

Some thoughts about section 25(2)(c) of the MCA and a court ruling by Mr Justice Poole (version 2 typos corrected from the original version)

I have been writing, in a rather fragmented fashion, about section 25(2)(c) of the Mental Capacity Act (MCA) in a thread on Dignity in Care at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-think-Mr-Justice-Poole-must-be-wrong-in-his-interpretation-of-section-254c-of-the-Mental-Capacity-Act/1138/>

This PDF can be downloaded from that thread.

This piece will attempt to discuss section 25(2)(c) and a court ruling by Mr Justice Poole more coherently, and in more detail. I will also at times refer to a piece the barrister Alex Ruck-Keene wrote about the court ruling. From now on, I will refer to Mr Justice Poole as 'Poole J' and I will refer to Alex as Alex (Alex and I have been co-authors of an academic paper). The court ruling by Poole J is at:

<https://www.bailii.org/ew/cases/EWCOP/2021/52.html>

The piece by Alex is at:

<https://www.mentalcapacitylawandpolicy.org.uk/advance-decisions-jehovahs-witnesses-and-what-does-doing-something-clearly-inconsistent-with-your-adrt-mean/>

When I write 'Poole J says' [or writes] or 'Alex writes' [or says], then I am referring to those two pieces. I will be numbering some sections of this PDF.

INTRODUCTION

There has been the concept of a mentally-capable person (a capacitous person) being able to project his decisions forwards into a future time of mental-incapacity (incapacitous person) for decades, in the context of healthcare. Usually the idea and/or documentation is called an Advance Directive, sometimes an Advance Decision. It is important to understand that **the detail** may, or may not, be defined within local law. In England and Wales, we have now got Advance Decisions which are defined/explained in the MCA. The law in Northern Ireland is different, and in Northern Ireland their version of the law does not have the same concepts of **valid** and **applicable** as the MCA has. In at least one state of Australia, their law describes a rigid process and an advance decision can only be created on documentation which is sourced from healthcare professionals. So, we need to examine the MCA itself in order to work out what our law, in England and Wales, is.

There is a section of the MCA which says this:

[25](2) An advance decision is not valid if P—

(a) has withdrawn the decision at a time when he had capacity to do so,

(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

In his ruling, Poole J states (50) ‘ I interpret s.25(2)(c) as allowing for the advance decision to be rendered not valid should the person who made the advance decision do “anything else” (other than withdrawal or granting an LPA which displaces the advance decision) which is “clearly inconsistent” with the advance decision remaining their fixed decision, before or after they have lost capacity to make the relevant treatment in question.’

I was disturbed when I read that – because I had always interpreted 25(2)(c) as only applying to things which happen/happened while the patient was capacitous, and covering ‘retraction of the ADRT ‘by implication’’. I must admit, I hadn’t thought through the consequences of my own interpretation of what 25(2)(c) means in practice, because as I think like a family-carer the situation is simpler. Poole J continues in section 50 by writing ‘The question will only arise after they have lost capacity but the court may consider things done before or after that time.’ and Poole J is wrong about that. I’m now going to start numbering things, to facilitate any future discussion.

1 I think like a family-carer who is living with a dying loved-one, usually a still-capacitous dying loved-one. I would know if there was an ADRT (at least, ‘chaos easily ensues if I don’t know about any ADRTs’!) and if my loved-one seems to have done something ‘clearly inconsistent with the advance decision remaining his fixed decision’ **then I would ask at the time ‘are you withdrawing your Advance Decision?’**. So – the question would arise during my loved-one’s capacity: the question would arise when the ‘doing something’ occurred, and I would know if my loved-one had intended to retract his ADRT almost immediately. So, Poole J is incorrect: the question doesn’t only arise during the person’s incapacity. The question will not be pondered by a judge while the person is still capacitous – but that is a different point.

2 As I’ve said, we need to work from the MCA. The words of 25(2)(c) do NOT tell us when the ‘question’ will arise. The words, if we simply read them, tell us when the Advance Decision becomes invalid. The ADRT becomes invalid, when the observation of the ‘anything else clearly inconsistent with the advance decision remaining his fixed decision’ **is made**.

3 If we only read what the Act says, **it doesn’t in any way restrict who the observer is**. As I’ve said, if it happened while my loved-one was capacitous and I was a family-carer, then I would promptly ask. But that observer could be anyone, so far as I can see, and in any situation: the Act’s wording doesn’t tell us who the observer is – a relative at home, a nurse in a hospital, anyone can observe an event – and it doesn’t say who decides if the event is ‘clearly inconsistent with the advance decision remaining his fixed decision’. Although logically, the person who thinks ‘that isn’t consistent with his ADRT’ will be the person who observes something. Certainly if things get to court, a judge might decide if an

ADRT is invalid because of the observation – but I don't want normal end-of-life to routinely end up in court.

4 If section 25(2)(c) applies to things which P during capacity, and an observer – a nurse, paramedic, relative, doctor etc – believes 'that surely must indicate he has retracted his ADRT' and the observer doesn't ask P, then how can we learn about the things which people do which are not intended to indicate a retraction of an Advance Decision but are interpreted by the observer as indicating that?

And I strongly suspect, that if a clinician says to a capacitous P '... but, you have just done something which is clearly inconsistent with your advance decision remaining your fixed decision' then if that wasn't P's intention, a sharp [and quite possibly swears!] response along the lines of 'I damn-well know what my intentions are – and what I did most definitely was NOT inconsistent with my Advance Decision!'. Now: will those exchanges – which inform us about misinterpretation of P's actions – ever be recorded in databases? My instinct is no: I suspect 'that evidence base' will largely not be available to us. Whereas we will have court rulings, containing the opinions of judges as to 'what people intended when they did things' - and we cannot assume, that those two data sets will be identical.

5 Technically – this is I suspect never going to arise in reality – it seems when you ponder 25(2)(c), that it is the observer's belief, at the time of the observation, which makes an ADRT invalid. It would appear, that even if a minute later the observer asks P, and 'P puts the observer straight', the ADRT has already been rendered invalid. It looks as if, P needs to then write a new ADRT if the refusal is of a life-sustaining treatment. I feel sure, that if most Ps worked that out, they would be thinking [and very possibly saying loudly] 'What idiot drafted this law!!!'.

6 The MCA usually (but not always – a point I will return to later) uses the two terms 'valid' and 'applicable' in its descriptions of Advance Decisions. There isn't really any reason to not use applicable and applicability, and it is understandable why the Act uses the word valid. But: as soon as you start writing 'valid' it might appear 'legalistic' and hence 'perhaps a bit hard to grasp' to some lay people.

It makes sense to use 'valid' when the creation of a written ADRT is being described: what it means there, is that the ADRT, such as Mrs W's ADRT refusing a blood transfusion, has been correctly witnessed, etc. Saying, about its creation, 'the Advance Decision is valid' in fact means that the Advance Decision has come-into-existence for legal purposes. But I think it is easier to think about an ADRT becoming invalid, in terms of 'the ADRT ceased existing'. This might simply be personal – but it is how I think. Either an Advance Decision still exists (it remains valid) or it no longer exists (it has been rendered, by something, invalid).

If an Advance Decision still exists (is still valid) at the time the person (P) loses mental capacity to make a decision about the treatment, then the ADRT must be considered in terms of its applicability.

7 In the case ruled on by Poole J, Poole J identified as the crucial issue whether the ADRT had previously been made invalid by application of 25(2)(c). Alex tells us:

On the evidence, Poole J was satisfied that it was clear that Mrs W lacked capacity to decide whether to accept or refuse a transfusion. The focus was therefore upon what

to do in face of the advance decision and, in particular, whether “in accordance with s.25(2)(c) of the MCA 2005, the advance decision is no longer valid because Mrs W has ‘done anything else clearly inconsistent with the advance decision remaining her fixed decision” (paragraph 47).

Alex then shows us sections 50 to 52 of Poole J’s ruling, and Alex comments ‘Poole J’s observations about the law in this area merit reproduction in full, given their clarity and lucidity in relation to a point that has not been the subject of detailed consideration since the MCA 2005 came into force.’.

Before I move on to those sections, I will make a fundamental point. Whether or not, section 25(2)(c) can apply to things done after the patient has lost mental capacity, it very clearly must involve a specific ‘thing done’ at a specific time. In the simplest case, we might compare a single ‘anything done’ to a boxer being felled by a single and vicious right-hook from his opponent. In a more complex case, a judge might use what I’ll term ‘cumulative justification’ – somewhat like ‘after a sustained flurry of blows from his opponent, delivered over the course of more than a minute, Jones collapsed to the canvas’. This is absolutely crucial, so I’m going to write it in a larger font size:

Even if a judge uses ‘accumulated evidence’ to assert that an ADRT was made invalid by means of 25(2)(c), there must be a specific point-in-time when the transition from validity to invalidity occurred, and [hence] there must be an identified ‘thing done’ (which, in the boxing scenario, would be the final punch in the series of blows which together caused the boxer to collapse).

If a judge asserts that an ADRT was made invalid by means of section 25(2)(c) WITHOUT making it clear when that invalidity occurred, and what the final ‘thing done’ was, then it must be legitimate for us to question if the judge has applied section 25(2)(c) correctly.

In Poole J’s case, we know that Mrs W’s ADRT was valid when she created it in 2001. She didn’t do something **while** Poole J was considering the case, which rendered the ADRT invalid. Poole J ruled that her ADRT was not valid, so we should be able to find a clear answer to the question ‘When did her ADRT become invalid, and because of what ‘triggering event’?’.

8 Poole J does, in his section 50, bother to justify why he thinks section 25(2)(c) applies irrespective of P’s capacity – so that issue cannot be ‘a settled question’. As Alex has very helpfully pointed out (I don’t read court cases for fun, so I don’t read many court rulings) ‘The (surprisingly) small body of case-law relating to advance decisions to refuse treatments has been added to by a judgment delivered by Poole J in difficult and urgent circumstances, but which grappled head on with the complexities to which they can give rise.’.

It seems, therefore, that ‘the door is still open’ for me to present my arguments, as to why section 25(2)(c) should be taken to apply only to event which happen while the patient is still mentally capable.

9 At this point, we need to see section 25(2) of the MCA as a whole, again:

[25](2) An advance decision is not valid if P—

(a) has withdrawn the decision at a time when he had capacity to do so,

(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

If, as I believe, section (c) means ‘has done anything else clearly inconsistent with the advance decision remaining his fixed decision [while P was still capacitous]’ (or, framed to fit with this section, [while section (a) applies]), then an obvious question arises: why doesn’t the Act say ‘while still capacitous’.

Poole J examined **some of** the wording of 25(2)(c) in his section 52:

52. Three words within s. 25(2)(c) require particular comment:

a. “done”: I read this to include words as well as actions. I am strongly reinforced in this view by what Munby said at paragraph [43] of his judgment in *HE v A Hospital NHS Trust* (above):

“No doubt there is a practical – what lawyers would call an evidential – burden on those who assert that an undisputed advance directive is for some reason no longer operative, a burden requiring them to point to something indicating that this is or may be so. It may be words said to have been written or spoken by the patient. It may be the patient’s actions – for sometimes actions speak louder than words. It may be some change in circumstances. Thus it may be alleged that the patient no longer professes the faith which underlay the advance directive.”

The statutory provision does not refer to words and actions, only what P has “done”, but it would be an odd restriction on the interpretation of “done” to exclude written or spoken words when the provision is addressed to previous written or spoken words in the form of an advance decision (an advance decision about treatment which is not life-sustaining treatment may be made verbally).

b. “clearly”: the court should not strain to find something done which is inconsistent with the advance decision remaining the individual’s fixed decision. Something done or said which could arguably be “inconsistent”, or which the court could only find might be inconsistent will not suffice.

c. “fixed”: s.25(2)(c) does not merely require something done which is inconsistent with the advance decision, but rather something done which is inconsistent with it remaining the person’s *fixed* decision. Fluctuating adherence

to the advance decision may well be inconsistent with it remaining their fixed decision. As with the other elements of the test, whether it is inconsistent will depend on the facts of each case.

Taking those in turn. As to (a), I find it beyond odd, that Poole J feels it is even necessary to explain why 'words spoken' count as 'things done' – I think that if you approached a Police Officer, stood in front of the officer and spouted a stream of forceful verbal abuse at the officer, it would quite quickly become apparent that for the purposes of the law 'saying things counts'. More interestingly, Poole J did **not** try to prove that 'words not spoken' count for the purposes of section 25(2)(c) – analysis of 'things not said' (and of things not done more widely) is much more informative, but Poole J did not do that. Although, Poole J seems to use 'words not spoken' within his arguments about whether 25(2)(c) applied:

Section 57: She granted to her children, whom she surely knew were hostile the Jehovah's Witnesses denomination, authority to make decisions about all medical treatment, other than life-sustaining treatment, on her behalf should she lose capacity to make such decisions for herself, without mentioning to them or including in the written LPA any preference or requirement not to receive blood transfusion or blood products.

Section 62g: Further, she has not mentioned the advance decision to her family or to any of the clinicians now treating her.

Section 31: Earlier this year Mrs W was very ill in hospital and was very clear that she wished to be resuscitated if the need arose. A "DNR" order had been mistakenly included in her medical notes and she insisted on it being removed. The children told me, through Ms W, that Mrs W had never mentioned the advance decision to them and they had been completely unaware of its existence.

It would be distracting, for me to analyse why a religious person might object to a DNACPR while forcefully refusing a blood transfusion, and why JW might have avoided mentioning her ADRT at various times, at this point – I will do that, later on.

Moving on to (b). The level of certainty which is necessary, is fundamental in the context of 25(2)(c). Poole J is absolutely right, to highlight 'clearly'. We need to know, what level of certainty is required. Is it a low bar – is it simply 'more likely than not' ('balance of probability') which is the MCA's standard for best-interests determinations [inevitably so – you could not apply a higher requirement, when you are required to apply best interests]. Or is it, more akin to 'beyond a reasonable doubt'? I think, the test for 'clearly' should be 'beyond a reasonable doubt'.

As for (c). The concept of 'adherence to' an Advance Decision is somewhat challenging. During capacity, it is obvious that P does not have to 'adhere to' what is written in his ADRT – Poole J makes this clear with the first sentence of his section 36:

36. A person who has capacity is not at all bound by their advance decision. They have capacity to refuse or consent to treatment as they choose, irrespective of what advance decisions they have made.

And if a person has lost mental capacity, such a person might not even be able to understand the concept of 'adhering to' anything.

Showing you 25(2)(c) again – mainly because I can't remember its exact wording:

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision

Poole J didn't decipher the word 'anything' – I take it to mean 'any thing' or simply 'a thing'.

And Poole J did not investigate 'his fixed decision'. Which I will now do.

I will examine the 'his decision' aspect, of 'his fixed decision'. In my 6 I wrote 'The MCA usually (but not always – a point I will return to later) uses the two terms 'valid' and 'applicable' in its descriptions of Advance Decisions'. The MCA **doesn't always** use valid and applicable. In fact, when at the very start of the MCA's sections covering ADRTs, we are told what an Advance Decision is **without either valid or applicable being used**:

24 Advance decisions to refuse treatment: general

- (1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if—
 - (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
 - (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

That is very clear: it doesn't in fact tie what here I'll describe as 'ownership of' an Advance Decision with P – it says that 'ownership of' an Advance Decision **rests with a capacitous P**. And, when you read that, the idea that the specified treatment in the ADRT might be carried out if when incapacitous P wants to be treated, conflicts with what we are reading. In normal language, that is saying 'You can use an Advance Decision to prevent a treatment being performed after you have lost the capacity to refuse the treatment at the time'. It isn't saying 'You can use an Advance Decision to prevent a treatment being performed after you have lost the capacity to refuse the treatment at the time – unless you ask for the treatment after you have lost the capacity to refuse the treatment'.

Furthermore, if 25(2)(c) only applies to things which happened while P was capacitous, there is not any real conflict with 24(1). In essence, it amounts to 'If P had done things while still capacitous which P intended to indicate that he had scrapped his Advance Decision, and after P has lost capacity we are satisfied that the actions we are considering carried that intention, then we should regard P's Advance Decision as being invalid'. Obviously, if someone such as P's life-partner sees P doing things which prompt the thought 'has P retracted his Advance Decision?' then if that happens while P is capacitous, P would be asked – and P would clarify the situation. But, if the things done are only considered after P has lost capacity – and especially if the 'evidence' is several different

events, which were each observed by a different person – there is a much greater chance of misinterpreting P's actions.

I will analyse the consequences of both interpretations of 25(2)(c) later, but at this point I am returning to Poole J's court ruling.

SOME COMMENTS ON POOLE J'S RULING

10 In section 3, we can read 'However, enquiries made by a doctor at the hospital revealed the existence of an advance decision made by Mrs W in 2001 which appears to have been held on a register of such decisions made by Jehovah's Witnesses.'

Alex tells us that this ADRT 'emerged' on the same day that the Poole J made his ruling. I'm not quite sure what I'm being told: was the original written document being kept by the Jehovah's Witnesses, or did they simply know it existed. Presumably, the actual document was produced. If the Jehovah's Witnesses only knew it existed, and armed with that information a search of Mrs W's home resulted in the actual ADRT being found, then that tends to suggest Mrs W had not decided to withdraw her ADRT. If it was physically-held by the Jehovah's Witnesses, it is trickier. The lesson, is *keep your own ADRT under your own control*.

I must say, that there appears to be a degree of coherence in these answers, which seems to indicate mental capacity during the conversation:

17. Dr J struck me as a careful and considered witness and an experienced clinician who sensibly returned to Mrs W 30 minutes after the conclusion of his first interview with her. On this occasion he noted that she recalled that they had talked about an operation but nothing else.

"On prompting about blood transfusions she said 'I won't have a blood transfusion'. On saying that she would die without a blood transfusion, she repeated, 'In that case, I'll die.'

'Why can't I have tablets' – 'they would work quickly enough'... 'in that case I'll die'.

I said her family wanted her to have a blood transfusion and didn't want her to die. 'that is their decision.'

I said that letting her die would be a very difficult decision, 'I have made my peace with Jehovah and will talk to him then.'

After 5 minutes I asked 'what would happen if you refused a blood transfusion?' She answered 'I will die.'"

What Dr J subsequently wrote (18) looks correct to me:

Our second conversation was different however, and she gave a clear rationale for refusing, understood the consequences (death) and was consistent with this.

We should always assume capacity and in this case her capacity is fluctuant so on balance I would say she does have capacity to refuse a blood transfusion even in a life threatening situation.”

Dr J then completely reverses his position (19 and 20). I am also struck by this, in 20:

He told me that he had reflected further and that whilst it could have been said that superficially Mrs W had capacity to refuse treatment, she was actually unable to discuss the reasons behind her responses. Her answers in the second interview were formulaic. He accepted a description of some dementia sufferers masking their inability to reason and process information by resorting to formulaic sayings which are a comfort to them. I understood his evidence to be that this was how he now viewed Mrs W’s presentation at their second interview.

There is **not** any requirement during normal ‘informed consent’, for the patient to explain why they are refusing an offered treatment. Doctors want to know why patients are refusing: they seem to read section 3(1) as if it is a test of capacity. It isn’t a test of capacity – section 3(1) is a description of how a capacitous patient arrives at his decision. This is section 3(1):

[3](1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).

Section (c) is not assessable unless a patient decides to explain ‘how I’m arriving at my decision’ and patients are not required to do that – in fact, in some 2010 guidance the GMC translates section 3(1) into this:

14 *If a patient has capacity to make a decision for themselves, this is the decision-making model that applies:*

(a) *The doctor and patient make an assessment of the patient’s condition, taking into account the patient’s medical history, views, experience and knowledge.*

(b) *The doctor uses specialist knowledge and experience and clinical judgement, and the patient’s views and understanding of their condition, to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.*

(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, it isn't for the patient to prove capacity – it is the assertion of incapacity which must be proven (MCA 1(2)):

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

And, the GMC states, with my added bolds here – if you decide 'for no reason at all' then you can't explain how you decided, can you (I think the GMC has taken the 'for no reason at all' wording straight from something a judge said, but although I think I came across the 'case' once, I didn't note the judge and the case):

*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**.*

It seems entirely possible – at least to me – that Mrs W, who was an 80 years old lady in hospital, was probably under considerable stress, could have been capacitous and **might have decided she simply didn't want to have a possibly 'fraught' conversation 'justifying' her religious belief**. So, instead of her responses being 'formulaic' she might have simply been giving answers intended to convey her decision and to avoid any in-depth discussion. In essence, informed consent/considered refusal is a process when the doctor offers a treatment, and informs the patient of the options and prognoses. If the patient says 'I don't want to be treated' the doctor can say 'have you considered [whatever]'. If the answer is 'Yes I have – I'm still refusing the treatment' then after all the 'have you considered' questions have been exhausted, that is it, and the patient has refused.

Read this, assuming that Mrs W was capacitous, didn't want a blood transfusion, and was fed-up of a lifetime of having her justification for refusing blood transfusions – her beliefs as a Jehovah's Witness - 'discussed and/or 'challenged":

"On prompting about blood transfusions she said 'I won't have a blood transfusion'. On saying that she would die without a blood transfusion, she repeated, 'In that case, I'll die.'

'Why can't I have tablets' – 'they would work quickly enough'... 'in that case I'll die'.

I said her family wanted her to have a blood transfusion and didn't want her to die. 'that is their decision.'

I said that letting her die would be a very difficult decision, 'I have made my peace with Jehovah and will talk to him then.'

After 5 minutes I asked 'what would happen if you refused a blood transfusion?' She answered 'I will die.'"

Viewed in the context I've just suggested – that Mrs W was trying to make clear her refusal of a blood transfusion and to cut the conversation as short as possible – do those answers look 'formulaic'?

I will point out, that the MCA does not require you to give reasons for the refusal you detail on a written Advance Decision. This is not completely obvious if you read the 'somewhat ambiguous' wording about the information which is necessary on an ADRT, given in 24(1)(a):

in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him,

The word 'may' indicates an option – if the stating of circumstances was a requirement, it would say 'in specified circumstances'.

But it becomes clear when we look at what makes an Advance Decision inapplicable, in 25(4):

[25](4) An advance decision is not applicable to the treatment in question if—

(a) that treatment is not the treatment specified in the advance decision,

(b) any circumstances specified in the advance decision are absent, or

(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

When you read (a) and (b) it is obvious that what the Act is saying that you should write an ADRT in the form of 'I am refusing [this treatment] if [this/these circumstance/s] are present'.

It then becomes problematic, to work out what you should write if you are refusing a treatment in all situations. In theory, if you write 'I refuse the treatment' then you have refused in all circumstances – there is no specified circumstance, so [from section (b)] there is no circumstance to be absent. If you write 'I refuse the treatment in all circumstances' then logically your decision is inapplicable – for any particular situation, the majority of 'all circumstances' must necessarily be absent.

In practice, judges seem to always avoid the issue I've just raised: instead judges also look at 'the meaning of' what is written in the ADRT.

In reality, the wording 'I am refusing 'specified treatment' in all of the situations which I have envisaged – I'm refusing the treatment, full stop!' would probably work if the ADRT was in front of a judge.

I am puzzled by this in the ruling:

23. Having regard to s.4(10) of the MCA 2005 (see below), and Mr A's evidence, I proceed on the basis that blood transfusion administered now to Mrs W should be regarded as "life-sustaining treatment". The decision about blood transfusion in this case is not,

however, an end-of-life decision. The current evidence is that Mrs W has an acute condition which would, under normal circumstances, not be likely to end her life. She is not in the late stages of a terminal illness.

I'm baffled – I've never come across this phrasing before – by 'The decision about blood transfusion in this case is not, however, an end-of-life decision.'. There is not, in my view, such a thing as 'an end of life **decision**'. There are situations when doctors believe the patient will die in the near future (although the NHS uses end-of-life to mean 'predicted to die within 12 months' - the term used for the final days of life is usually 'dying phase' I think) but that is not a 'decision'. And the MCA doesn't make any reference in section 4 to how long a patient is expected to live: it only introduces a distinction between life-sustaining interventions, and other interventions.

I have absolutely no idea, why Poole J writes 'The decision about blood transfusion in this case is not, however, an end-of-life decision'. I can't see its significance.

Poole J writes this in his ruling:

53. The Trust asserts that the advance decision is not now valid because s.25(2)(c) is made out. I treat the burden of proof as being on the Trust which must establish that on the balance of probabilities Mrs W has done something inconsistent with the advance decision remaining her fixed decision.

It seems possible – without having explained why – that Poole J has decided that the words 'clearly inconsistent with' in 25(2)(c) indicate that the required level of certainty is the 'balance of probabilities' test, which inevitably applies to best-interests decisions: for best interests, whichever seems to be the best available option will be chosen. And (2(4) tells us 'In proceedings under this Act or any other enactment, any question whether a person lacks capacity within the meaning of this Act must be decided on the balance of probabilities.'. But section 25(2)(c) isn't a best-interests decision, nor is it an assessment of capacity.

SPECULATION AND THINGS NOT DONE

11 This isn't going to disentangle 25(2)(c), but it is worth pondering.

We know, that sometimes after a conversation, doctors and patients will have different recollections and perceptions of what was said during a conversation, and of what was meant during the conversation. So, I'm merely pointing the following out.

Actually, those two conversations could be perfectly reasonable if we assume that Mrs W was capacitous during both and that there is some [very-possibly inadvertent] mis-reporting or misunderstanding around 'clean', and I'm not sure (there is some reasonable 'speculation' involved) that this has been drawn out. The point is:

- 1) Although 'the NHS' likes all of your ADRTs to be on a single document, you can have as many ADRTs as you like: an Advance Decision is treatment specific.
- 2) There are differences of view among the believers even within 'the same religion'.

Mrs W used a JW-designed ADRT form about twenty years ago. That first conversation with Dr J has a degree of complexity in my mind – I'm not sure if she was describing her decisions, or if she was describing a conflict within her thinking about blood transfusions. But, we should think of her having TWO SEPARATE Advance Decisions.

One, which we must assume was her position when she wrote her ADRT, amounts to a refusal of ANY blood. The second, is a refusal of HER OWN BLOOD being put back into her.

So, read this as if she was capacitous:

I asked her if she would have a blood transfusion – 'I'd have to think about it.' I asked if she would have a blood transfusion if it meant this would save her life, and not having it may cause her to die – 'in that case I would have it, if it was clean blood'. 'What do you mean by 'clean' blood?'; 'Blood free from diseases'.

Did she really mean 'free from diseases' when she said 'clean'? Logically, if she had dissented from the mainstream JW belief that transfusions of her own blood back into her were forbidden, might she now believe that her own blood was okay? Did she really mean by 'clean' 'my own blood'.

Certainly, if you make her position that she will accept her own blood, which in religious terms she might have decided is, contrary to the mainstream JW position, 'clean', then when we add the second conversation that would also be consistent with capacity:

"On prompting about blood transfusions she said 'I won't have a blood transfusion'. On saying that she would die without a blood transfusion, she repeated, 'In that case, I'll die.'

'Why can't I have tablets' – 'they would work quickly enough'... 'in that case I'll die'.

I said her family wanted her to have a blood transfusion and didn't want her to die. 'that is their decision.'

I said that letting her die would be a very difficult decision, 'I have made my peace with Jehovah and will talk to him then.'

After 5 minutes I asked 'what would happen if you refused a blood transfusion?' She answered 'I will die.'"

So, if she were capacitous, her hypothesised change of position to accepting her own blood, but refusing other people's blood, would amount to a retraction of ONE OF the two ADRTs which she had made years ago. But – and this is the speculation, although I can't

really see how this would be wrong – she wasn't being offered her own blood. I'm not sure what it is she was expecting to have to talk to Jehovah about: it presumably can't be about dying because she had refused a blood transfusion. *Might it be, that she was going to discuss with Jehovah whether he had ever intended that believers should refuse a transfusion of their own blood?*

12 A lot of things Mrs W did not do, seem to be taken as being contrary to the Advance Decision remaining Mrs W's 'fixed decision'.

It seems reasonable, that Mrs W would have known that the ADRT refusing blood transfusions had survived the coming-into-force of the MCA. I'm not at all sure, that when she made the LPA, Mrs W understood that she was giving her attorneys section 6(6) authority over non-life-sustaining blood transfusions. I suspect, she probably thought 'my Advance Decision prevents blood transfusions'. The situation she ended up in, with her attorneys having authority over non-life-sustaining transfusions but her ADRT forbidding life-sustaining transfusions – when clearly the refusal of the life-sustaining transfusion 'seems more serious' - is arguably a little 'odd'. We are told that she didn't mention the ADRT when setting up the LPA – but, I don't think we are told if it was made clear to Mrs W that she was giving authority over non-life-sustaining blood transfusions to her attorneys. If she had been asked 'are you intending to allow your attorneys to decide about non-life-sustaining blood transfusions?' then doubtless her position on her Advance Decision would have emerged.

13 I am not religious, but as I understand it, many religions 'want' followers to strive to stay alive. Refusing life-sustaining interventions, is therefore not such a believer's desire: the person's objective, is to try and stay alive.

This, if you do understand how doctors work, becomes somewhat tricky if you are a Jehovah's Witness: you want all of the other life-sustaining interventions to be attempted, **except for** blood transfusions.

Refusal of a life-sustaining transfusion, isn't identical to refusing attempted cardiopulmonary resuscitation. But we know – there is quite a lot of literature on this – that once patients 'are DNACPR' other life-sustaining interventions tend to be offered and applied less often, than for patients who are not 'DNACPR'.

We also know, that if they are acting on a 'best-interests basis', doctors have an inherent bias towards departing from the MCA's description of best interests, and instead trying to achieve the best clinical outcomes. Mr Justice Charles in his published ruling in 'Briggs' mentioned this:

<https://www.judiciary.gov.uk/wp-content/uploads/2016/12/l-briggs-v-p-briggs-others.pdf>

(37) In her statements and oral evidence Dr Mahendran was at times more optimistic than Dr Walton but very properly she accepted that parts of her statements were in language that gave a misleading impression of the degree of improvement demonstrated by Mr Briggs since his SMART assessment. In her second statement she referred to "medical best interests" and orally she confirmed that her view throughout has been and that it would not be ethical to withdraw CANH from a patient in MCS because of the possibility of

improvement or continued improvement. When asked her position in respect of someone who is diagnosed as being in a permanent MCS because it has lasted 5 years she replied that it would not be her decision and she would seek advice.

(38) As the treating consultant on an acute ward this ethical and/or medical best interests approach by Dr Mahendran to the preservation of life is understandable and commendable. I accept the submission made on behalf of the NHS Trust and the WCCG that it is difficult to see how the treating team could have adopted a different approach to that which they have taken since Mr Briggs' accident. I do so because of the difficulty they face in assessing and giving weight to the evidence about what Mr Briggs would have wanted. Hindsight is a wonderful thing and with it I suspect that improvements could have been made by both sides in the communications between the treating team and the family but this would not have altered their rival positions.

The court case was observed, and we can also read a little about what was said during the case – I have reproduced (page 13 in the PDF, and shown below in smaller type) some of what we were told in my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/468/>

Charles J was, it seems, 'kinder' to the doctors in his published ruling, and rather more explicit about the fact that MCA Best Interests and Medical Best Interests are very different things ('medical best interests' isn't an MCA concept – we just need to know about medical prognoses):

Professors Celia and Jenny Kitinger had permission from Mr Justice Charles to report on what was happening during the Briggs ruling, and they have put-together a teaching tool about the case:

<https://cdoctraining.org.uk/paul-briggs/>

What most strikes me, is that the judge seems to be quite forcefully drawing-out during the court proceedings, that the treating doctor simply does [did] not understand MCA best interests:

Treating doctor is asked if she's had formal training in the Mental Capacity Act.

This question was raised by counsel for Paul's wife. The treating doctor was asked about training in the Mental Capacity Act 2005 because some of the doctor's statements did not seem consistent with having acted in accordance with the Act.

The treating doctor's answer was 'No', she had not had formal training on the Act.

3. The Judge questions the treating doctor's use of the term 'medical' best interests.

The judge queries the use of the term 'medical best interests' because best interests decisions, by definition, involve a holistic assessment which goes well beyond medical information and includes consideration of the person's past and present wishes. See Section4(6) Mental Capacity Act 2005.

4. Treating doctor is questioned about her own ethical position.

Questioned about her own ethical position the treating doctor says it is always unethical to withdraw a feeding tube from any minimally conscious patient in Paul's situation, simply because we know improvement can occur.

This questioning, and the response from the doctor, suggests that this doctor may have found it hard to carry out a 'proper' best interests assessment for Paul Briggs as an individual, taking into account what he would have wanted in this situation. Instead she was taking a generalised position based on her own ethical beliefs about minimally conscious patients in general (and Paul Briggs was only 16 months post injury, and further recovery was possible). It may be that she should have declared a conscientious objection and passed the decision over to someone else.

5. Judge questions treating doctor: "You have not carried out a best interests exercise - instead a significant factor has been your own ethical views".

In the published judgment the judge said that he thought her ethical approach was understandable and commendable, but pointed out that it was not an approach that Mr Briggs himself would have taken.

The courtroom discussion reflected that fact that: 'best interests' are not the same as the patient's 'medical interests' and it is not correct to assume that one **must** continue to provide life-sustaining treatment for a patient simply because they have potential for recovery. The discussion also highlighted that believing that a particular course of action is 'always' right for patients in a particular category is not compatible with making person-centred best interests decisions for individual people in your care and that healthcare professionals should not impose their own ethical values on their patients.

Actually, if a blood transfusion is **not** being considered when life-sustaining treatments are being considered on a best-interests basis, then Mrs W was arguably more-likely to receive them if doctors were unaware of her ADRT refusing a life-sustaining blood transfusion. We can't be sure – we don't know what Mrs W knew, and in fact there are aspects of the case which serve to impede a correct-analysis of 25(2)(c). I will now move on, to such an analysis – retaining from the case, the most fundamental issue.

THE TWO CONVERSATIONS WITH DR J THOUGHT THROUGH

14 What we definitely do know, is that there were two conversations between Dr J and Mrs W. In most cases, we might view something as a single conversation with an interruption within it – here there was a 30-minute gap between two conversations which appeared to conflict with each other (apparent contradictions in themselves, would not indicate that something was not a single conversation) and, crucially, Dr J judged that Mrs W's mental capacity was not consistent.

So without making any further assertions, we can examine four possibilities which involve two hypothetical conversations – we only need to be clear that the thrust of the first conversation seems to be inconsistent with the ADRT, whereas the second conversation seems to be consistent with the ADRT. It follows, that we have only four possibilities to analyse for the purposes of section 25(2)(c):

1/ A conversation which seems to contradict an ADRT, followed by a conversation which seems consistent with the ADRT, and a capacitous patient for both;

2/ A conversation which seems to contradict an ADRT, followed by a conversation which seems consistent with the ADRT, and an incapacitous patient for both;

3/ A conversation which seems to contradict an ADRT, followed by a conversation which seems consistent with the ADRT, with the patient being capacitous for the first conversation and incapacitous for the second conversation;

4/ A conversation which seems to contradict an ADRT, followed by a conversation which seems consistent with the ADRT, with the patient being incapacitous for the first conversation and capacitous for the second conversation.

I remind the reader, of the point I stressed in my 7 – there **must be** a specific point-in-time when an Advance Decision which had been valid until that time, becomes invalid.

Poole J seems to attach more force, in the context of 25(2)(c), to statements made when a patient's 'level of capacity' is greater. It follows, that Poole J and I both think that the conversations in 1/ carry the most weight. **If the first conversation with the capacitous patient doesn't 'trigger' 25(2)(c), it is hard to understand why the first conversation with an incapacitous patient could trigger 25(2)(c).** However: if I hand my written ADRT to a doctor, and the doctor reads it and then says 'but – you've just done something inconsistent with this Advance Decision, so it is no longer valid' then I would simply take the document back, resign it [with a date], then hand it to the doctor and say 'witness my signature'. *That isn't going to get to a court, is it!*

The same thing can happen, if a doctor decides a conversation with an incapacitous patient invalidates the ADRT, and it is followed by a conversation when the patient is capacitous – the patient can reinstate a valid ADRT.

So in my list of possibilities, for 1/ and 4/, then if we assume there is only a 30-minute gap between the two conversations, we would have a valid Advance Decision after the second conversation.

In 2/, when the patient is considered incapacitous during both conversations, the relevant question when thinking about 25(2)(c) is 'does the first conversation make the ADRT invalid?'. If it does, then the second conversation cannot make the ADRT valid again – for that to happen, the patient must be capacitous at the time of the second conversation. If the first conversation did not make the ADRT invalid, then the ADRT is still valid at the time of the second conversation – so, the question becomes 'does the second conversation make the ADRT invalid?'. The answer is clearly no – in all of my scenarios, the second conversation is 'supportive of the ADRT.

Possibility 3/ leaves us with an invalidated Advance Decision. But, *it shouldn't* – because if a doctor thinks that a capacitous patient has somehow withdrawn an ADRT during conversation but without actually saying 'I'm withdrawing my ADRT', then during the conversation the doctor should ask 'Are you withdrawing your Advance Decision?'

Poole J, doesn't seem to have applying the obvious logic that 'if there are two different conversations, and an Advance Decision cannot be both valid and invalid at the same time, then only one of the two conversations must be the trigger for invalidation of an Advance Decision'.

Poole J writes:

57. The determination of whether Mrs W has done something clearly inconsistent with the advance decision remaining her fixed decision has profound consequences and requires the most anxious consideration. I recognise that the evidence before me does not all go one way. However, weighing all the matters discussed, I am satisfied, on the balance of probabilities, that Mrs W has done things clearly inconsistent with the advance decision remaining her fixed decision. She granted to her children, whom she surely knew were hostile the Jehovah's Witnesses denomination, authority to make decisions about all medical treatment, other than life-sustaining treatment, on her behalf should she lose capacity to make such decisions for herself, without mentioning to them or including in the written LPA any preference or requirement not to receive blood transfusion or blood products. The advance decision was widely drawn and did not restrict the refusal of consent to blood transfusion or blood products by way of life-sustaining treatment. Her actions at the time of granting the LPA were in my judgment clearly inconsistent with the advance decision remaining her fixed decision. For the reasons stated earlier, I must presume that she had capacity at that time.

58. Likewise, Ms W's actions earlier this year on requesting the removal of the DNR notice, without qualification and without telling her children or, to their knowledge, her clinicians, about the advance decision or that she would refuse a blood transfusion or blood products is, in my judgment inconsistent with the advance decision remaining her fixed decision.

59. Mrs W's stated wish at 1500 hours on 17 September 2021 to have transfusion of blood "free from diseases" if she might die without it, was an expression of wishes and feelings which were inconsistent with the advance decision remaining her fixed decision. Whilst she later expressed wishes and feelings which were consistent with her advance decision, the test under s.25(2)(c) requires the court to consider whether Mrs W has done anything clearly inconsistent with the advanced decision remaining her "fixed" decision. I find that when she expressed wishes and feelings inconsistent with the advance decision she was expressing genuine wishes and feelings with more clarity of thought than when she spoke with Dr J half an hour later. It would be open to the court to dismiss both, contradictory expressions of her wishes and feelings as having no weight because of her cognitive impairment. But I am satisfied that some weight should be given to what she said to Dr J, in particular in the first conversation when, in his considered view, she was not resorting to formulaic expressions. Even if equal weight were given to both, contradictory assertions of her wishes and feelings, it could hardly be said that Mrs W was acting consistently with the advanced decision being her "fixed" decision.

Poole J seems to be doing what is correct when making a best-interests decision: considering everything relevant, at the time the decision is being made. **But section 25(2)(c) is not a best-interests determination, and the fact that an Advance Decision must become invalid at a particular time, means we cannot apply the same type of thinking. If we do not say when the ADRT became invalid, and which particular 'thing done' triggered the change to invalidity, then we cannot claim to have applied 25(2)(c) correctly.**

I note that Alex tells us:

The Trust asserted that the advance decision was not now valid because s.25(2)(c) was made out: this meant, Poole J considered, that “*the burden of proof [was] on the Trust which must establish that on the balance of probabilities Mrs W has done something inconsistent with the advance decision remaining her fixed decision*” (paragraph 54).

I don't see that in section 54 of the ruling – but it is in 53:

53. The Trust asserts that the advance decision is not now valid because s.25(2)(c) is made out. I treat the burden of proof as being on the Trust which must establish that on the balance of probabilities Mrs W has done something inconsistent with the advance decision remaining her fixed decision.

If we are being told – and it does look as if we are being told this so far as I can see – that Poole J has decided to read section 25(2)(c) as saying

(c) has done anything else PROBABLY inconsistent with the advance decision remaining his fixed decision.

then I don't believe that a judge has the power to do that – it is clear that these two forms of wording imply different levels of certainty

(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

(c) has done anything else PROBABLY inconsistent with the advance decision remaining his fixed decision.

and the Act has chosen the first version. There is a very obvious difference, between saying ‘something is probably true’ and saying ‘something is clearly true’.

Poole J does return to the Act's wording at the start of 57:

57. The determination of whether Mrs W has done something clearly inconsistent with the advance decision remaining her fixed decision has profound consequences and requires the most anxious consideration.

If we are being told in 53 that ‘the Trust must, on the balance of probabilities, establish that Mrs W has done something CLEARLY inconsistent with the advance decision remaining her fixed decision’ then I would agree – but, that isn't what 53 says. However, what I'm saying is that section 53 should have said:

53. The Trust asserts that the advance decision is not now valid because s.25(2)(c) is made out. I treat the burden of proof as being on the Trust which must establish that Mrs W has done something inconsistent with the advance decision clearly remaining her fixed decision.

PONDERING SOME SCENARIOS

15 It is a matter of 'happenstance' that Poole J was for practical purposes, considering the validity of the ADRT at the same time the treatment would have been applied or withheld.

Often, we will have situations when the patient lacks capacity, we know there is an ADRT, and we [very sensibly] want to decide if the ADRT has been made invalid by something in the past – not because the treatment is being considered at the time, but because it might be considered at a future time.

It is not unreasonable to envisage a situation, when the patient is incapacitous (that often happens during end-of-life) and there would be a disagreement between doctors, relatives, family-carers, nurses about whether something in the past had caused an Advance Decision to have been made invalid by means of section 25(2)(c). Does Poole J believe that all such situations should be sent to court, for a ruling about the validity of the ADRT? **Because, there could be a lot of such situations.**

In the case of Mrs W, because she stated that it was her religious belief that was her motivation to refuse a blood transfusion, if it appears that her religious beliefs had lapsed or been modified, then that might point towards her ADRT no longer reflecting her position on blood transfusions. But even so, Poole J was drawing inferences which I find unreasonable – for example, it is not reasonable to cite her objection to the DNACPR as being incompatible with an ADRT refusing a blood transfusion.

Covid Jab Man

Consider a 60 years old man, who is considering Covid vaccinations. And, what would be his position if he lost capacity. We could have many things, influencing his thinking, including the following:

- * He has had several Covid jabs – the most recent jab, gave him some painful side-effects
- * He believes he has had Covid at least twice after his first jab, and that he had Covid once before his first jab – none of these infections, seemed more serious than a typical mild cold
- * The Covid virus seems at present to be becoming ever-more-infectious, and at the same time increasingly less dangerous when it causes an infection (this might change – a more-damaging variant might appear)
- * Covid infections become more dangerous as you get older
- * The 'party line' from the NHS, always seems to be to encourage people to accept booster jabs when they are made available
- * It seems to take roughly as long for a vaccine to be created, as for the next variant to emerge: put simply, we seem to be offered vaccines which were designed to cope with the previous variant, not necessarily the current variant

* Some of the vaccines are being manufactured with 'recently-developed processes' which, while they might well be 'safe', have not got a long-term track-record to examine

* The chance of being exposed to the virus, depends on how much virus is circulating

* If he has lost mental capacity, and if he is made [on a best-interests basis] to have a job and that job causes bad side effects, would that make his incapacitous-self distrust clinicians and carers?

I can see no reason, why the man might not put those things together, and decide to make an ADRT which refused Covid vaccinations if he was younger than 75. And while he was still capacitous, he would consider all of those factors whenever a Covid booster was available for him – so, he might at times accept a booster jab, and at other times decline a booster jab.

So, if he creates his ADRT aged 60, loses his mental capacity aged 69, and it is known that after he had created his ADRT [which refuses Covid jabs if he is younger than 75] he accepted two booster jabs, then THAT DOES NOT CONFLICT WITH HIS ADRT.

It simply isn't logically the case, that accepting an intervention while still capacitous necessarily indicates that the person's refusal of the intervention in an Advance Decision [which the person only intends to apply AFTER incapacity] has been 'retracted' via section 25(2)(c).

Even if he explains the things he has considered when making his Advance Decision, there is every reason to think that different individuals would arrive at different ADRTs when pondering that list of things.

A Monty Python sketch?

If section 25(2)(c) applies during my mental incapacity, then the reason for making an ADRT seems to be thwarted – and, this conversation [with the doctor's position being 100% constrained by section 25(2)(a) for the patient's first statement, and by section 25(2)(c) for the patient's second statement] does seem totally absurd:

Patient to Doctor: I am withdrawing my Advance Decision to refuse the treatment.

Doctor to Patient: I'm sorry, but in my opinion you don't have the mental capacity to withdraw your Advance Decision.

Patient to Doctor: But I'm not necessarily refusing the treatment any more – I might want that treatment.

Doctor to Patient: Ah – what you've just told me, means that your Advance Decision is no longer valid.

Patient to Doctor: So, my ADRT doesn't exist any more?

Doctor to Patient: Yes – your ADRT doesn't exist because you've told me you might want the treatment refused in the ADRT.

Patient to Doctor: Right. One of us, apparently, lacks mental capacity. You've just told me that I couldn't cause my ADRT to cease existing by telling you I was withdrawing it – but I could make the ADRT cease existing by telling you I might now want the treatment the ADRT refuses. Can you explain that to me, doc?

The above strikes me as ridiculous: if my actions after I've lost capacity can invalidate my ADRT, then it seems very-close-to-pointless for me to create the ADRT. Especially to any lay person who is thinking of making an Advance Decision, goes to the trouble of looking at the MCA, and reads section 24(1).

It has been put to me, while I was discussing 25(2)(c) and Poole J's ruling with various people, that perhaps I think a future-incapacitous-person should always have his/her fate determined by an Advance Decision. The wording in the e-mail I received was:

Hi Mike

I might frame your dialogue like this:

Would you always want to be bound by your advanced decision, no matter what you said or did, at the time when it might be relevant?

Um..

Did you know that MCA provides a framework to think through this dilemma?

Oh good

Well, this entire piece, is discussing the 'framework' the MCA provides to think this through.

And my answer to the question is 'no'. I think that Happy Dreamer should be treated for his pneumonia, in this scenario, despite Grumpy Thinker's Advance Decision refusing treatment for pneumonia:

Grumpy Thinker to Happy Dreamer

Grumpy Thinker, is capacitous but doesn't enjoy being alive all that much. He creates a series of Advance Decisions which refuse various life-sustaining interventions.

Subsequently, something happens to Grumpy Thinker: if you insist on an elaboration of that 'something' then take your pick from a stroke or a car accident. The point is, the event turns Grumpy Thinker into Happy Dreamer. Happy Dreamer is physically very healthy, but is living 'in his own world'. Happy Dreamer appears to be very happy and to enjoy being alive. But, if you try to engage Happy Dreamer in conversation, usually Happy Dreamer ignores you. Sometimes he looks at you, and smiles. When he is developing pneumonia, and you ask 'Do you realise that you are poorly – we need to give you medicine to make you better' Happy Dreamer responds with 'Pretty flowers'.

I absolutely, think Grumpy Thinker's Advance Decision should be ignored – thinking ‘as a human being’ it is wrong to deprive Happy Dreamer of what would probably be many more years of a life he is enjoying, by not treating his pneumonia (which, if treated, would almost certainly be quickly cured and he would be restored to his previous physical health within days). **But I can't see – even with 25(2)(c) – how we get to ‘Happy Dreamer should be treated’ from the MCA.**

CLOSING

16 I don't see why Poole J has concluded that the appropriate level of certainty when considering section 25(2)(c) is balance of probabilities. The MCA tells us that capacity is to be decided on that basis – but the MCA also sets a very-low-bar for capacity, in sections 3(2) and 3(3).

I think that the level of certainty when applying 25(2)(c) should be the beyond a reasonable doubt test. We should have a strong reason, to override a decision which was made by the person when capacitous.

17 Who decides?

How is a dispute between family and clinicians, or within family or within clinical ranks, resolved? Surely we don't want enormous numbers of cases going to the Court of Protection for a ruling? Do people who would possess section 6(6) authority over best-interests decision-making, stand above everyone else when 25(2)(c) is being applied? I can't see where we are told ‘who decides’ in the Act, if we are to avoid a judge deciding. But if everyone involved tried to honestly apply a beyond-a-reasonable-doubt interpretation to ‘clearly’ in 25(2)(c) then there would be fewer unresolved situations than if the balance-of-probabilities interpretation is applied.

I suspect, that if judges applied 25(2)(c) correctly – and were clear about what ‘anything’ had rendered the Advance Decision invalid, and when the ‘anything’ had happened - then there would also be [probably many] fewer cases of judges ruling that 25(2)(c) had made an ADRT invalid. Poole J's reasoning is clearly not compatible with an Advance Decision necessarily being either valid or else invalid at any given time, and that once having become invalid the ADRT cannot subsequently simply become valid again. Poole J seems to think of Mrs W's Advance Decision as some sort of Schrödinger's ADRT – it can exist as both valid and invalid (which we can frame as ‘existing and not existing’) for all of the time until he ruled on its validity, when he in effect only says what amounts to ‘it isn't valid **now**’.

It is also worth noting, that Jackson J's ruling

<http://www.bailii.org/ew/cases/EWCOP/2015/60.html>

might suggest that careful consideration should be given to the second of the conversations with Dr J – that it should be considered, that if Mrs W was still of the belief that accepting a blood transfusion would, in effect, mean that she had broken God's law, then perhaps she would feel that even if she hadn't consented she would not be going to

heaven. That, she might be alive, but feeling 'sinful' for the rest of her life. We know that Mrs W did seem to continue to believe 'on the face of it':

10. The evidence establishes that Mrs W is 80 years old. She is a Jehovah's Witness. Her late husband was a very committed Jehovah's Witness. Her children believe that she joined the denomination to be a "good wife" to him but they also told me that she continued to attend meetings, including by a video link facility, until very recently when she went into a care home.

Alex tells us:

The analysis and observations of Poole J about the concept of "doing" something inconsistent are not a licence simply to ignore an ADRT on this basis – he made clear both the burden of proof and the threshold which needs to be crossed. However, it seems to me that this approach to the meaning of "doing" must be right, both legally and ethically. The very important corollary of this is that, as set out in more detail here, advance decisions may well be more 'brittle' than some may understand to be the case – and that it is extremely important that any advance decision includes a values statement so as to be able to guide decision-making in the event that (as here) the decision is ultimately one made by reference to best interests, rather than simply loyally seeking to abide by the ADRT.

As should be obvious, I am not as enthusiastic about Poole J's reasoning as Alex is – and I also consider that Poole J has set the 'certainty bar' too low by using a balance of probabilities test, instead of a beyond reasonable doubt test. I don't think that an Advance Decision should include a values statement unless the situation is simple – such as 'I'm refusing blood because of my religious beliefs'. 'Covid Jab Man' could not give a 'values statement' of the type which Alex seems to want, even if he tried to. Grumpy Thinker might give a values statement along the lines of 'if I can't make my own decisions, then I think I would be better dead'. **And if there is an Advance Decision, I want it to be considered before anyone starts pondering what they would do if best-interests decision-making became necessary.** *It is also far better, if this is possible, to appoint a welfare attorney (or several) with section 6(6) authority and to keep your attorneys up-to-date, by conversation, with your 'values'.*

Anyway, Hayden J has explained what amounts to 'ask close family and friends for 'the person's values':

<http://www.bailii.org/ew/cases/EWCOP/2014/4.html>

The patient was in a minimally conscious state and the section of real interest is this one:

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.

I absolutely agree with Alex, that Advance Decisions are far more 'brittle' than most lay people would believe – they are usually told what amounts to 'if you want to make a legally-binding refusal of a treatment, you can make an Advance Decision'. There are already serious problems with ADRTs refusing CPR, as I have described in a piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/449/>

and which I will reproduce in the appendix. Having now examined 25(2)(c), I think the problems are even worse than I had previously thought!

This is a version of a previous PDF which had some proof reading errors in it. I have also posted (07/03/23) some descriptions (taken from the internet) of how various organisations describe an Advance Decision in my DiC thread. So far as I can see, almost nobody informs lay readers about section 25(4)(c), how it works in practice, and its possible consequences. One very lengthy document about Advance Decisions **which is aimed at professionals** says:

Under 'IS THE ADVANCE DECISION VALID'

Has the person done anything that is clearly inconsistent with the advance decision remaining his/her fixed decision?

YES: This is not a valid advance decision. It is important to identify what the person has done, discuss this with anybody close to the person, explain why this is inconsistent with the advance decision remaining his/her fixed decision, and record your reasons.

It seems to me, that this is very-much framed in the context of what a doctor or similar person should do, from both logical and 'self-protection of the doctor' perspectives. It also probably carries an implication that it will be the professional who would apply the treatment.

I write about cardiopulmonary resuscitation when the loved-one/patient is at home, and when family-carers or other relatives are involved:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Clinicians-and-Relatives-Consensus-Uncertainty-Emergency-and-Trust-a-continuation-from-a-Journal-of-Medical-Ethics-paper/1112/>

Unlike a blood transfusion, many family-carers could attempt CPR – so we can't assume that only the professionals could apply the treatment. So, if a loved-one/patient loses mental capacity during the 'dying process', and the validity of an Advance Decision which refuses CPR is being argued over, nobody is in a position to 'decide' whether CPR will be attempted or withheld: it would hinge on whether a person at the arrest considered that the ADRT was valid or invalid. Advance and Future Care Planning require such things to be worked-through before events actually happen, and before an event it isn't (except for CPR – CPR is always 'life sustaining' in an MCA context) possible to know whether the treatment would be life-sustaining either.

There seems to be something – I'm not sure whether to describe it as 'an attempt to 'exclude' family-carers' or as 'a failure to appreciate that family-carers must be involved in making these plans' – in 'NHS Thinking' at the moment, which is insufficiently-inclusive of family-carers during ACP and FCP:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Comments-on-some-NHS-Advance-Care-Planning-Guidance-about-the-principles-of-ACP/1120/>

End-of-Life-at-Home is not similar to a court ruling being made by a judge: at home, we will either have genuine collaboration between family-carers, relatives, doctors, nurses and 999 paramedics, or else we will have a combination of chaos and conflict in many situations. **And I don't want people who are dying, to be dying surrounded by conflict and chaos.**

Written by Mike Stone, March 2023

Twitter @MikeStone2_EoL

APPENDIX

Jane, Mary, Tony and their Advance Decisions

Advance Decisions are described in sections 24-26 of the Act, and the section which is most useful for 'revealing what an ADRT is' is section 25(4):

25(4) An advance decision is not applicable to the treatment in question if—
(a) that treatment is not the treatment specified in the advance decision,
(b) any circumstances specified in the advance decision are absent, or
(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

Of passing interest here – because in reality 'everyone seems to ignore this 'as a technicality'' - it appears that an ADRT can only be phrased as 'I refuse 'specified' treatment if 'qualifying circumstance/s'. From 25(4)(b) it looks as if you can write 'I refuse CPR' and that would mean 'I refuse CPR in all situations'. Or you might write 'I refuse CPR if I am in my own home' which would allow CPR anywhere else, for example if you were in hospital. But 'I refuse 'treatment' unless 'circumstance''

doesn't fit with 25(4)(b).

The core objective of an ADRT is, to my mind, revealed by 25(4)(c) – unless there is good reason to believe that the person had not considered the situation when making the ADRT, the ADRT should be accepted and followed. And even then, knowing the person had not considered something is not enough: to 'refute' the ADRT, we must have a reasonable belief that the person who made the ADRT did not know about something, and had he known about it he would have accepted the treatment.

Jane lives to be sporty and active, and one of her passions is rock climbing. Jane cannot conceive of being alive but bedbound, or even worse alive with brain-damage and being kept alive by clinically-assisted nutrition and hydration (CANH). So Jane wants to use an Advance Decision(ADRT) 'to refuse such future outcomes'. In essence, Jane is worried that she might fall while rock climbing, and then end up in a situation she 'dreads'. But, Jane cannot refuse a future situation using an ADRT – she can refuse treatments. It isn't immediately obvious, what Jane should refuse: perhaps something such as 'I refuse artificial life-support if it has already been in place for 7 days' (then, if she hadn't become capacitous after 7 days on life-support, the life-support would have to be removed). I'll leave the reader to work out what Jane might write on her ADRT, and in passing I will point out that whatever her ADRT says, it is unlikely to prevent immediate treatment if she is found at the bottom of a cliff by 999 paramedics.

Mary, is very ethically-aware. Mary considers that a drug, Traficulivir, was developed as a consequence of ethically-unacceptable research. Mary wants to be treated if she needs to be treated, but she forbids the use of Traficulivir for any purpose at all. A simple ADRT saying 'I forbid the use of Traficulivir to treat me, for any purpose whatever' should work for Mary. NOTE: 'Traficulivir' is a fictional drug [I hope!].

Tony, is faced with a potential future which he wants to avoid. He doesn't want to face 'his prognosis' if he can avoid it. So Tony writes an ADRT refusing CPR, if his heart has stopped beating for any reason. He wants to use the opportunity which a cardiopulmonary arrest would present, to avoid a future he prefers not to face. If Tony is 80 yrs old and frail, many people might easily understand this refusal. But Tony could be young, and 'still 'healthy'' but with a horrible degenerative-prognosis hanging over him: when he writes an ADRT saying 'I refuse CPR, and this refusal stands whatever caused my heart to stop beating' he means exactly that.

In my experience, the clinically-authored material on ADRTs often says what amounts to 'there might come a time, when your medical condition has deteriorated to a point when you might consider refusing CPR or other interventions'. Which is true, but not 'necessary' - you can decide to create an ADRT while you still seem to be 'very healthy'. The point is – **it is your decision, and you decide what is relevant and important yourself.**