Inspired by something Lucy Series tweeted

Lucy series posted a tweet which I definitely had an issue with:

https://twitter.com/TheSmallPlaces/status/1103944978223505408

The tweet said:

Basically, what I'm pondering is whether - absent legislative efforts to better implement supported decision making - we could hack deputyship (or even LPAs) so that a person not only chooses who supports/acts for them, but they must give effect to their wishes?

I promptly tweeted back (if you go the URL above, the series of tweets should come up):

ABSOLUTELY NOT! Attorneys and deputies are clearly - MCA 6(6) - primarily intended to make any necessary best-interests decisions: 'instructions' should be in the 'patient autonomy' side of the MCA (i.e. ADRTs) and we should NOT conflate the two aspects of decision-making!

After some fragmented discussion on Twitter, which included from Lucy:

LPAs were envisioned as a more flexible means to give effect to P's autonomy. Attorneys are subject to *both* the principles of the MCA and "any conditions or restrictions specified in the instrument" http://www.legislation.gov.uk/ukpga/2005/9/part/1/crossheading/lasting-powers-of-attorney …

and from me:

I note 'envisioned' - but surely we need to work with what was enacted? If you leave LPA 7 blank [and apparently most people do] then you instruct people via ADRTs, and you EXPLAIN TO your attorney what you would want [if everything is to be written - why do we need attorneys?].

I asked Lucy:

@TheSmallPlaces Lucy - WHY do you think there is a need, for 'binding instructions' on attorneys? What 'is your context' [and is it a very different context, than why I want attorneys {to make the best-interests decisions 'during 'emergencies''}?

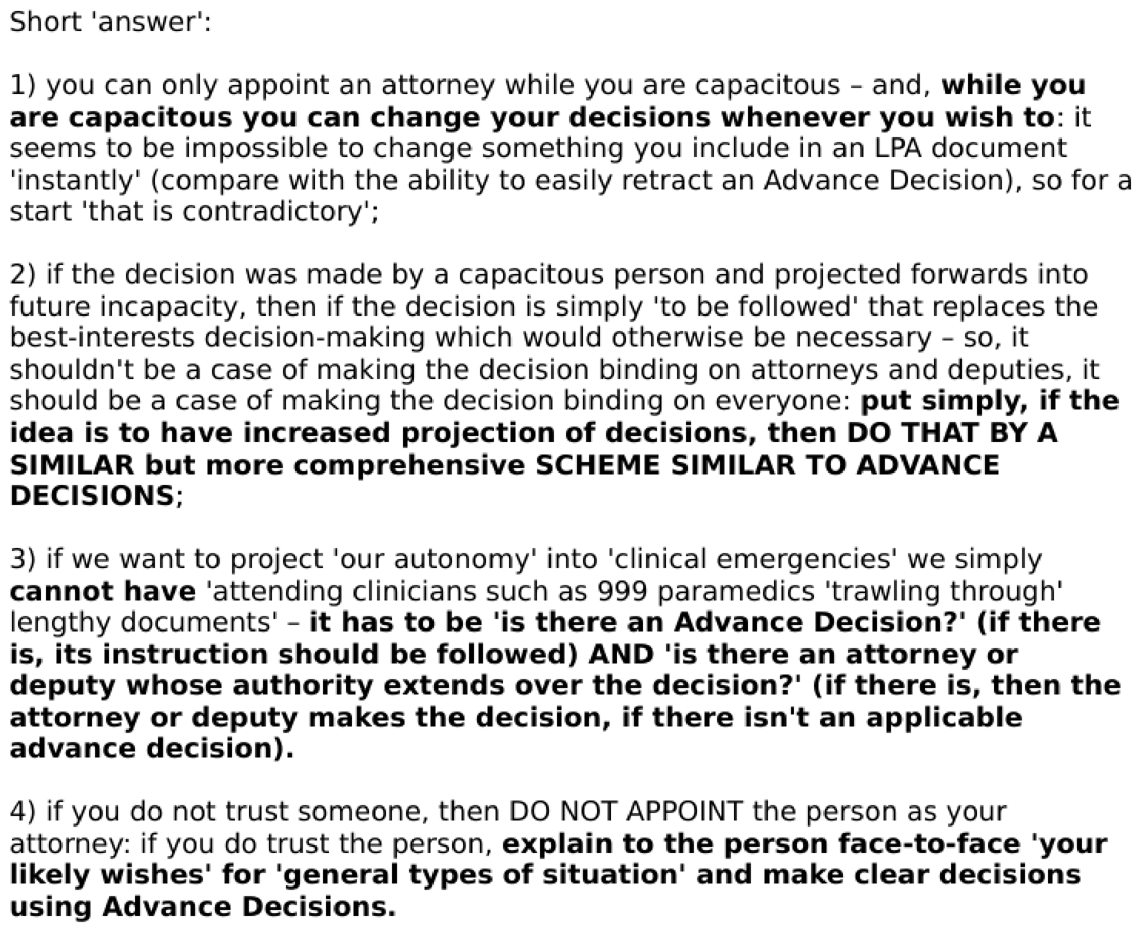
Lucy replied:

Because I'm interested in whether we can create mechanisms analogous to co-decision making agreements via LPAs (or deputyship), where decisions must be made jointly with P. And whether people can instruct attorneys to make decisions others might regard as not in best interests

During the tweets, I had posted a 'text image' which outlined my basic position on this issue of why we need attorneys and deputies – from my 'end-of-life at home' perspective:

https://twitter.com/MikeStone2_EoL/status/1104011780861370370

The short analysis of this - see also https://www.bmj.com/content/352/bmj.i26/rr-16 … and the letter from the OPG at 19/10/18 in the thread at https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mike-Stones-PDFs-I-hope-to-post-various-PDFs-about-EoLMCACPR-in-this-thread/944/ … And also my PDF at https://www.dignityincare.org.uk/Discuss-and-debate/download/337/ … @KitzingerCelia @TorButlerCole @DrMarkTaubert @JennyKitzinger



Short 'answer':

1) you can only appoint an attorney while you are capacitous – and, **while you are capacitous you can change your decisions whenever you wish to**: it seems to be impossible to change something you include in an LPA document 'instantly' (compare with the ability to easily retract an Advance Decision), so for a start 'that is contradictory';

2) if the decision was made by a capacitous person and projected forwards into future incapacity, then if the decision is simply 'to be followed' that replaces the best-interests decision-making which would otherwise be necessary – so, it shouldn't be a case of making the decision binding on attorneys and deputies, it should be a case of making the decision binding on everyone: **put simply, if the idea is to have increased projection of decisions, then DO THAT BY A SIMILAR but more comprehensive SCHEME SIMILAR TO ADVANCE DECISIONS**;

3) if we want to project 'our autonomy' into 'clinical emergencies' we simply **cannot have** 'attending clinicians such as 999 paramedics 'trawling through' lengthy documents' – **it has to be 'is there an Advance Decision?' (if there is, its instruction should be followed) AND 'is there an attorney or deputy whose authority extends over the decision?' (if there is, then the attorney or deputy makes the decision, if there isn't an applicable advance decision).**

4) if you do not trust someone, then DO NOT APPOINT the person as your attorney: if you do trust the person, **explain to the person face-to-face 'your likely wishes' for 'general types of situation' and make clear decisions using Advance Decisions.**

Then, I asked Lucy if it was situations such as my 'Anne, David and Dr Jones' scenario that she was thinking about (here and here), and I also asked Lucy was she thinking of situations when the patient/person was capacitous, or when the patient/person lacked capacity.

Then, the next morning, it occurred to me that by analysing 'Anne, David and Dr Jones' and 'tweaks' to the scenario, it is reasonably to 'investigate' Lucy's suggestion.

I have analysed the original scenario online, so here I will only restate the essentials, after showing the original scenario.

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 ?

In the original scenario, it would be perverse to assert that Anne is capacitous for the decision when both her husband and her GP consider she clearly is not – so we can move directly to the decision-making.

The Mental Capacity Act (MCA) is very clear – all decisions which are 'MCA decisions' should be made in compliance with section 4 of the MCA, which is to say 'should be best-interests decisions'. If we read MCA section 4, it is obvious that there are only two people who might be able to make a satisfactory best-interests decision in this scenario: David, and [perhaps] Dr Jones:

4(6) He 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.

4(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

It is also clear – even if most doctors appear to be unable to grasp this – that neither David nor Dr Jones can 'impose their best-interests decision on other people' in this situation, because such legal authority is only given by section 6(6), and that section does not apply in my scenario:

6(6) Section 5 does not authorise a person to do an act which conflicts with a decision made, within the scope of his authority and in accordance with this Part, by—
  (a) a donee of a lasting power of attorney granted by P, or
  (b) a deputy appointed for P by the court.

6(7) But nothing in subsection (6) stops a person—
  (a) providing life-sustaining treatment, or
  (b) doing any act which he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.

It is important to note that there are different types of decision being made here: the doctor offers the tablet because it would be effective on clinical grounds (so nothing to do with the MCA) and the tablet 'is funded' [assume by the NHS – which now means 'by the CCG' as I understand it]). But whether or not Anne should take the tablet, is an MCA best-interests decision. And, if you read the sections of the MCA which I have shown (note in 4(9) 'In the case of an act done, or a decision made, by a person other than the court') then logically you should arrive at what I wrote in a BMJ rapid response – please note the text I have italicised here:

https://www.bmj.com/content/352/bmj.i222/rr-0

If there is not an attorney or deputy with the powers described in section 6(6) of the Act, then in my opinion the Act does not give any person decision-making authority: but, it does impose the duty to comply with section 4(9) on anyone who makes a decision. Section 42 somewhat complicates this, but only by allowing senior clinicians to lead the bahaviour of more junior clinicians (actually, section 42 is clearly potentially problematic in application).

Compliance with 4(9), requires that the guidance available from section 4 is applied by any decision maker: and, section 4(6) of the Act does not explain exactly 'what best interests means' but it does link the concept to 'the patient's individuality'. The people who understand the patient as an individual, are the patient's close family and friends - this is presumably why the COP 'increasingly prefers the relatives' view of best interests to those of the medical profession'. Danbury's phrasing there is interesting - 'the relatives' view(s) of best interests' - because I have always claimed that the relatives are indeed 'expressing best interests decisions' [which, however, cannot be imposed on others] while traditionally clinical authors have claimed that 'the relatives contribute information which the best-interests decision-maker then considers'.

If we adopt my position, that unless somebody is empowered by section 6(6) everyone should be contributing whatever they can to the formation of the best possible best-interests decision (clinicians contribute clinical prognoses, family and friends individually answer the crucial question of 'what would the patient have decided ?'), and with luck a unanimous decision emerges, then that unanimous decision is the one to be adopted by everyone. But, if there isn't unanimity, where does 'mediation' fit in ? *An honest consideration of section 4 of the Act, first requires a person to answer the question 'Am I sufficiently well-informed to properly consider section 4, and thereby to defensibly claim compliance with section 4(9) ?'. If the answer is no, you would not be involved in 'mediation' [about 'what is the best best-interests decision']. If the answer is 'yes', then your own best-interests decision is the one you must follow: that is obvious, from the wording of 4(9).*

So – without someone given authority over best-interests decisions by 6(6) [and if we are only considering the interactions between clinicians and laymen, so that section 42 is irrelevant], there is a disagreement between David and Dr Jones, which can only be resolved by either them coming to an agreement, or by a court ruling being sought and obtained.

TWEAK No 1

If David has been appointed as Anne's Welfare Attorney ('LPA'), or as Anne's Court Deputy, then provided the administration of the tablet is within the scope of David's powers, it is clearly true that sections 6(6) and 6(7) are applicable: in this case, it is David who decides whether it is in Anne's best interests for the tablet to be taken by Anne.

I see nothing 'complex' about that – sections 6(6) and 6(7) are very clear, and those sections are correctly 'translated' in the current version of the MCA's Code of Practice:

> 7.29 Attorneys must always follow the Act's principles and make decisions in the donor's best interests. If healthcare staff disagree with the attorney's assessment of best interests, they should discuss the case with other medical experts and/or get a formal second opinion. Then they should discuss the matter further with the attorney. If they cannot settle the disagreement, they can apply to the Court of Protection (see paragraphs 7.45–7.49 below). While the court is coming to a decision, healthcare staff can give life-sustaining treatment to prolong the donor's life or stop their condition getting worse.

Note: if the best-interests decision decision about the administration of the tablet is not within the powers of the attorney or deputy, then we go back to the impasse of the original scenario: it is **NOT** as so many clinicians appear to believe 'unless there is a suitably-empowered attorney or deputy, the best-interests decision falls to the clinician' – **IT IS** 'an individual's best-interests decision is legally defensible if section 4(9) has been satisfied, **unless** section 6(6) has defined the best-interests decision maker'.

TWEAK No 2

This isn't really worth explaining – but, unless someone is asserting that Anne lacks the mental capacity to decide whether to accept or decline the offer of the tablet, it is as simple as 'Anne decides'.

TWEAK No 3

This is more interesting – and, probably also something that is often true in real-life situations.

I've posted this 'tweak' in my online discussions of 'Anne, David and Dr Jones' (12/06/18 addition to the thread here) and it poses a challenge which isn't 'what makes legal sense' – it is 'does what seems to make sense in legal and logical terms, **fit with** 'NHS protocol'?':

The third of those tweets, is on the theme [an obvious assertion] of 'it is better when people agree', and there is a variation of 'Anne, David and Dr Jones' which raises an interesting question about 'NHS Process even if the people 'on the inside' 'have agreed''.

I'm not certain, but there might be a connection between what I am about to analyse, and a tweet by Dr Mark Taubert:

https://twitter.com/DrMarkTaubert/status/1006144901233463297

This is the twist. Suppose that we change the situation in 'Anne, David and Dr Jones' to one in which there isn't agreement as to whether or not Anne is mentally-capable with respect to 'should she take the tablet'. And, remove the disagreement between Dr Jones and David - now, Dr Jones wants to prescribe the tablet, and David is happy to try and arrange that Anne takes the tablet. And, also remove the 'Anne doesn't like taking tablets' issue: instead, change that to 'when the tablet is discussed with Anne, she wants to take the tablet'.

A common-sense approach to that, would be 'if Anne is capacitous, it is her decision and she wants to take the tablet'. If Anne is not capacitous, then both David and Dr Jones think it is in Anne's best interests for her to take the tablet'. So - looked at 'using common sense' - there appears to NOT be a problem: Dr Jones prescribes the tablet, and David does his best to see that Anne takes the tablet.

But - HOW DOES IT WORK IN TERMS OF 'NHS PROTOCOL'?

We have NOT established, whether or not Anne is capacitous for this decision: does 'protocol' REQUIRE that capacity or incapacity is 'established'?

And we have NOT established 'who made the decision' - in my original scenario, I had two people making different decisions with no obvious way of resolving the conflict: in this modified version, I have an agreed course of action but it is impossible to claim that we have established who is the decision-maker [although, we clearly CANNOT assert 'all three of them' because the MCA makes that impossible].

So, HOW WOULD NHS protocol handle that situation: what would be recorded, and is the 'common-sense solution' even 'acceptable' within the constraints of 'NHS process'?

I had mentioned this 'tweak' to one of the people who discusses Mental Capacity Act issues with me, and the person commented 'I can't see a problem with that – it seems to make sense legally and 'logically' – and indeed it does. For Anne, David and Dr Jones – but, not necessarily for NHS protocol writers, or for NHS protocol followers.

I have pointed out, in a short piece about some obvious problems when you try to combine ACP with EoL, that:

In EoL, sometimes things can happen – clinical deterioration or clinical improvement which wasn't predictable, or a 'clinical development in an unanticipated direction' – which can throw a spanner into 'the best-made plans of mouse or man'.

And I am going to make an assertion about the way that decisions are often made during EoL at home:

Often there is no alternative to the decision being made by a group which is a happenstance mixture of patient, family, GP and nurses [depending on who happens to be present] and very often 'common-sense compromises' will be adopted: not 'idealised decision-making' and not 'theoretically-perfect decision-making', but decisions which 'everyone settles for'. It is a case of ‘compromising and ‘muddling through’’ in many situations.I am stating 'that is the reality of how it works' – that what happens during EoL at Home is hugely complex, and frequently 'the decisions made are the decisions which 'seem sensible' to the people involved'.

In theory, while the patient is capacitous, put loosely 'the patient makes the decision', and if the patient isn't capacitous, the legal situation is much more complex. I also think that it isn't legally possible to 'consent to the ACP': legally it is case of 'ongoing consent [or best-interests decision-making] to each intervention within the 'ACP' at the time of the intervention'. For example, 'the ACP' might involve taking blood samples twice a day – but if the patient wants to, a capacitous patient can just decide and say at some point 'I've had enough of these blood samples – you can't take any more blood samples'.

It is very difficult to 'translate' what I have described above, into the 'neatness beloved of the NHS' – into ACP, protocols and guidance.

And attempts to do that – to 'impose neatness onto reality' – often tend to be inadequately thought through. For example, it takes very little thinking, to realise that there is a fundamental difference between 'planning' made while the patient is mentally-capable, compared to 'planning' made after the patient has lost mental capacity. It wouldn't be surprising, to discover that clinicians decided to invent different words for the two situations – that planning made while the patient was capacitous might be talked about as (for example) 'CACP' and planning made after the patient had lost capacity might be talked about as IACP.

But – patients are not definable as 'capacitous' and 'incapacitous'. The law defines mental capacity as being both decision and time specific: at any given time, a patient might be capacitous for some decisions but incapacitous for others; and for the same decision, it can be capacitous on one day, and incapacitous on the next day [or vice versa].
Throw in that it will often be uncertain, and perhaps disputed, about whether or not the patient is capacitous for a given decision at a particular time, and I wouldn't be surprised

if 'the experts' came up with labels and the like for ACP during EoL, which definitely wouldn't cope with that 'uncertainty around capacity', and definitely with 'paper-work' that doesn't fit with my:

Often there is no alternative to the decision being made by a group which is a happenstance mixture of patient, family, GP and nurses [depending on who happens to be present] and very often 'common-sense compromises' will be adopted: not 'idealised decision-making' and not 'theoretically-perfect decision-making', but decisions which 'everyone settles for'. It is a case of ‘compromising and ‘muddling through’’ in many situations.

Now, I think we patients and relatives, want the doctors to help – we want our GPs to use common sense to help, not to try and shoehorn us into 'neat boxes and neat protocols'.

In essence, while the NHS and probably Social Care 'loves records and likes decisions made in advance', I want the principles of the MCA to be supported by professional behaviour – **not thwarted by** professional behaviour. And you cannot reduce the Code's 'Attorneys must always follow the Act’s principles and make decisions in the donor’s best interests' to a process which tries to solely base decision-making on 'what has been recorded and 'verified by professionals'.

Everyone should be 'following the Act's principles' when making decisions, and those principles are, in essence:

Unless 'proven' incapacitous for the decision in question, the person/patient makes and expresses the decision, and such a capacitous person is allowed to 'project a decision forwards for application during future incapacity';

If the above doesn't apply, then best-interests decision-making becomes necessary, and if there is someone empowered by MCA 6(6) to make the necessary best-interests decision, then [subject to 6(7)] that person should be the decision-maker.

From my 'family-carer during end-of-life at home' perspective, 'the NHS' seems incapable of accepting that if only a family-carer is available to listen to the patient, then only the family-carer can listen to the patient:

https://www.dignityincare.org.uk/Discuss-and-debate/download/298/

That there **isn't** a fundamental distinction between treatment and care – most easily thought-through if you consider cardiopulmonary resuscitation (CPR) which is taught as first aid, and hence could be attempted by some family carers during end-of-life.

That while best-interests decision-making is incredibly difficult to 'explain' in many situations, we can now assert that logically it does equate to substituted judgement for life-sustaining treatments:

https://www.dignityincare.org.uk/Discuss-and-debate/download/353/

Clinicians seem to 'dispute' even the clearly-given legal authority of attorneys:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Can-other-people-see-what-I-can-see-in-these-different-descriptions-of-the-decision-making-authority-of-welfare-attorneys-/924/

I do understand, that if the MCA is 'applied without distortion' then that is very challenging for professionals:

https://www.dignityincare.org.uk/Discuss-and-debate/download/322/

https://www.bmj.com/content/358/bmj.j3257/rr-4

This piece is long enough – to close, I will direct the reader to the piece titled 'Decision-Makers and the MCA' which is the second page of the PDF at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/264/

That is how we should be approaching best-interests decision-making: first, trying to avoid best-interests decision-making by getting anticipatory-decisions from capacitous patients, and then if best-interests decision-making becomes necessary by adopting the approach I described in 'Decision-Makers and the MCA'.

Written by Mike Stone, March 2019.

@MikeStone2_EoL

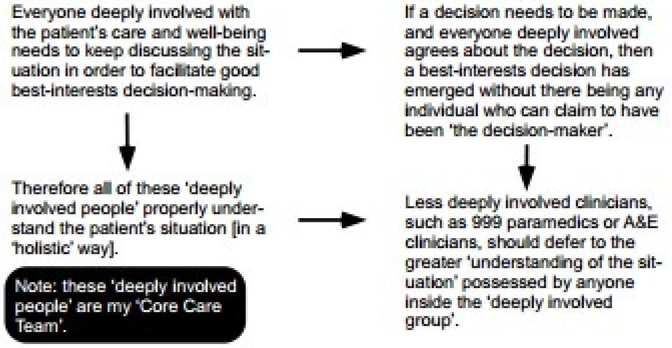
Decision-Makers and the MCA

'The system' becomes deeply unhappy, if there isn't 'a defined decision-maker': but once it has been accepted that section 4(9) imposes a legal duty on any person who makes a best interests decision, and that section 6(6) is the only section of the MCA which imparts 'true legal authority' to individuals for best-interests decision-making, a different [and more 'holistic' and 'intuitive'] understanding of section 4 of the MCA 'leaps forwards'.

In particular, if there is uncertainty about 'who the decision-maker is' then the idea that 'the decision-maker consults other people' is impossible to apply - so section 4(7) becomes 'a lot of deeply-involved people need to talk to each other, in case any one of them is faced with a decision to make [and other less-involved but potentially informative people must also be talked to]'. And in the same way that the Montgomery ruling has made it clear that the adequacy of the information supplied to a mentally-capable patient during a conversation about consent has to be judged from the patient's perspective, the decision about 'who to discuss things with' [for section 4(7)] then has to be looked at 'from the perspective of the decision being made' (and not from the perspective of a person who makes that decision). Section 4(6) then becomes 'and try to consider everything reasonably discoverable which might affect the decision being made'. Put at its simplest, the whole 'ethos' of section 4 then becomes:

> Best-interests decision-making involves asking everybody who could contribute to a better decision being made, to contribute whatever they can towards the making of a better decision.

So if section 4 of the MCA is approached without assuming a decision-maker, it becomes:



Everyone deeply involved with the patient's care and well-being needs to keep discussing the situation in order to facilitate good best-interests decision-making.

If a decision needs to be made, and everyone deeply involved agrees about the decision, then a best-interests decision has emerged without there being any individual who can claim to have been 'the decision-maker'.

Therefore all of these 'deeply involved people' properly understand the patient's situation [in a 'holistic' way].

Note: these 'deeply involved people' are my 'Core Care Team'.

Less deeply involved clinicians, such as 999 paramedics or A&E clinicians, should defer to the greater 'understanding of the situation' possessed by anyone inside the 'deeply involved group'.

4(6) He 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.

Note: section 4(6) is clearly about 'trying to work out what the patient would [probably] have decided'.

4(7) He must take into account, if it is practicable and appropriate to consult them, the views of—

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
(b) anyone engaged in caring for the person or interested in his welfare,
(c) any donee of a lasting power of attorney granted by the person, and
(d) any deputy appointed for the person by the court,as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).