

## Can an Advance Decision be used to forbid transfer from home to hospital?

I was prompted to investigate this question – by asking on Twitter, Facebook, etc – after Jenny Kitinger, while talking on BBC Radio 4 about various end-of-life issues, mentioned that her mother had an Advance Decision (ADRT) which refused transportation to hospital.

It isn't at all obvious, if the Mental Capacity Act's rules for advance decisions (see sections 24 – 26 of the MCA) allow for an ADRT to validly refuse transport to hospital: but, if we patients and families are to properly 'plan for our end-of-life', we need to know the answers to questions such as that. In particular, it is deeply unsatisfactory to create an ADRT saying 'you must not take me to hospital, whatever is wrong with me, and even if this decision to stay in my own home puts my life at risk', and for your family carer to understand your decision, if you then collapse, your carer calls 999, and a 999 paramedic says 'an ADRT cannot validly forbid transport – transport isn't a treatment, and an ADRT can only refuse a treatment'.

Before I get into a legal analysis, I will first explain:

### **Why This is Important**

When my own mother was dying, it was clear to me that she placed dying at home ahead of any medical interventions which might have extended her life: in fact, 'she actually wanted to be left alone to die, at home, without any clinical involvement'.

Many people would make a different choice, but *if a family carer sees their loved-one rejecting treatments because of an over-riding objective of dying at home, then if 'at the last moment' their loved one is 'whisked off to hospital' and dies in hospital, the family carer will, rightly, be very annoyed or angry about that.*

A few years ago, a nurse who was also a Ward Manager, described her own mother's death during an online Nursing Times discussion. She told us (my bolds to point at the parts of relevance to this ADRT discussion):

*'I am a Registered Nurse working as a Ward Manager caring for patients at the End of Life.*

*Having looked after my own mum at home, at the end of her life, I can honestly say the process was exhausting and lonely. We had a lot of support from our local hospice and macmillan support too but we didn't get night care every night and care in the day was very limited. Here in lies the problem. **For those patients who wish to die at home the support needed for those who are caring for that person is immense. The stress and worry it brings can be immense and there just isn't enough support out there to achieve it well all the time. When we receive a patient onto my Ward for end of life care from home it is very often the relatives who can no longer cope at home. This is a very telling reflection on the committment caring for someone at home at the end of their life requires for these families and is very hard to achieve.***

***Having done it and succeeded, if you like, in giving my mum her death at home, I feel there needs to be much, much more support and resources made available if this ideal is to become a reality and its needed now not tomorrow. For time limited people now is all you have !!!!!!!!!!!!!!!!'***

The nurse was then asked, how would she have felt, if her mum had not died at home:

'I think your mum had made it clear to you that she wanted to die at home (as mine did) and you managed to facilitate her wish. I am interested in how you think you would have felt, if you had failed and your mum had actually died in hospital ?'

The nurse replied with:

*Thank you for query via your post and also just noticed my spelling is not great today- apologies to all*

*In answer to what you said I really would have felt like I betrayed her as it was her only request to me and my sister(Radiographer in the NHS) and we knew we just had to give her what she wanted.*

*Having said that we were very much the daughters and not a Nurse or a Radiographer if that makes any sense. It was just about us as a family doing what we could to give her what she so desperately wanted.*

*We were not better at it than anyone else and my heart goes out to those who don't manage to avoid going into hospital when it isn't what is wanted. Bereavement is bad enough without the added burden of guilt too.'*

This is **deeply important** to many family carers:

*my heart goes out to those who don't manage to avoid going into hospital when it isn't what is wanted. Bereavement is bad enough without the added burden of guilt too.'*

While I am filling-in some 'background', the RCP End of Life care Survey 2011 included this comment from a doctor:

*'Having lost both parents and other friends/relatives in different ways wrt EOLC I have learnt the most from this. I also believe that time and maturity at the job make a huge difference and hence my reticence to learn from colleagues who are too junior.'*

When my own parents were dying, my position was that **I supported their decisions**: partly, this is because of a 'desperate desire' to not impose a 'bad future' onto a loved-one because of a decision which I made – in consequence, I (and I suspect many or most family carers) are really motivated to try and 'get decisions from their loved one' and to follow those decisions. Extracted from a recent piece of mine:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/293/>

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

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

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

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

my loved-one, so:

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

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

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

A recent Twitter Poll I posted, seems to back this up:

[https://twitter.com/MikeStone2\\_EoL/status/931819196207509504](https://twitter.com/MikeStone2_EoL/status/931819196207509504)

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

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

From the dying patient 92%

From the GP and nurses 2%

From nobody 6%

Total votes cast 60

I might be 'cynical' but, from my family-carer perspective, I 'see' two very common themes, when clinicians write about family carers. One is 'the family demands futile treatment' and the other is 'the relatives want the patient to die for their own selfish motives'.

**I don't often see 'the family have spent a lot of time talking to, and listening to their dying loved-one, and family carers are battling with clinicians who have not spent anything as like as much time listening to the patient, to simply try and get the clinicians to do what the patient would have wanted'.**

## **The legal analysis of my question**

The first point, is that the MCA clearly 'builds on' its rules for consultations during capacity, in its rules for Advance Decisions.

The description of 'the consent process during mental capacity' is this:

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).

That does **not** in fact require the patient to explain why the treatment is being accepted or refused: the clinician needs to understand the patient's clinical objective – the 'I've got a pain in my back – could it be fixed?' - but, once a potentially-successful treatment has been identified and offered, the clinician describes clinical options and prognoses, and the patient then simply says 'yes or no' to the offer. This is 'Informed Consent'.

In principle, you could envisage a consultation with a mentally-capable patient, as 'an 'unlimited' series of offers from the clinician'

'I could do this – do you want me to do that or not?'

during which the clinician offers all possible treatment options one at a time, and the patient might say 'no' to every offer.

Clearly, in theory, this face-to-face consultation process could result in 'a refusal of all treatment'.

The problem is: do the MCA's rules for its Advance Decisions, which we know only cover the 'refusals', also impose other restrictions compared to face-to-face consultation?

Advance Decisions are a 'projection of informed consent's 'negative' - which I usually call Considered Refusal – into future incapacity which was anticipated by the patient': the MCA is very clear about the difference between an ADRT and best-interests decision-making:

5(4) Nothing in this section affects the operation of sections 24 to 26 (advance decisions to refuse treatment).

So, as an Advance Decision is clearly a projection of a part of Informed Consent/Considered Refusal, and that process does **not** require an explanation of 'why I am refusing the offered treatment', we should ponder 'why would an ADRT need to contain an explanation of why the refusal has been made?'

The answer – despite what some clinicians keep writing – **is that an ADRT is not required to 'give its reasons'**:

24(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.

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.

‘Circumstances’ may be specified – and it is an absence of a specified circumstance, which makes the ADRT not applicable.

In fact, the MCA describes this format for an ADRT:

‘I refuse [specific treatment] if [optional specific circumstance]’.

If you write ‘I refuse CPR if I am in my own home’ then you are refusing CPR at home, but not elsewhere [such as if you arrested in hospital].

But it does not - ‘technically’ - appear possible to write:

‘I refuse [specific treatment] unless [optional specific circumstance]’.

You apparently cannot write:

‘I refuse CPR unless my arrest appears to have been caused by a blocked breathing-tube’.

This is a problem which is probably ‘ignored in reality’ - the idea of an ADRT is ‘that its instruction must be clear’: despite any ‘awkwardness of the Act’s wording’ most people would, I think, accept ‘I refuse CPR unless my arrest appears to have been caused by a blocked breathing-tube’.

Less clear – but definitely a problem – is that if you write ‘I refuse [specified treatment] under all circumstances’ it seems to be ‘technically inapplicable’ because most of ‘all circumstances’ cannot possibly be present: **think about 25(4)(b)!**

**According to 25(4)(b), if you write just ‘I refuse CPR’ then that should be a refusal of CPR in all circumstances – in reality many clinicians would not agree about that, so we urgently need to be told what to write on an ADRT to indicate that ‘my refusal is absolute and applies in all circumstances [which I have considered]’.**

**The circumstances mentioned on an Advance Decision, serve to ‘qualify’ or ‘restrict’ the refusal of the treatment.**

**Clinicians instinctively ‘think about the clinical situation’, but there is no reason for the circumstance to be a clinical circumstance: the circumstance can be anything which would affect the patient’s refusal. For example:**

**‘I refuse cardiopulmonary resuscitation if my new Will (being prepared by my solicitor as I write this) has been signed and witnessed’**

**makes perfect sense – but the restriction is ‘wider life’ circumstance, not a clinical situation.**

Before I move on to answering the 'refusal of transportation' question, I will point to section 25(4)(c) – the circumstances in 25(4)(c) are not mentioned on an ADRT (certainly not in the 'instruction' section – it might make sense to add a 'footnote' along the lines of 'the following circumstances [give them] would not change my decision to refuse the treatment'). I have written about 25(4)(c) and I will extract from that here:

<http://www.bmj.com/content/356/bmj.j1216/rr-4>

*Section 25(4)(c) is worth paying attention to. It amounts to 'if the person reading the ADRT and considering treatment, is aware of something the patient was unaware of, and it is reasonable to believe that this new factor would have caused the patient to accept the treatment, then the treatment can be applied'. Personally, I cannot see how any 999 paramedic - who cannot possibly 'know the patient' - can claim, whatever the paramedic thinks might be a 'new factor', to reasonably believe that this new factor would have changed the patient's mind: a person who 'knows the patient', such as a family carer or a relative, might be able to reasonably believe that some new factor would have changed the patient's mind. But 999 paramedics, or A&E clinicians - surely not, if they do not know the patient well, then how can they use 25(4)(c) as a justification to ignore the refusal recorded on the ADRT ?*

So – my own answer to 'Can an Advance Decision be used to forbid transfer from home to hospital?': I am not sure.

It isn't clear, that 'transport' is 'treatment'.

However – it is logically possible to prevent transfer to hospital, using Advance Decisions.

You could in theory (note that an ADRT is defined by the treatment being refused – so you can have as many ADRTs as you want, provided each specifies a different treatment) write one or more Advance Decisions, which amounted to:

'I refuse all treatments if I am in hospital'

There would be no obvious justification for clinicians to transport a patient to hospital, if the patient could not be treated when in the hospital.

But, it 'now gets very messy'.

It isn't entirely clear, that you are allowed to write 'all treatment' on an ADRT, either. And the MCA's Code of Practice doesn't help – it is both vague and also legally wrong, when it addresses this issue. The Code says:

**9.13 An advance decision refusing all treatment in any situation (for example, where a person explains that their decision is based on their religion or personal beliefs) may be valid and applicable.**

The first point – **the clearly legally wrong point** – is that the MCA does not require 'my reasons for refusing' to be given on an ADRT: that is some sort of 'anachronism from an earlier time' which had clearly been discarded by the time the MCA was enacted [the MCA allows patients to make choices for their own reasons, and their reasons are irrelevant and do not matter: unless proven mentally-incapable 'patients just decide'].

The second point, is the 'may be valid and applicable' wording: I would find it more helpful if it had said:

9.13 An advance decision refusing all treatment in any situation can be valid and may be applicable.

So, if you can refuse all treatment, you could write on a single ADRT:

'I refuse all treatments if I am in hospital'

If you cannot write that, then you could in theory write a separate ADRT refusing every possible medical intervention:

'I refuse cardiopulmonary resuscitation if I am in hospital'

'I refuse blood transfusions if I am in hospital'

'I refuse the taking of blood samples if I am in hospital'

'I refuse artificial ventilation if I am in hospital'

Etc. The legal concept beneath both Informed Consent and also ADRTs was very clearly expressed by Mr Justice MacDonald:

<http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWCOP/2015/80.html&query=court+and+of+and+Protection+and+Justice+and+MacDonald+and+sparkle&method=boolean>

The ruling explains the law in its first two sentences:

'A capacitous individual is entitled to decide whether or not to accept medical treatment. The right to refuse treatment extends to declining treatment that would, if administered, save the life of the patient.'

Deeper into the ruling, we can read the admirably clear:

'... others in society may consider C's decision to be unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society in general. None of this however is evidence of a lack of capacity ... C has capacity to decide whether or not to accept treatment [so] C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists). As a capacitous individual C is, in respect of her own body and mind, sovereign.'

## **Closing Comments**

I explained earlier, why this is important – because 'unwanted transfer to hospital' can be very upsetting for family carers and patients, especially during end-of-life – and, therefore, why it needs to be clarified.

I will also show a tweet posted by Jenny Kitzinger, about how her mother's 'ADRT refusing transportation to hospital' was actually used – it wasn't used 'in a discussion with 999 paramedics 'during an emergency'' but in a rather 'simpler' situation:

<https://twitter.com/JennyKitzinger/status/949326889977597952>

**Jenny Kitzinger** @JennyKitzinger Jan 5

Replying to [@MikeStone2\\_EoL](#)

Thanks & hope yr question is answered re the law tonight. In practice, my mother's AD helped when GP surgery tried to insist on transfer to hospital. She said no. They questioned her capacity. We read out her AD refusing hospitalisation & she stayed home.

There is a complication in that. If Jenny's mum was mentally-capable, then she could simply say 'I'm not going to hospital'. If Jenny's mum was mentally-incapable, and the ADRT refusing hospitalisation was valid and applicable, then again {subject to the possible challenge of 25(4)(c)} she could not be taken to hospital. If the GP Surgery considered that an ADRT refusing transportation cannot be legally valid, it would still have to be considered during best-interests decision-making – and, as a document signed and witnessed, and which the author had clearly thought 'was legally binding', given a lot of weight during best-interests decision-making. Or – cynically – was the GP Surgery 'using the ADRT for the purposes of 'back-covering' without too deeply investigating whether an ADRT could validly refuse transportation – and, at the same time, ducking any more investigation of the mother's mental capacity'?

So, we do not know exactly why the ADRT of Jenny Kitzinger's mum was 'effective'.

But it is important:

**A valid and applicable Advance Decision removes the need for any best-interests decision-making – which should be an objective of everyone, because best-interests decision-making is a fraught and complex process!**

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See also, for further analysis of Advance Decisions and of Advance Decisions versus Best Interests Decision-Making:

[http://www.dignityincare.org.uk/Discuss\\_and\\_debate/Discussion\\_forum/?obj=viewThread&threadID=865&forumID=45](http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=865&forumID=45)

In that piece, I analyse the essential difference between 'informed consent' and best interests decision-making by referring to an SCIE online learning tool.



There is also – unfortunately – a lot of obvious confusion caused by this section of the MCA:

25(6) A decision or statement complies with this subsection only if—

(a) it is in writing,

I have analysed that restriction in many places, online. Most recently, I have written about it in my 26/08/17 addition to my post at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-the-BBC-Radio-4-broadcasts-about-Mr-C./958/>

I think it would be useful to reproduce that here, so I will do so.

'... AND WATER IS WET, AS WELL!'

A Twitter conversation, on one of my old 'favourites', cropped up yesterday: does the MCA's requirement that a valid ADRT refusing a life-sustaining treatment must be in writing, mean that a verbal refusal of a life-sustaining treatment cannot be legally binding?

The answer is clearly 'no, it doesn't mean that' - I find that most of the rest of the world say 'yes, it does mean that', and to be frank 'it almost makes my brain hurt' that I need to keep arguing about this one.

I'll have yet another go – using a 'general point about the MCA', and then using 3 'collapsed into a cardiopulmonary arrest scenarios'.

#### GENERAL POINT

The MCA, is clearly about strengthening patient control: about increasing patient autonomy. It would surely be contrary, to introduce legally-binding written ADRTs and to introduce 'this now means that your expressed refusals are not legally binding on the people you tell, until you also write them down and get them witnessed'. That would be 'absurd and bonkers' so such an interpretation, simply must be 'missing something'.

Here goes – yet another way of arguing this, to add to my earlier versions.

#### SCENARIO 1

You are a 999 paramedic. You arrive at a house, there is a man lying on the floor next to a table. He is holding in his hand what seems to be a valid written and witnessed advance decision (ADRT), refusing CPR, and he is in arrest. The woman who lives next door is in the house, and she explains to you that he had fallen the week before, she had minutes ago heard a thudding noise so came round to his house, and found him on the floor, so she called 999.

You might be pondering 'why is he holding his ADRT'. You might think 'was he about to write 'I retract this decision' across the written ADRT because he had

changed his mind – is that why he was at the table, with his ADRT?’. Or you might think ‘did he feel unwell, and was he reading his written ADRT because he somehow felt he was going to arrest, and he wanted to check that if he arrested with the ADRT next to him, its wording would prevent a 999 paramedic such as myself from attempting CPR?’

You COULD NOT ANSWER THOSE QUESTIONS. There is no possible way, for you to know the answers.

## SCENARIO 2

You are a GP visiting a patient, about his bad knee. At the end of this visit, he asks you about his ADRT refusing CPR, which you already knew about, because he consulted you when he created it 2 years ago. He gets out his written ADRT, puts it down on a table, and questions you about its wording, because he is not convinced that it will definitely prevent attempted CPR. You tell him that the wording on the ADRT should prevent 999 staff, or A&E staff, from attempting CPR. You (GP) are walking to the front door to leave when you hear a thud, and you turn round to discover that he has collapsed and arrested, and he is on the floor next to a table with the ADRT in his hand.

## SCENARIO 3

You are a GP visiting a patient, because he is going to write a written ADRT refusing CPR, and he wants to consult you about its wording. You have spent 20 minutes discussing what he should write in the ‘instruction section’ of his written ADRT, you have both agreed about what it is best for him to write in that section to convey his instruction, and OF COURSE YOU UNDERSTAND HIS REFUSAL BECAUSE YOU HAVE BEEN DISCUSSING IT WITH HIM. The patient has just picked up his pen, to complete his ADRT. But before he writes anything, while he is making a final check of what is already written on this ADRT-in-preparation, he suffers a sudden cardiopulmonary arrest, and falls to the floor next to the table, with the paper in his hand.

Three situations, but there is no ‘reasonable doubt about the patient’s instruction’ in 2 and 3, despite there being a valid ADRT in 2 but not in 3. By contrast, there is much more ‘uncertainty’ in 1 than in 2, despite there being a valid ADRT in each.

The only logical way, to make sense of this, is to assume that the thrust of the MCA – its shift away from ‘paternalism’ towards ‘patient self-determination’ - means that the ADRT must be written, precisely because the paramedic might ponder those questions, with no possible way of answering them: which means that the paramedic should withhold CPR if the ADRT is prima facie valid, and if it is apparently applicable. If the risk of a written ADRT refusing CPR being followed, has not been transferred to the ADRT’s author when the ADRT was created, then the ADRT is pointless! ‘I was told verbally by the patient 3 months ago that he was refusing - but I have not seen him since then’ is the reason the refusal of a life-sustaining treatment AS AN ADRT must be written: you cannot know, whether he has changed his mind. But it says ADVANCE decision - if you are in ongoing contact with a patient, and he verbally expresses a refusal to you, you know he has not retracted it if he has not told you that he has changed his mind. Perhaps we need a new term about these refusals: an ADVANCE decision to refuse life-sustaining treatment must be in writing, but a verbal ‘PSEUDO-CONTEMPORANEOUS’ decision to refuse life-sustaining treatment is also legally binding.

But it is BLINDINGLY OBVIOUS that in both 2 and 3 the understanding of the GP, that his patient has INSTRUCTED HIM TO NOT ATTEMPT CPR, is identical.

Advance Decisions are INSTRUCTIONS – if you have no doubt about the instruction, then as Mr Justice MacDonald explained:

'C has capacity to decide whether or not to accept treatment [so] C is entitled to make her own decision ... As a capacitous individual C is, in respect of her own body and mind, sovereign.'