

An analysis of the concept of ‘advance care planning’ from first-principles, considered from the patient and family-carer perspective.

Foreword

I look at end-of-life from my perspective as a former family-carer when my own parents were dying, and as a potential patient myself. I am not pleased, by some aspects of what I find, when I read material written by clinicians and other professionals. It will be necessary to start by mentioning something about the Mental Capacity Act which seems to often be ‘sidelined during thinking’, and to explain my own position as a family carer.

Introductory

The Mental Capacity Act (MCA) is often considered to be about the ‘care of’ people who lack the mental capacity to make their own decisions. In fact, the MCA starts by very clearly explaining the rules for mentally-capable people:

- * That mental capacity is assumed present until ‘proven’ absent;
- * That mentally-capable people, once adequately informed, make and express their own decisions [notably, there is an absolute right to refuse interventions such as medical treatments];
- * That the right to refuse treatments, can be projected forwards into future mental incapacity, if the person has considered the future situation.

Only **afterwards**, does the MCA move on and describe the situation when people lack mental capacity: it introduces a ‘best-interests requirement’ which is the replacement during incapacity, for the patient autonomy {also described as self-determination or informed consent: ‘considered refusal’ is a useful way of thinking about a refusal of treatment, because it fits nicely with section 25(4)(c) of the MCA}.

MCA ‘best interests’ is, during incapacity, the replacement for ‘normal consent’ during capacity.

The clearest description of patient autonomy which I have come across, was from Mr Justice MacDonald in a [court ruling](#), where he wrote:

INTRODUCTION

1. A capacitous individual is entitled to decide whether or not to accept medical treatment. The right to refuse treatment extends to declining treatment that would, if administered, save the life of the patient. In *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 102 Lord Donaldson observed that:

“An adult patient who...suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered... This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.”

121. 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.

My Own Position when I was a Family Carer for my Dying Parents

1 I would push for any interventions my loved-one wanted

2 I had **a deep aversion** to 'arguing with my dying loved-one'

3 If my loved-one had lost the capacity to make and express his or her own decisions, I desperately did not want 'the burden' of making life-or-death decisions which would affect my loved-one, so:

3a I tried to make sure that I got the decision from my loved-one if possible, so

3b I spent a lot of time listening, 'enquiring', and 'picking-up-on' the 'wants' of my loved-one

4 Horrible though the burden of making decisions is – see 3 – **one thing would have been even worse**: if I had allowed clinicians to impose on my incapable loved-one, treatments and interventions which I felt sure my loved-one would have refused.

I mentioned 'picking-up-on' in 3b – family and friends do that, and it is what being close to the person means. As Mr Justice Hayden [explained](#) (my added bolds):

53. If ever a court heard a holistic account of a man's character, life, talents and priorities it is this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. **He 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.** I

have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.

During a discussion on Nursing Times (online) a few years ago, someone – probably a nurse – posted this:

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounded by his family.

Now, I cannot actually 'prove' this – but I am of the view that this is how the vast majority of family carers 'come to terms' with the final stages of a loved-one's dying: we pay great attention to discovering what our loved-one wants to happen, and we support our loved-one's decisions.

I recently carried out a Twitter Poll, and the result seems to be in line with my views:

https://twitter.com/MikeStone2_EoL/status/931819196207509504

I asked this question in my poll, and offered 3 answers: 60 people voted, and I show the results:

A mentally-capable adult is 'dying' ['end-of-life' = 'sometime within predicted final year of life'] at home. Who should the family-carers living with their dying loved-one be taking instructions from? Please retweet - an analysis of answers would be 'interesting'.

From the dying patient	92%
From the GP and nurses	2%
From nobody	6%

Total votes cast 60

In an earlier poll on Twitter, I had asked a related question:

https://twitter.com/MikeStone2_EoL/status/919195401898680321

An 82 years old man is diagnosed as terminal. He and his 79 years old wife 'invite clinicians to help while he dies'. Does that invitation of itself, imply that if he loses the ability to make his own decisions, he wants the clinicians, and not his wife, to make them?

Yes it does	8%
No it does not	92%

Total votes cast 79

Why Contemporary guidance around 'making decisions in advance' is flawed.

I have posted a series of linked tweets about 'advance care planning' and the first one is at:

https://twitter.com/MikeStone2_EoL/status/935093494053572615

Where the current clinically-authored guidance, protocols, templates etc, are correct, is in pointing out that things which are under the control of mentally-capable patients – so, Advance Decisions [to refuse treatment] and ACP – can be created and withdrawn **whenever the patient decides to do that.**

However, there is nothing in the law, nor in perspective-balanced-sense-and -logic, so far as I can see, to back-up many of the things which clinicians write, such as:

- * Relatives cannot be the witness to a written ADRT;
- * If you create a written ADRT you should distribute copies [as opposed to distributing the information that the ADRT exists];
- * That things such as DNACPR Forms which are signed only by clinicians, should be followed more readily than Advance Decisions signed by patients: legally, this is very clearly backwards;
- * That a verbal refusal of CPR is 'not legally binding': this is absurd, because **a verbal refusal of CPR is clearly completely legally binding during a situation of continued contact:**

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-the-BBC-Radio-4-broadcasts-about-Mr-C./958/>
(see the second addition to the post at 26/08/17)

<https://www.dignityincare.org.uk/Discuss-and-debate/download/264/> (see the fourth of the short PDFs in that longer PDF, 'There is a problem with Advance Decisions')

- * There is a 'promotion of best-interests decision-making' going on at present, within things such as 'ReSPECT', as well as rampant incorrect description of the MCA: because best-interests decision-making is very complex and often 'fraught', **we should instead be promoting Advance Decisions:**

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-believe-that-Advance-Decisions-should-be-encouraged-but-that-advance-statements-should-be-discouraged/814/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-SCIE-Robyn-and-Anne-scenario-compared-to-my-Alan-and-Liz-scenario-the-essential-difference-between-informed-consent-and-best-interests/865/>

<http://www.bmj.com/content/356/bmj.j876/rr-7>

* Not only is there 'an implication that normal family-carers cannot make best-interests decisions about the provision or withholding of medical interventions' – which is clearly wrong, because lay welfare attorneys acquire on appointment legal authority over those decisions, without having acquired any extra legal or clinical knowledge – but in many situations it isn't even possible to distinguish between a relative and a clinician. For example, a relative who has been taught CPR as first aid, or the very simple situation I discuss in my 'Anne, David and Dr Jones' scenario:

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

https://twitter.com/MikeStone2_EoL/status/906073527236907009

At its Simplest

The point is – and I'll stick with CPR here, because unlike many interventions CPR is really simple: no CPR equals death, and the outcome of attempted CPR is so uncertain as to be virtually impossible to usefully describe.

If I am talking to my GP in my own home, and I make it clear to the GP that 'if I arrest from now on, then whatever is the reason for the arrest, I definitely forbid you from attempting CPR' then unless the GP has some reason to suspect that I've changed my mind, the GP must not attempt CPR. He might say 'you need to create a written ADRT, and I should do a DNACPR', but suppose the GP does say that, and while they are talking about how to do those things, **and the patient arrests**. The GP **UNDERSTANDS THAT** the patient has forbidden CPR – whatever has been written down, he has been told, he understands the refusal, and he has no reason to believe the patient has changed his mind.

Suppose my father, who is sharing a home with me, explains to me at 10pm one evening that he definitely would no longer want CPR, if he arrests under any circumstances. After such a discussion [and I had a similar discussion with my mother] the relative **DEFINITELY KNOWS THAT CPR HAS BEEN FORBIDDEN**. If my father happens to arrest before this decision has been communicated by him to anyone else, then **I STILL KNOW**. *If I also know that should I phone 999 – to confirm that my dad has indeed arrested – that 999 would 'ignore my word' and attempt CPR, then I am in an INTOLERABLE DILEMMA!*

As someone who has listened to one of those 'I don't want any treatment - I want to die now' instructions, I can assure you that 'once you have been told, you know!'.

Unless family-carers and the professionals are working together it isn't possible to properly respect the patient's legal right to self-determination – full stop. Currently the professionals are trying to impose 'behaviour sets' which make life easier for the professionals, and which are **not** 'perspective-balanced'. And fundamentally it is your understanding of the patient's decision which matters - NOT whether it is written down [and during a face-to-face conversation with a patient, you can ask the patient to clarify any uncertainty - you cannot 'ask a written document to clarify itself'].

I wrote a piece last year, which can be downloaded from:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/289/>

I ended it, with something which would enforce change almost overnight: the presence of many more welfare attorneys:

Something which 'rather gives me hope'

I'll finish off now - I could go on (and on, and on, and ...) but by now anybody who isn't already very familiar with the MCA will probably have lost interest, and the people who are deeply interested in the MCA and who are reading this will be few, I suspect.

This is 'the ray of hope'.

The problem, for most family carers, is a combination of two things: one is that the MCA is very difficult to apply if you are a working professional, and the second is that the professionals [incorrectly in my opinion] assert that THEY 'make the decisions'.

If many more people appoint Welfare Attorneys, then this unsatisfactory situation - which amounts to 'we professionals are the experts, and our views are the ones which count' - will be swept away: because it is 100% clear that welfare attorneys are the people 'whose decisions/views count'.

And those welfare attorneys will almost certainly be largely laymen - if I were my father's welfare attorney, why would I 'downplay or disregard' the opinions of my brothers and sisters, etc, and why would I prefer the views of doctors and nurses ?

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This piece is long enough, so I'll finish here, with a few pointers to relevant pieces:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/A-paper-by-Kitzinger-et-al-about-the-Briggs-ruling-and-MCA-best-interests-is-well-worth-reading-and-my-but-if-you-were-a-welfare-attorney-analytical-tricktool./950/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/MCA-Best-Interests-compressed-to-a-single-sentence-an-ansatz/972/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Not-much-point-in-me-going-on-Twitter-saying-something-that-isnt-the-law/959/>

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