'… form an advance statement in my mind'.

https://twitter.com/NWAmb_Kieran/status/1105044603768619009

Kieran Potts @NWAmb_Kieran

Replying to @MikeStone2_EoL

I'll always endeavour to listen to those on scene to build an 'Advance Statement' (in my mind) from the available info on scene. We should ALL be striving to respect the person's wishes (HCPs + family). It's not always ideal to go into these situations *blind* as Paramedics.

Kieran Potts, a paramedic, tweeted the above, after I had pointed him at my PDF which discusses decision-making for cardiopulmonary arrest at home, which can be downloaded from the thread at:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-reconciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./1031/

There seems to be an unwarranted over-promotion of 'advance statements' within the NHS at the moment – so, it is worth a bit of analysis of the term 'advance statement'. It is not an easy term to define – unlike Advance Decision, which is defined withing sections 24 – 26 of the Mental Capacity Act, **and which we should be promoting instead of** 'advance statements':

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

The MCA describes two different decision-making frameworks: it describes Informed Consent if patients are mentally-capable and can make their own decisions, and it describes 'best-interests decision-making' if the patient is not mentally-capable. Advance Decisions have got a full three sections of the MCA (sections 24 – 26) describing them – in contrast, 'advance statement' does not appear in the MCA (the Act itself) even as a term, and the whole 'advance statement 'industry'' seems to have been based on something in section 4(6):

4(6) He must consider, so far as is reasonably ascertainable—

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
(b) the beliefs and values that would be likely to influence his decision if he had capacity, and
(c) the other factors that he would be likely to consider if he were able to do so.

All the MCA says, is that a person who is making a best-interests decision 'must consider … any relevant written statement made by him when he had capacity'.

Now, there are many things which could qualify for the poorly-defined term 'advance statement', and loosely they fall into two categories:

1) A statement which is less clear than an Advance Decision – so 'I would **be likely to** refuse' instead of an Advance Decision's 'I **am** refusing';

2) A clear decision, but not a clear decision which can be expressed as an ADRT: because an Advance Decision can only be used to refuse a treatment, something like 'I would always want CPR to be attempted, however 'clinically poor' it appeared the outcome would be probably be' would be 'an advance statement'.

All decisions – whoever is making them – involve considering the current situation, the future, and the consequences of the decision made. The 'basic idea' behind an Advance Decision is that if the patient had considered the situation, and had adequately understood the 'future probabilities' and the consequences of the decision the patient had expressed in advance of incapacity, then the patient's decision should be followed during that anticipated future incapacity (see MCA 25(4)(c)). This doesn't require 'perfect knowledge' nor 'perfect foresight' - it requires an acceptable level of 'understanding of the issues' [and, as it happens, there is clear misunderstanding of the reason why the MCA requires certain ADRTs to be written – for a clear analysis of that **very vexing** issue see pages 26 – 33 in this PDF] so it requires 'the level of understanding and certainty which is achievable in the real-world'.

That raises another issue, different from the ones I have already mentioned. If the patient had considered the consequences of the decision, but had not arrived at a firm 'yes or no' position, then the patient cannot express an Advance Decision – the 'decision' expressed by the patient, would not be 'a decision' it would be the more awkward [in legal terms] 'preference'. But **if the patient had not even formally considered** an intervention, then neither an Advance Decision nor a 'formalised' 'advance statement' is possible: ***however, best-interests decision-making is still required by the law***.

I have analysed the objective of a best-interests decision in my piece at:

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

And my conclusion – my attempt 'to make it more transparent **without legal distortion**' was:

The objective is to make the best-interests decision which would result in the most satisfactory future when considered from the perspective of the incapacitous person as an individual

Nobody can clearly explain, exactly what the MCA's best-interests concept 'means' although I

think that sentence is correct – however, for cardiopulmonary resuscitation and other life-sustaining treatments, it seems clear that best-interests is virtually identical to the legal concept of Substituted Judgement:

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

Substituted Judgement amounts to 'working out what the patient would have decided, if the patient had been the decision-maker, and then doing that' [with the 'concept of' '… the patient as an individual, and with the capacity to make the decision' as a caveat implied in my sentence].

And, despite the problems with 'defining' best interests, it is clear from section 4(6) of the MCA, and from court rulings (see these court rulings), that a best-interests decision-maker is required to try and work out 'what would the patient have decided?'.

So I will now re-frame and simplify Kieran's statement, to:

The paramedics will be trying to work out what the collapsed or incapacitous patient would have decided or wanted.

We now arrive, at my objection to what clinicians write (see my objections to ReSPECT), which I will express here as a question:

Which is logically the more possible? To describe to a collapsed patient's life-partner, the clinical situation and the likely outcomes of the possible treatments, and to then ask 'what would the patient have decided?' - or to, during an emergency, ask 'how does you life-partner 'think as an individual?'.

Put another way – see the scenario I posed at the end of this piece:

To Close: (hypothetical)

I have been sharing a home with my now 'dying partner' for 20 years, although my partner has only been 'dying' for about six months. I have talked to my partner a lot during this six months, and during those 20 years. The GP has talked to my partner a little, especially recently. We both talk to the district nurses who have visited a couple of times a week for the last 6 weeks – but they are often different nurses each visit.

My partner has just collapsed. I have called 999 to find out why my partner has collapsed. I am now standing over a 999 paramedic, who is doing something to my unconscious partner. Why on earth, should I accept that this paramedic decides what happens next ?

What on earth, do the people who write end-of-life guidance, think that the people living with terminally-diagnosed patients are doing? In my opinion, most of us are very concerned to '**build an 'Advance Statement' (in my mind)**' and to '**be striving to respect the person's wishes**' - and **we are doing that all of the time 'while our-loved one 'is dying"!**

Except for 'the details of the clinical situation' we family-carers already have that 'advance

statement' in our minds, along with 'Advance Decisions' - the idea that a 999 paramedic could 'acquire that level of understanding during an emergency is bonkers!'.

Unless most family-carers during end-of-life, are very different from I was when my own parents were dying, family-carers are very keen indeed to understand what their dying loved-one wants to happen – we do that over weeks and months **and it is already 'in our minds'** if for some reason we have called 999.

If it is being asserted that best-interests decisions can be formed during 'a clinical emergency' [and, I have my doubts which I have explained in my piece which suggested 'rules for' CPR, about whether that is possible] then family-carers might be able to form best-interests decisions: but 999 paramedics clearly cannot, and the tendency will clearly be for paramedics to therefore 'default to preservation of life': and, the whole ethos of the MCA's description of best interests, is that 'default to preservation of life' has been relegated to a last resort concept. I doubt that even family-carers, would 'form' best-interests decisions about life-sustaining interventions during an emergency – as I have written in the context of CPR:

And: this is much simpler for CPR - it is much more difficult for things such as strokes in my opinion. You can be sure that 'CPR isn't wanted': either because your loved-one has made it very clear to you that CPR is not wanted, or because your loved one has made it clear 'I would now prefer to be dead'. It is probably also 'simple' for a refusal of blood transfusion made on religious grounds. It isn't simple, if it turns out your loved-one has collapsed, seems to have suffered a stroke, and the paramedic says 'looks like a stroke - might be dying, but might live on with a lot of clinical damage - if we don't treat he might die within minutes but he might not die, and he might live on with clinical damage which would be reduced if we did treat him'.

That level of certainty is in reality not 'making a best-interests decision during an arrest' – it is in fact the application of the patient's self-determination during the arrest. And although it seems clear that conceptually, if it were possible to 'consider a best-interests decision during an arrest' then that decision would in fact be the answer to 'would dad want CPR or not?', it is in reality unrealistic to expect genuine best-interests decision-making to be taking place during a cardiopulmonary arrest (CPA).

To close this piece, I will point to a piece I have written which analyses the law around CPR when various different groups of people are present at a cardiopulmonary arrest:

https://www.dignityincare.org.uk/Discuss-and-debate/download/343/

Mike Stone

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