Glyn Elwyn et al have written](#) that for a hypothetical consultation their

paper discusses, 'The various guidelines relevant to Jan's acute and chronic conditions exceed 500 pages', and Margaret McCartney has [commented](#) that GPs are being bombarded by what I shall term 'objectives from above'. Margaret's paper included 'We now have bureaucracy, intrusive checking of often irrelevant "performance" data, and an entire (expensive) industry professing to regulate us' and in a comment to her paper [I wrote](#) 'I strongly agree with the thrust of Dr McCartney's piece: it seems to me that 'objectives from above are turned into shackles' and that 'expertise and also common sense become lost in a sea of tick-box bureaucracy'".

This probably would not matter, if it were not for the fact that:

- 1) Much guidance is so lengthy, and 'confusingly written', that the very people whose behaviour it is intended to influence, often misunderstand and misapply it;
- 2) The 'trickier issues' are usually not dealt with even in lengthy guidance;
- 3) The combination of 1 and 2, leads to 'inexpert readers' 'believing the guidance contains all the answers', and 'the experts' arguing with each other about how significant the 'mistakes' in the guidance are, and exactly how the guidance could be improved.

I fall prey to this 'writing at length' thing – although my excuse is that I'm not writing guidance, so much as trying to prove why current guidance is flawed: often legally flawed, and that means I need to properly run through my arguments. If I were simply 'stating my conclusions' – in other words, just writing about 'what the guidance should say' without also 'explaining why I'm right' – then I could keep it much shorter.

There is also something interesting about this 'long and frequently 'confusing'' guidance – it often gets things across, less well than shorter things can. Janice Trelore has put a 'poster' she made for the nursing home she works at, on the Dignity in Action Facebook page:

<https://www.facebook.com/groups/289089744481097/>

Janice's poster is an example of the effectiveness of a few words, when those words are carefully thought out:

OUR RESIDENTS DO NOT LIVE IN OUR WORKPLACE.

WE WORK IN THEIR HOME. **By Janice Trelore: posted on Facebook**

Of course, even if the 'writing of' guidance is perfect, there is still the question of whether the 'instruction' inside the guidance is right: and there, serious issues of 'perspective' come into play. This is especially problematic when doctors [and nurses] apply our law for mentally-capable patients, because most

doctors have a strong desire to achieve 'good outcomes', [but our laws are framed not in terms of the assessment of outcomes, but in terms of definition of the decision-maker](#).

A 'Piece of Weirdness' - the Mental Capacity Act's position on 'good outcomes'.

This, seems to be all true, so far as I can see.

The law requires that any challenge to a patient's mental capacity is made before any discussion of the actual treatment begins – if the patient isn't 'proven to lack capacity' then the patient can make a foolish or self-destructive decision, and the 'stupidity of the decision' must **not** be used to challenge the patient's mental capacity.

But if the patient lacks mental capacity, some other person decides – and there is a 'sort of idea' that 'what is best for the patient' should guide the decision. But – and this is 'logically true' - the law still wants the patient's 'individuality' to guide the decision: you cannot simply decide 'we should do whatever leads to the best clinical outcome'.

So, 'the best clinical outcome' is always no more than a factor during decision-making: it is never legitimately 'the thing the decision is based on' - it is more correct to suggest that 'the patient's individuality is the thing the decision is based on'.

This legal situation – made very clear [when a judge explained](#) that a suicidal patient could not be legally treated against his will, because he seemed to be mentally capable – clashes with concepts such as 'clinicians having a duty of care' and also with 'medical paternalism'. But, our law has settled on this approach of being clear that mentally-capable patients decide whether to accept or refuse an offered treatment, or as I usually express this:

'Mentally-capable patients do not make decisions 'in their own best interests' - they just decide'.

I have described this 'destruction/removal' of the concept of 'duty of care' by our law's adoption of patient autonomy (which can also be called Informed Consent) in [a short BMJ piece](#).

THE PROBLEMS WHICH NEED TO BE SORTED OUT

I come at these things from my own limited experience and perspective – doctors, nurses and other professionals ‘come at it from different places’. So, this is a list of my positions, and of questions which clinicians and I often answer very differently: these questions, need some sort of agreed answers.

A) At the moment, many (or most) doctors, seem to want to apply ‘medical ethics’ as well as law: not ‘a resort to ethics if the law is unclear’ but the more problematic ‘a resort to ethics when we [doctors] do not approve of where the law leads us’. It is legitimate, and a good thing, ‘for doctors to be guided by a desire to care – it only becomes problematic, if a doctor seeks to use his/her ‘desire to care’ to thwart the patient’s legal right to autonomy’.

Judges have recently, and in increasingly plain and impossible-to-misinterpret language, made it very clear that the law in England (and almost certainly in the UK as a whole) is Informed Consent: the role of doctors is to provide clinical information, and **the patient is the decision-maker in Informed Consent**. Judges have also made it clear, that there is now an expectation that clinicians will be open and honest with patients. This is the background to recent court cases, which have effectively told doctors that they should explain to patients, or family/friends, when cardiopulmonary resuscitation (CPR) will not be attempted ‘because it could not succeed’. This was never part of our law – because our law never required that a treatment which could not be clinically successful, should be offered. But it causes enormous upset to patients and families, when they discover ‘do not resuscitate orders’ (DNACPR) which they had not been told about.

David Oliver and some other doctors, [have suggested](#) that these court rulings which are trying to make doctors inform patients when medical opinion is that CPR could not succeed, [will have the perverse real-world consequence](#) of impeding discussions about DNACPR – I’m tempted to ‘throw my arms in the air’ and shout ‘so what the heck are the judges supposed to do, when doctors are ignoring the law !’. There is also [a case to be made](#), that in many situations not discussing CPR equates to ‘culpable negligence’ of some sort.

Informed Consent does not require a perfect understanding of consequences on the part of the patient (as some doctors mistakenly think it does), [it simply requires that the clinical consequences of the patient’s decision\(s\) are explained in as clear terms](#), by the clinicians to inform the patient’s decision-making, as is possible at the time.

So, we need to get everyone to apply, and to stop trying to impede, Informed Consent. **We all need to be** [‘using the same rules’](#).

B) There is something – either rampant confusion, or something else which I’m not clear about – going on, which afflicts the patient autonomy inherent in the law’s Informed Consent, and is especially problematic for Advance Decisions. It is an absurd ‘implication’ that a treatment is refused because of the clinical events which made the treatment ‘necessary’ - in fact the decision-maker

would consider the outcomes: you decide whether or not to accept a treatment, **by considering the future** with and without the treatment.

This is particularly problematic with decisions for CPR, when there is also conflation between 'should CPR be attempted ?' and 'if the patient died could the death be certified ?'. There is also a serious problem with the concepts of 'expected' and 'unexpected/sudden' death, which is strongly connected to 'the CPR problem'.

It isn't easy to briefly describe this set of interconnected problems, around cardiopulmonary resuscitation – but I have described the problems in pieces such as these:

<http://www.bmj.com/content/348/bmj.g4094/rr/702748>

<http://www.bmj.com/content/348/bmj.g4094/rr/703333>

<http://www.bmj.com/content/350/bmj.h2640/rr-0>

<http://www.bmj.com/content/350/bmj.h2640/rr-2>

<http://www.bmj.com/content/350/bmj.h2157/rr-1>

<http://www.bmj.com/content/350/bmj.h2877/rr>

<http://www.bmj.com/content/352/bmj.i1494/rr-3>

There is a really serious problem with Advance Decisions which needs to be resolved. It is the problem I call 'the Alan and Liz scenario'. Basically, Alan wants to refuse any attempt at CPR, if his heart stops beating while he is in his own home – he 'prefers the certainty of being dead, to the very uncertain future he would face if CPR re-started his heart'. But, it is 'living with serious illness and disability' that Alan is trying to avoid. So he would want treatment if he collapsed but would 'live on if untreated', if being treated would result in less clinical damage. So, if he had collapsed, and the cause was a stroke which wouldn't kill him, Alan would want active treatment to prevent as much clinical damage as possible. Alan explains this to his wife, Liz – and as Liz isn't a clinician, she will need to call 999 if Alan collapses.

In theory, if Alan writes an Advance Decision which forbids attempted CPR 'if my heart has stopped beating, from any cause' it should prevent 999 paramedics from attempting CPR – [in reality is probably wouldn't stop 999 paramedics from attempting CPR](#) (the Alan and Liz scenario appears a little way in as QUESTION 1), and **this needs sorting out urgently.**

There is also [a very serious problem, with the behaviour by police after certain Home End-of-Life Deaths](#), and **this also needs sorting out urgently.**

C) We need to come to an agreement, about two further things, which interplay. They are:

* **Are family carers to be treated as honest by default, and as full members of the patient's support team ?**; and

* **Who, the professionals, or the family and friends who know the patient as an individual, is logically the best-placed to 'make section-4 MCA best-interests decisions ?'.**

It seems clear to me, that best-interests decision-making fundamentally requires the application (**we are not clear how**) of an understanding of the patient as an individual: and that this understanding is applied to the clinical situation of the patient. That is consistent with the people best-placed to make best-interests decisions, being the family and friends who understand the patient (put another way, it seems to me that there cannot be an application of section 4(6) of the MCA, by a person who doesn't 'understand the patient as an individual').

If the professionals do not 'trust the integrity' of the family and friends, or the family and friends doubt the clinical competence of the clinicians, it becomes very problematic. I am deeply offended personally, by this 'attitude that the family can legitimately be distrusted', and I make that very plain in pieces such as:

<http://www.bmj.com/content/352/bmj.i996/rr-6>

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=859&forumID=45

<http://www.bmj.com/content/350/bmj.h3181/rr>

In the second of those, I wrote:

If an elderly patient 'dies suddenly' at home, you tend to have police involvement, and the police tend to 'interrogate' the live-with relatives. This leads to worse, and stronger, memories of the death, for those relatives.

If a clinically identical elderly patient 'dies suddenly' in hospital, I feel sure that the police are not summoned to the hospital to 'interrogate' the nurses on the ward.

Neither death can be 'certified without some investigation [into its cause] and/or discussion with the coroner' - but the deaths are essentially identical.

SO HOW COME THE RELATIVES ARE TREATED AS SUSPECTS BUT THE NURSES ARE NOT ?

But we can be 100% certain of one thing: the professionals are **not** 'the experts for best-interests decision-making'. And we can be certain that the

possession of clinical expertise, is **not** a requirement in a best-interests decision-maker. We know those things, because of the MCA's provision for the appointment of normal, not clinically or legally trained, people as Welfare Attorneys, and the decision-making authority given to Welfare Attorneys by section 6(6) of the MCA.

D) There are many court cases, where 'who said what to who' is really unclear. This is **not** satisfactory during end-of-life.

The obvious solution, is to get more 'lay signatures' inside 'the official records' - and that would also clean up some legal flaws (such as DNACPR best-interests decisions made by a Welfare Attorney, but 'signed off by' a doctor [clearly legally incorrect !]). See:

<http://www.bmj.com/content/352/bmj.i26/rr-5>

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=705&forumID=45

There is also the thing I described in 'Both Parties to a Story need to Tell It' at:

<http://www.bmj.com/content/351/bmj.h4259/rr>

E) There is still some work to be done, before people properly understand the Mental Capacity Act. One notable 'piece of confusion' is the widely-held **but clearly incorrect belief** that 'a verbal refusal of CPR is not legally binding'. See my pieces:

<http://www.bmj.com/content/350/bmj.h2877/rr>

and my 11/04/13 - 13:32 addition in my piece at:

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

F) **The tendency to 'design behaviour which suits the professionals and then force patients to fit in' has to be swung more towards 'designing behaviour which responds to the needs of patients and making services fit that'.**

See, for example, my piece about 'single main family carers' and EpaCCS:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=804&forumID=45

G) I admit to becoming 'increasingly vexed' by this one: **we need to stop deliberately promoting 'advance statements' and instead we should be strongly promoting Advance Decisions.**

I explain why in my piece at:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=814&forumID=45

The fundamental 'issue' here, is that because professionals seem to think 'we make the decisions in the end', but there are lots of professionals who become involved who logically cannot defend their ability to make the decision, 'the professionals go down the wrong track'.

The MCA contains an implied legal duty, to become very familiar with individual patients, so that if you are faced with a decision to make in the future, you can apply the 'best-interests principles': **but that does not equate to 'making best-interests decisions in advance'**. Only patients can make decisions in advance and project these decisions into the future – that is why 'Advance Decision' are so titled.

There is also an interesting argument, **about whether someone such as a 999 paramedic can legally make an MCA best-interests decision.** I consider the answer to be 'no – the paramedic cannot understand enough about the patient as an individual, to comply with 4(9). I **believe that a family carer who called 999 often could claim to have defensibly made a best-interests decision, if informed of the clinical situation by the attending paramedic.**

There is also nothing in the MCA, to suggest it does not apply 'during emergencies' – so, if you are subject to the MCA, you should not be trying to defend your actions 'using necessity'. This does lead to something both obvious, logical, and 'very annoying when debating who should do what with the NHS' – it leads to:

A family carer involved with a known terminally-diagnosed patient, has a duty to act according to the MCA (because the ongoing involvement with the patient, places a duty to 'think ahead' and to be prepared to consider section 4 of the MCA 'if an 'emergency' occurs') – but a 999 Paramedic, or an A&E doctor, who becomes involved, cannot have had the opportunity to 'prepare in advance' and, therefore, cannot either make best-interests decisions, or be 'subject to the MCA'.

I have explained this in detail, in 'Poser no 11' within my 'poser series' at:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=692&forumID=45

The 'guts of' the argument, posed as questions, are:

Should decisions be made by whomever is logically the best-qualified to make the decision, when several potential decision-makers are present at the same time ?

The legal defence of 'necessity' is based on 'justifiable ignorance'.

The legal protection the MCA offers to a decision-maker, is based on the application of an 'adequate understanding of the situation' and the ACQUISITION OF THAT UNDERSTANDING is an 'implied duty' within the Act.

If an unconscious patient arrives at A&E unaccompanied, necessity has to apply.

If an unconscious patient arrives at A&E accompanied by a family carer, the question is does the family carer's understanding of the situation make an application of 'necessity' inappropriate ?

If a patient who is on some sort of 'EoL register' collapses at home, and a family carer calls 999 to be more certain of the medical situation, isn't the family carer's decision about what should happen next (a decision, which the carer MUST defend in terms of the MCA's test - as a long-term carer for the patient, a failure to satisfy 4(9) of the Act 'would be negligence') logically 'better' than any decision made by a 999 paramedic which would be defended by 'necessity' ?

PUT SIMPLY, isn't a decision made by the person who understands the situation best (there, the family carer) the best decision available ?

H) We need to allow for - as opposed to ignoring or over-simplifying - the inherent uncertainty within end-of-life.

Everyone needs to stop 'asking for impossible proof and for unknowable knowledge'. For example, if I was one person in a two-person conversation, and the other person collapses and becomes unconscious, I can tell you what I was told during the conversation - **but 'asking me to prove it' is absurd**. And it is equally 'absurd' to seek to 'know why someone died' when typically all you can know is 'are there any **observable signs** to suggest an unnatural death'.

Etc.

I) We need to be clear that mentally-capable patients, 'run their own risks'.

In other words, 'you should not 'safeguard' mentally-capable patients' - the law describes patient autonomy, and you cannot have a law which says 'patients decide which risks to accept' and at the same time 'safeguard patients against those risks'.

An example of where this 'safeguarding mentality' crops up, and to my mind becomes very problematic, is when a mentally-capable person wishes to refuse a possible treatment, **with the assumption** that he will be mentally-incapable at the time the clinicians become involved.

Suppose I want to forbid attempted cardiopulmonary resuscitation (CPR) if I arrest while I'm at home. And assume that I only lose my mental capacity at the time of my arrest. Until that arrest happens, I can change my mind: I can retract any refusal of CPR which I had made, or I can at any time decide to refuse CPR. In this situation, I would need to create a written Advance Decision refusing CPR – such a written ADRT has to be witnessed, but not witnessed by a clinician or a lawyer. That is all I can do – I can only write my ADRT, sign it, get it witnessed, and try to ensure that any attending paramedic would be able to read it, by, for example, making sure that anyone living with me, knew where the ADRT was kept.

But attending 999 Paramedics, seem deeply unhappy with this type of 'new to them and not 'embedded within clinical records'' advance decision: the paramedics tend to 'want to check that signatures are genuine, etc', **so they tend to ignore ADRTs in 'emergencies'**.

But I would have written that ADRT, knowing that 'being in arrest 'is an emergency'' – so what else can I do, to achieve my legal right to forbid attempted CPR ?

I consider that if the ADRT 'looks on the face of it to be valid and applicable' the 999 Paramedics should follow it – the risk of it being followed, surely rests with its author, and not with its reader: but we need to sort out this 'difference of opinion'. People need to know whether their written Advance Decisions will be followed – it is not acceptable to tell people 'you can write an ADRT to ensure your refusal is followed' if 999 Paramedics then do NOT 'accept ADRTs'.

J) The Mental Capacity Act is an essentially 'logical formulation' of a law which is founded on the principle of the decision-making autonomy of mentally-capable patients. It wasn't written, from the perspective of the various clinicians and others who would have to 'interface with' the MCA during their working lives. And it is very difficult to simply 'follow what the Act states' – consequently, many professionals are distorting what the Act actually contains.

In particular, a very 'problematic in practice' aspect of the Act, is that there seems to be no legal requirement for a mentally-capable person, to 'explain why I decided the way I did' – but, as soon as the patient has lost mental-capacity, 'understanding how he used to think' is a fundamental requirement of best-interests decision-making.

I have discussed this issue, in my piece 'My reasons are my own - it is entirely up to me, whether or not I decide to share them':

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=870&forumID=45

And I have discussed something very closely connected, in my piece 'I believe that Advance Decisions should be encouraged but that 'advance statements' should be discouraged':

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=814&forumID=45

A FEW OTHER THINGS

We – we as in 'society' – have made it much more unusual than it once was, for people to die in their own homes: as a consequence, far fewer people these days will have looked after a dying loved-one at home, all of way through to the death.

Consequently many people – and I include people such as police officers, clinicians who work in hospitals and surprisingly even some 999 paramedics – seem to have little understanding of how complex the discussions and communications within the patient/family/GP/district nurses group surrounding and supporting the patient is, nor do some professionals seem to understand that a series of 'compromises' tend to occur, which often 'look and seem right' to the people inside that patient/family/GP/DN group, but which might seem 'strange and wrong' to anyone outside of that group.

My conclusion from this, is that 'process-based behaviour' might be satisfactory and successful within a hospital, **but it can never be satisfactory for end-of-life at home**. 'The professionals/policy writers' see 'the answer' as 'more 'tick box' guidance' but I see the answer as less guidance and an entirely different approach – an approach which I call 'the Core Care Team'.

You can find something about the Core Care Team as 'poser no 8' in my series at:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=692&forumID=45

My differences with the professionals, seem to come from our different perspectives – not easy to 'summarise', but for example see my pieces [here](#) and [here](#).

CONCLUSION

There needs to be both a 'tidying up' of some legal issues, but also a much

more co-operative attitude between the family and friends on the lay side, and the doctors, nurses and other clinicians on the professional side, if the support of dying patients is to be improved. We need to arrive at a situation where there is more 'mutual trust', more 'consensus', and more 'perspective-balance' within behaviour.

And we all – patients, doctors, family, friends, nurses, paramedics, etc – need to be talking to each other, so that we can better understand the issues which need to be addressed: without that 'talking to each other' you end up with 'silo perspectives and silo thinking'.

I have no idea if anybody will read this, or if anybody does read it, whether it will be 'at all useful'. But I say to anyone trying to improve end-of-life behaviour, 'well done',

Mike Stone July 2016