I don't know if this will help at all, but I'm prompted to write it to try and address Claud's suggestion that I am selective in how I read the Act, the Act/Code issue, and the test/process issue.

I do (as in 'originally did') not read and memorise the Act word-by-word: I read it, 'extract an understanding from it', then read it again checking if my understanding appears to conflict with anything in it.

I also start from the firm belief that patients can refuse treatments, while I think doctors tend to start from a sort of vague idea that they are in control of treatments (I have no real idea what the police think, if anything).

I also seek 'conceptual clarity' and 'lack of ambiguity in instructions' – in that light, I'll start with 1(2) of the Act:

1(2) A person must be assumed to have capacity unless it is established that he lacks capacity.

I pointed out to Claud, that he had altered this to 'A person should be assumed to have capacity ..' on one of his documents – that is a really serious alteration.

By stating 'must be assumed to have capacity' the Act removes ambiguity: so, for example, if you are reading an ADRT dated 18 months ago, and you are unsure whether the person was mentally capable at that time, then you have to assume the person was mentally capable (until there is definite knowledge that he wasn't). This is enormously significant – it means that the mindset, revealed in some literature/guidance, that 'we need to check on mental capacity' is contrary to the Act: you should check, but prior to the knowledge that someone was/is incapable, you must behave as if they were/are capable.

So 'Was the patient mentally capable when he wrote this ADRT ?' isn't a legitimate question for a 999 paramedic to consider (because there will not be any time to check up on that – and if you can't check, capacity is assumed to exist).

Now, **as a whole** the Act keeps going on about 'the patient making decisions': 1(3), the whole of section 3 and also the provision for Advance Decisions: section 3 in particular sets 'a very low bar' for a person's self-determination {3(1)}, and stresses that you really must try and enable people to make their own decisions {3(2) and 3(3)}.

Why is the Act, which covers incapacity, placing so much emphasis on the person's own decision-making – obviously if the person is making the decision, the Act isn't applying (except for ADRTs) ?

My interpretation: this emphasis is because part of the Act is expressly intended to support patient self-determination, but 'projected into periods of mental incapacity'.

The Act **also** covers long-term mental incapacity, when of course such projection isn't really possible: however, I'm largely concerned with the limited situation of:

EoL patients who are mentally capable either until they arrest or until they lose capacity during their deterioration towards death, and who are in their own homes

Returning to 'conceptual clarity', this idea of 'shared decision making' is conceptually muddled: it is only conceptually clear, if after group discussions there is either:

1) A single decision which is arrived at by a vote of the group's members, or

2) The outcome that each person in the group can legitimately arrive at his own decision after the group discussions.

As it happens, the MCA does not anywhere support 1), it does appear to support 2), and it also has a few situations involving Welfare Attorneys (and for non LSTs Court Deputies) when there is a known 'proxy-judge' (someone whose decision is 'almost' enforceable). The NHS and organisations in general, have a lot of trouble with 2) – but the MCA does lead to 2) in most situations.

The NHS/system falls onto the Code to try and impose a hierarchy for decision-making 'authority' onto situations in which no such hierarchy exists, by claiming without proof that clinicians can make decisions about the provision of treatments while normal relatives cannot do that – this cannot be proved by reference to the Act itself, and it implies that a live-with relative is not obliged to follow section 4. In my Father and Son scenario, the son has been told something by his father that has not yet been communicated to anyone else – he has to either call 999, or not call 999, etc, and if the son is subject to the Act, then

1(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

must apply when the son decides whether to call (act done) or not (decision made). If we consider the Act applies at all, as opposed to believing that in Father and Son it is 'simple direct self-determination being followed by the son'.

Staying with 'conceptual clarity', Claud seems to not quite appreciate why I am 'so picky' about the words 'valid' and 'applicable' in connection with Advance Decisions. By contrast, I feel certain that Carol understands 100% why I 'get technical' about valid and applicable.

The point is, sections 24 – 26 very clearly explain the meaning of valid and applicable.

'Valid' simply indicates things which are necessary for an ADRT to be 'prima facie in existence' – if things such as signatures are present, it is not the reader's job to start investigating their validity, etc, if there is no time to do that: if a 999 paramedic is shown an ADRT that appears to be signed and witnessed, then in terms of signatures it is valid.

Also, there is no concept that any person can 'validate' an ADRT (a court, possibly – a GP or hospital doctor, no).

The main point about 'applicable' is section 25(4)(c), which clearly explains that only circumstances the patient would have considered are relevant – this 'you must attempt CPR if you know the death could not be certified' is nonsense ! **25(4)(c) is again, very clearly, going back to the fundamental principle of patient self-determination.**

Also on 'clarity', section 42 of the Act is much misunderstood in terms of its implications (and I would point out that section 4(5) is not so much as misunderstood, as not dealt with at all in current writings) but the GMC's 'Treatment and care towards the end of life: good practice in decision making' is interesting, if read in conjunction with its draft version. Covering disagreements during incapacity, the draft version had this:

42. You should aim to reach a consensus about what treatment and care would be of overall benefit to the patient. If disagreements arise, either between those close to a patient and the healthcare team, or between you and other members of the healthcare team, and they cannot be resolved through informal processes or independent review (*Consent: patients and doctors making decisions together* paragraph 77), you must seek legal advice about applying to the appropriate court or statutory body for a ruling. You should alert, as early as possible, the patient or those acting for them and those with an interest in their welfare, so that they have the opportunity to participate or be represented.

But the final version of the guidance, had instead these:

47 You should aim to reach a consensus about what treatment and care would be of overall benefit to a patient who lacks capacity. Disagreements may arise between you and those close to the patient, or between you and members of the healthcare team, or between the healthcare team and those close to the patient. Depending on the seriousness of any disagreement, it is usually possible to resolve it; for example, by involving an independent advocate, seeking advice from a more experienced colleague, obtaining a second opinion, holding a case conference, or using local mediation services. In working towards a consensus, you should take into account the different decision-making roles and authority of those you consult, and the legal framework for resolving disagreements.

48 If, having taken these steps, there is still significant disagreement, you

should seek legal advice on applying to the appropriate statutory body for review (Scotland) or appropriate court for an independent ruling. The patient, those authorised to act for them and those close to them should be informed, as early as possible, of any decision to start such proceedings, so that they have the opportunity to participate or be represented.

It is worth thinking about that – why did one section, become two sections in the final version ?

Look at where they differ:

42 implies that if a doctor is in disagreement with other members of the healthcare team, the doctor must seek legal advice about applying for a court ruling.

But 47 deals with attempting to reach a consensus, then in 48 there is no direct mention of the rest of the MDT – actually, the (practical) consequence of section 42 of the MCA is that the senior clinician can impose a sort of 'pseudo-legal authority' over the other members of the MDT, but **not** over normal relatives and friends (as for 'those authorised to act for the patient' then if that is a suitably-empowered Welfare Attorney, it is the WA who is doing the consulting here, not the doctor).

This is getting lengthy, so I will finish with a comment that not only is the Act complex, but **in parts it is demonstrably wrong**.

This section, is incorrect:

1(5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

We know that is incorrect, because the Act tells us it is incorrect – the Act includes the sections covering Advance Decisions, and we know that following an Advance Decision does not involve a best interests decision (because we know that best interests means in accordance with section 4, and section 5(4) is excluding Advance Decisions from the best interests requirement of the Act).

I only pointed that out, in case it might help with my 'DNACPR Justification no 1 does sit at the top, even thought it isn't an ADRT or a section 4 decision' issue – but it probably won't !

Best wishes, Mike

Further to the above

As I think I have pointed out, I start from this basic set of beliefs:

a) Patients have the right to refuse treatments (at the time or in anticipation)

b) Clinicians decide what treatments to offer

c) Relatives will usually be supporting the choices/wishes of their dying loved ones

I would also add in this one, as 'something that should be true': as GPs provide NHS care, as do DNs, and Ambulance Services are NHS Trusts, then **it is legitimate for patients and relatives to see all of those professionals as being part of a single system.**

So, going back to the Thinking Clearly series, as Alan and Liz clearly do have a legal right to refuse future CPR, the surviving spouse must surely have a reasonable expectation to not be harassed by the police simply because his/her partner has refused CPR even if the arrest is 'sudden', and it isn't at all clear what else Alan and Liz are able to do other than to go and ask their GPs how to achieve their objectives, what Claud writes strikes me as 'systemically defective or negligent':

> As Alan has arrested the paramedics do not have time to run through the required checks of the best interests process or check the validity of the LPA order and they are likely to start CPR.
>
> However, many ambulance Trusts send out a second team for arrests and that extra paramedic can look through the documentation. If they confirm this is the correct type of LPA they can stop CPR and/or not admit Alan to hospital.

It isn't for 999 paramedics to prevent the self-determination of Alan/Liz by questioning the validity of things that are prima facie correct - writing into protocols such behaviour, amounts to a systemic undermining of the patient's right to refuse a treatment. As Carol stated in an E-mail:

> Point 1 - the MCA does not ask anyone to prove or disprove the validity of an advance decision. It is not for the health professional to do this - unless there are actions or comments that cause a high index of suspicion and then they refer to the police or coroner; but not at the time of delivering care. So unless everyone is going to undergo CPR because the default stance by paramedics .

is that everyone is behaving in a way that causes suspicion about the patients death is crazy and unworkable. I hope you understand this Mike as I know what I mean but may not be making myself clear.

In essence health professionals have to work on trust, if we find out after the fact that a relative told an untruth then we should report it to the Coroner who decides whether or not to get involved. However we would only know if we have been misled if the relative themselves told us or another relative vented concerns, if the latter happens we refer the relative to the coroner for them to have a discussion.

This is the academic argument around the MCA in that we do not know whether or not a third party is in actual fact expressing the wishes/beliefs of the patient - we just have to trust that they are. Also a written directive - it is not up to us to prove or disprove the validity of a signature. As the MCA states a directive can be in any written form, so now we see why it would be better to have one drawn up by a solicitor.

As people all work differently and put their own interpretations on things this may be difficult to address. However I do agree that there is not enough knowledge about the MCA out there and this is what does need addressing.

The NCEPOD Chair (a lawyer) sees this failure to anticipate a future event as tantamount to systemic legal culpability by negligence, and so do I - from the 'Time to Intervene ?' report's Foreword:

> It was in the hope of finding out how far that ethical obligation sounds in modern medical practice that I approached this report. Alas, the results are profoundly disappointing and as I read these pages I wondered how many of these interventions would be defensible if charged as assaults before the criminal courts, or as professional misconduct before the GMC. The GMC recognises that CPR should be administered in an emergency, but it is not good medical practice to fail to anticipate the needs of the patient before an emergency arises. If the failure is deliberate or reckless then I suggest that it is arguably criminal.