

Some comments on a paper about euthanasia and assisted-suicide

A week or so ago, Dr Mark Taubert tweeted a link to a paper by Irene Tuffrey-Wijne, Leopold Curfs, Ilora Finlay and Sheila Hollins. The [paper](#) is titled 'Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012-2016)'.

Mark commented on Table 1 in the paper (please note: for the rest of this piece I will use 'the paper' to indicate that paper by Tuffrey-Wijne et al), and as it happens I have read the paper without reading all of table 1 - I will be making some comments, one 'quite personal', about the paper in the context of the Mental Capacity Act (MCA).

My Approach in this piece

I do not often stray into assisted-suicide and euthanasia, and when I do, my thinking is inevitably influenced by my views on what I do normally write about: end-of-life, cardiopulmonary resuscitation (CPR) and the meaning and application of the MCA. It is worth pointing out, that my interpretation of 'what the MCA says' is not identical to the interpretation of many clinicians.

So, this piece will discuss assisted-suicide and euthanasia (the paper uses the composite term 'EAS') in the context of the MCA, and I will seek to examine this question:

If England had a law legalising assisted-suicide and/or euthanasia, then for the law to be consistent with the MCA, what 'properties or principles' would the EAS law need to contain?

England does not have such a law, but we do have court rulings which apply the MCA to 'life-sustaining treatments' and in particular to the withdrawal of clinically-assisted nutrition and hydration (CANH) and to CPR. I have collated some such court rulings [here](#).

There are also 'tricky issues' within the MCA, and those issues are reflected within the EAS paper: I will discuss some of those issues within my comments on the paper.

The MCA as it applies during capacity

The MCA and also the Dutch law, involve the issue of capacity to make decisions: if for a moment we treat EAS 'as if it were a treatment' then presumably the principle so clearly expressed by Mr Justice MacDonald in [this](#) case would also

be applied to any English EAS law. In the case a woman was refusing life-sustaining treatment, and Mr Justice MacDonald's words were very clear indeed:

The decision C has reached to refuse dialysis can be characterised as an unwise one. That C considers that the prospect of growing old, the fear of living with fewer material possessions and the fear that she has lost, and will not regain, 'her sparkle' outweighs a prognosis that signals continued life will alarm and possibly horrify many, although I am satisfied that the ongoing discomfort of treatment, the fear of chronic illness and the fear of lifelong treatment and lifelong disability are factors that also weigh heavily in the balance for C. C's decision is certainly one that does not accord with the expectations of many in society. Indeed, others in society may consider C's decision to be unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society in general. None of this however is evidence of a lack of capacity. The court being satisfied that, in accordance with the provisions of the Mental Capacity Act 2005, C has capacity to decide whether or not to accept treatment C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists). As a capacitous individual C is, in respect of her own body and mind, sovereign.

So, the MCA does not apply 'societal norms' to the decisions made by patients if a lack of mental-capacity has not been established: '*C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists)*'.

The decision during capacity hinges on '*her own personality and system of values*': so, we come to my first observations about incapacity.

Does the MCA, seek to apply during incapacity a similar concept of 'patient individuality' or does it seek to apply 'societal norms'.

Clearly, it must be one or the other which takes 'priority': put simply, does the trust of the MCA seek to retain the patient's individuality when best-interests decisions are made, or does it seek to impose 'what most patients would chose' during incapacity. This is a question, the answer to which always appeared to be, when I read the MCA in 2009, 'it seeks to apply the patient's individuality'. Although prior to about 2014, I came across court rulings which seemed to apply different principles - notably 'sanctity and preservation of life'. Since 2014, I have increasingly read court rulings which seem to agree with my own position

on what the MCA says. I will mention two such rulings next.

Mr Justice Charles, within a [ruling](#) which in my opinion was unnecessarily long and also 'wandered down several side-roads and pointless detours', explained for the withdrawal of CANH:

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.

About two years previously, I had published a DNACPR Justification Hierarchy [here](#), and on the penultimate page of my PDF I included some notes to the hierarchy:

Note 1 This is not, apparently, a 'genuine' section 4 best interests decision. The reason, is that in this situation there is no plausible reason to doubt the patient's decision - it is the most clearly-understood of all possible refusals from a patient. It isn't relevant if there is a written ADRT, because if the patient is mentally capable until a CPA occurs, his explanation of the meaning of the ADRT defines its meaning: the patient's explanation of what his ADRT means, is superior to anybody else's interpretation of its meaning.

Note 2 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.

Note 3 If CPR would be clinically futile, it will not normally be offered - this is a 'clinical DNACPR' and it is not a section 4 best interests decision, because it is not dependent on the patient's wishes (and section 4(6) of the best interests test, stresses the importance of discovering the patient's likely wishes).

It might not be immediately obvious, but what I wrote in my Note 2 is the same

rationale for the withholding or withdrawal of a potentially life-sustaining treatment: basically, and with a caveat that the MCA's Best Interests is not Substituted Judgement [but see [here](#) for a discussion of that], we both concluded that because of section 4(5) of the MCA, a best-interests decision 'which leads to death' must be very close indeed to the application of substituted judgement.

A very recent [case](#) was somewhat misunderstood on Twitter - some tweeters seemed to believe the judge had said that 'clinically-pointless CPR must be attempted'. Those tweeters misunderstand the difference between 'CPR could not restore life' and 'CPR might restore life, but it it did then the clinical situation of the patient would almost certainly be 'awful' - as the judge explained:

'... key to the decision must be the wishes and feelings of HB and it is plain that administering CPR in the event of a further collapse and giving her, albeit a very, very small chance of life, is what she would wish'.

On page 15 of the paper, there is some mention of 'norms' and values: I believe the correct interpretation of the MCA's position, is that **in theory** the values of a best-interests decision-maker **should have no effect on** the best-interests decision arrived at. Put another way, 'if aware of the same information, and when making a best-interests decision in a particular situation, all best-interests decision-makers should in principle make the same decision: if the situation and the available information is the same, and the objective of best-interests decision-making is contained within the MCA, then the 'best' decision should be invariant across decision-makers'. If the decision-makers can validly influence the best-interests decision - then almost any decision 'is legitimate': which 'is absurd'.

Clearly in reality different best-interests decision-makers can arrive at different decisions - but that should NOT be because the decision-maker is deliberately imposing his or her 'values' on top of the MCA's description of best interests.

There is an interesting 'conceptual problem' within the MCA (and also an interesting logical conclusion about which individuals are best-equipped to make best-interests decisions) which flows from the foundation of MCA best interests on 'the person's individuality'. Section 3 of the MCA, describes capacity in terms of 'understanding the consequences of the decision' and that is reasonably simple to grasp, and to check on. If we only apply section 3 of the MCA, then the following is true, for this very clear if somewhat 'extreme' example:

If a person standing on the roof of a tall building says 'I'm going to jump off, and

fall to my death', then the person is both mentally capable and also suicidal;

If a person standing on the roof of a tall building says 'I'm going to jump off, and fly away', then [unless the person can indeed fly] the person is not mentally capable, and probably isn't suicidal either.

However: there is also a provision for what I will term 'mental illness' to remove capacity, even if the person understands the consequences of the decision – the 'concept' is within section 2 of the MCA, and the 'application' is invariably framed in the context of section 3(1)(c), which says '*to use or weigh that information as part of the process of making the decision*'. In the paper, this issue pops up on page 15. The MCA's complexity rests within the words 'use or weigh [the information]' and the paper refers to 'to weigh up options using reasoning and logic'.

My problem, is the 'circularity' of 'the person's reasoning is affected by a mental disorder, despite the person seeming to understand the consequences of the decision'. In fact, at least one judge, and also the GMC, have stated that capacitous patient's can decide to accept or refuse an offered treatment 'for no reason at all': some GMC guidance (Treatment and care towards the end of life: good practice in decision making' 2010) described the patient's decision-making during capacity using these words in its section 14 (my added italics):

- (c) The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor *or for no reason at all*.

And, setting aside the MCA's basic acceptance that people apply their own 'values and mindsets' to their own decision-making (my 'individuality'), the paper seems to imply [although I might be wrong about his] that during consideration of capacity for EAS 'to weigh up options using reasoning and logic' should be assessed. Well – can logic be used to prove that God does indeed exist?: and, as someone who considers the answer to that question is 'no', does that mean anyone who believes in God would fail the test for capacity?

Now – writing 'personally', and as someone who thinks he could reasonably be described as Asperger-*ish*. On page 3 of the paper, I read:

Autism spectrum disorder is a complex and usually lifelong developmental disorder that can cause problems with thinking, feeling and language, characterised by persistent difficulties with social communication and social interaction [15]. Although autism spectrum disorders are common among people with intellectual disabilities, not all people with autistic spectrum disorder have an intellectual disability. Asperger's syndrome, for example, is a type of autism that is characterised by average or above-average intelligence.

Is it being asserted, that people with Asperger's but without 'an intellectual disability', and bearing in mind that the situation has been described as 'lifelong', cannot be distressed to the point of wanting EAS?

A fundamental 'conceptual issue' with the MCA's description of 'mental disturbance', is 'disturbed from what, exactly?': clearly capacitous people are allowed to change their minds, and as I hope I have illustrated the MCA has moved away from 'what most people would decide, and/or what 'society would 'expect'', to a concept based on the patient's own individuality – an easy concept to work with when Mr Justice Charles applied it to CANH in Briggs, and similarly easy when I consider a cardiopulmonary arrest when the arrest itself is the thing which removes the patient's capacity. Much more difficult, during something like long-term severe dementia, and in my opinion even more so if it is asserted that a non-delusional mental situation (a situation when the person does understand the consequences of the decision) can remove capacity even if the person is of 'above-average intelligence'. The paper touches on this on pages 2 and 13, and I will not discuss it further here, because it does not directly affect the answer to the question I set out to analyse:

If England had a law legalising assisted-suicide and/or euthanasia, then for the law to be consistent with the MCA, what 'properties or principles' would the EAS law need to contain?

An issue with terminology

When I was reading the paper, I couldn't understand why I kept coming across 'EAS' – euthanasia and assisted-suicide. I couldn't understand why we were not being told about the two things, separately. Mark Taubert [tweeted](#) the answer to me:

PAS is where a doctor prescribes/makes available a poison that the individual wanting to commit suicide ingests. Euthanasia is where one individual applies a lethal poison to another, usually via an injection. PAS usually eventl gives way to Euthanasia

And I [tweeted](#) the reason why I had been puzzled by the 'lumping together' of assisted-suicide and euthanasia:

Ah - not the way I distinguish. I distinguish by decision-maker: if the patient decides then it is assisted-suicide, and if the decision-maker is anyone other than the patient it would be 'euthanasia' or (as in Nazi Germany) murder.

So the law in Holland, 'in my terms' is only a law which allows for assisted-suicide, but for the authors (I'm not actually sure if the Dutch law does use two distinct terms or not - and to be honest, I'm not sufficiently motivated to 'dig that out') they have used euthanasia as what I would regard as a sub-division of assisted suicide.

This is getting long enough - and 'ethics can be debated endlessly', something I am not doing here - so I will move to my conclusion as to the answer to the question I posed.

CONCLUSION

In England, assisted-suicide and/or euthanasia are illegal - hence, they cannot be considered to be 'medical interventions' or 'treatments'.

In England, the NHS exists to offer to patients treatments which might be clinically effective, within constraints such as 'can the NHS afford to offer the treatment while being fair to all patients as a whole?'

And: the MCA's best-interests framework, exists to replace consent when consent cannot be validly given - the easiest way to think of best interests in the context of medical interventions is

' ... potentially helpful medical interventions which can be offered, are offered irrespective of the patient's capacity: then, if the patient is capacitous the patient decides, and if the patient lacks the capacity to consent a best-interests decision has to be made to decide if the intervention should be performed'.

It is an obvious [at least to me!] logical conclusion, that if we had a law which allowed assisted-suicide and/or euthanasia to be offered to capacitous patients, **then to be consistent with the MCA is should also be possible to proceed with the intervention on best-interests grounds.**

It is obviously 'trickier' when the patient lacks capacity, as I pointed out in my BMJ piece [here](#):

I feel that I must comment on the response by John Julian Kennedy.

Many of us are [it appears to me, from what I come across in the media] in favour of the principle that individuals should be in control of their own deaths: when applied to end-of-life, and in particular to EoL when patients are suffering or predicted to suffer, this means that we support the concept of [medically] Assisted Suicide. The aspect of that which I support, is the fact that the decision is made by the patient.

If Euthanasia is in any way a different concept - in particular, if it involves any decision-making by someone other than the patient - then my instinct is to be somewhere between 'against the idea' and 'very cautious about the idea'.

This does raise some complex issues, if a long-term seriously demented patient, and a mentally-capable patient, are each apparently suffering intolerably as they near death: I have no problem with the capable patient and 'assisted suicide', but I'm much less happy with any suggestion that the demented patient 'can be euthanised'. It troubles me that the demented patient's intolerable suffering cannot be removed, because of the inability to consent to the termination of his/her life - hence the problem I struggle to resolve.

I fail to understand, why somebody else's ideas about 'pro life' can justify the elongation of my own suffering, if I wish to end my suffering: surely my life is mine. I am not religious.

None of this, is to say that I would want the same doctors and nurses who had been treating me before I decided that I wanted an assisted suicide, to be involved in that assisted suicide - I would not, and I would want different doctors [and, I feel, no nurses at all] involved for my assisted suicide.

When Parliament was discussing the Marris Bill, [I pointed out](#) that its 'safeguards' risked undermining the MCA's principles, where I wrote:

The 'safeguards' in the Marris bill did not protect a mentally-capable person's rights: they effectively constrained the person's right to self-determination in such a way as to take that right away. In particular, a person near the end-of-life would presumably want to be able to chose to end his or her life 'nimply' as and when the situation became 'too distressing to bear' - the Marris bill required far too much 'advance planning' by such a person, and also when our law currently assumes mental capacity, why did a judge need to 'assess that' ? The safeguards fitted distressed but not terminal patients, and they did not sensibly fit 'end-of-life' patients.

For almost a decade after the enactment of the MCA, we had a 'conceptually muddled' and in my opinion deeply unsatisfactory situation, when CANH 'was not viewed as being subject to the principles of the MCA' - fortunately that situation has recently been corrected.

It would not be satisfactory, 'in MCA terms', if, should England enact assisted-suicide and/or euthanasia laws, the provisions of those laws departed from the principles of the MCA, as was the situation with CANH for so long.

In that context, I am concerned that a possible implication or interpretation of the paper, is that for EAS 'decision-making requirements which go beyond, and therefore inevitably conflict with', those described by the MCA would be necessary - I'm already having enough trouble with the MCA without such an added problem to contend with!

Cobbled together by Mike Stone, and almost certainly not adequately proof-read by the author, April 2019

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PS I admit that both my perspective and experience are as a former family-carer during end-of-life, and it is in the context of improving end-of-life that I write, and within which I usually discuss the MCA. So, I am deeply influenced by things such as Reginald H Pyne's 2014 BMJ [rapid response](#) and also by how a friend of mine [died](#).

