

## She Wrote, He Said – let's call the whole thing off

I'm increasingly vexed, that the problems facing family-carers during End-of-Life-at-Home are being either inadequately considered and addressed, or possibly wilfully-avoided, by 'the system'. There seems to be a barrier, and perhaps the only way for patients and relatives to break that barrier down, is for 'us' to be more assertive in 'our' interactions with 'them': 'them' being principally doctors, and 'us' being patients, family-carers and legal proxies in particular.

Another 'lay campaigner', in the context of how 'the system' works and how the Mental Capacity Act (MCA) isn't being applied correctly and in response to some tweets of mine, recently tweeted:

*Yep, I'm deeply vexed too. It's all down to the need for a piece of paper to validate a relationship, responsibility or decision. It's wrong, and yes I agree MCA is widely misapplied, but we either go with it or find ways round it.*

I'm going to start, by explaining what I think many relatives and in particular 'family-carers' (see footnote) who are sharing a home with a dying loved-one, sometimes 'definitely know'.

Sometimes, a family-carer will be as certain as it is possible to be, that a loved-one/patient does not want cardiopulmonary resuscitation (CPR) to be attempted. And I think this 'instruction' is most likely to have been expressed as 'If my heart has stopped beating, I want to be left alone to die in peace' or 'If I'm dying, I want to be left to die'.

Sometimes, a family-carer will be as certain as it is possible to be, that a loved-one/patient does want cardiopulmonary resuscitation (CPR) to be attempted. Again, I think this will probably have been expressed as 'I want everything possible done, to try and keep me alive'. See reference 1.

In a real-world sense, a family-carer will be as certain as it is possible to be, that a loved-one/patient has not changed his or her mind about previously-expressed decisions – because 'we are living together – **I would have been told** by my loved-one, if he had changed his mind about CPR' [or about anything else 'of importance'].

Ref 1: <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-I-believe-that-CPR-should-be-attempted-if-a-mentally-capable-patient-had-asked-for-CPR-to-be-attempted/1051/>

FOOTNOTE: The term 'family-carer' does not imply that the carer is a relative, and it can also be a friend. In some senses, for the purposes of this discussion it isn't the 'caring' that really matters: what matters more, is the 'living with the person/patient aspect'.

If your loved-one has made it very clear to you, in conversation, that she doesn't want CPR to be attempted (or the opposite – that however unlikely it is that CPR might succeed, she wants CPR to be attempted) **then you know that**: you know it, and from your perspective it doesn't matter if the conversation has not been recorded, or 'disseminated' – **BECAUSE YOU KNOW**. See references 2 and 3.

What as a family-carer you probably are much less certain of, or almost entirely-ignorant of, are 'the clinical situation' and 'NHS Process'. So, you might be certain that your loved-one, who has now collapsed, definitely doesn't want CPR to be attempted, but not sure if the collapse is due to a cardiopulmonary arrest. And, you probably have very little idea of how 'NHS process' handles end-of-life, and of the intricacies of things such as Future Care Planning, Advance Care Planning, and of documentation such as 'DNACPR documents'. See references 4 and 5.

**In general: a family-carer will be informed by conversation (with their loved-one and involved clinicians) and will not be informed by 'documentation'** [although family-carers and relatives, should be involved during the creation of certain 'NHS documents' – and, patients and family-carers can, if they are 'clued-up', create their own documents even without involving any clinicians].

I could at this point move on to 'what clinicians know' but I've decided to do that later – here, I will discuss how decisions about treatment are made: this will be a logical analysis of the situation, and it will focus on decisions about CPR.

The law which covers most medical interventions in England and Wales, is the Mental Capacity Act (MCA), and in a nutshell the MCA explains 'consent' and during mental incapacity what replaces 'consent'. See reference 6. We can add-in, to what the MCA tells us, the logical assertion that 'a decision should be as up-to-date, and as-well-informed as is possible': which means '**we consider decisions 'in the now'**'.

Ref 2: <https://www.dignityincare.org.uk/Discuss-and-debate/download/298/>

Ref 3: <https://www.bmj.com/content/351/bmj.h6631/rr-0>

Note: the title should have been 'Why would you argue with a dying patient ?'

Ref 4: <https://www.dignityincare.org.uk/Discuss-and-debate/download/454/>

Ref 5: <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-Policy-in-Wales-now-seems-to-be-to-offer-CPR-to-patients-who-request-it-even-if-the-clinicians-believe-CPR-could-not-work-and-I-approve-of-that./1116/>

Ref 6: <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-think-we-need-a-different-way-of-explaining-and-teaching-the-Mental-Capacity-Act-MCA/1114/>

The Resuscitation Council UK (RC(UK)) is doing its best, so far as I can tell, to teach CPR to the entire public. So we can perhaps assume that as time passes, increasingly family-carers will know how to perform CPR. This doesn't really affect the issue of family-carers and decision-making around CPR, because very obviously a lay person who cannot perform a treatment can arrive at a defensible best-interests position for that treatment, but in a sense the situation is easier to describe if a family-carer could attempt CPR – there are then no complications arising from MCA s4(10):

[4](10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.

It doesn't in fact matter – obviously CPR is always a [potentially] 'life-sustaining treatment' and as such section 4(10) is 'attached to CPR' and is not in any way dependent on the view of whoever might attempt CPR – although clinicians will presumably be better at actually performing CPR, and in theory clinicians should be better at deciding that CPR could not be a life-sustaining treatment because CPR could not work.

The RC(UK) is also supportive of 'ReSPECT' and of the main ReSPECT Form. It is not a secret, that I dislike the ReSPECT Form. To critique that form here – in a slightly different way to my previous critiques of the form – we need to start in the right place. And the right place, is to consider how a decision about CPR would be made if the loved-one/patient had a cardiopulmonary arrest **now**.

Suppose we have a loved-one/patient who is in arrest, and a family-carer, a GP and a district nurse in attendance. If a clinician believes that CPR could not restore life, then [at the moment – and I think this should be changed as I explain in reference 1] the clinician will not usually attempt CPR. But a GP cannot order a family-carer to not attempt CPR, even if the GP is withholding CPR 'because CPR couldn't work'. It is rather tricky, to work out if the GP could 'order' a district nurse to not attempt CPR – it depends on what exactly the nurse's professional guidance says, the 'chain' being section 42 of the MCA and then the final sentence of section 5.31 in the MCA Code of Practice (original version):

*Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.*

If CPR might restart the patient's heart, then the decision about attempting or withholding CPR often becomes a best-interests decision. I say 'often becomes'

because if there is a valid and applicable Advance Decision refusing CPR, then CPR should not be attempted and the best-interests process should not be considered (actually advance decisions (ADRTs) are quite tricky, and often ineffective, in practice). Best-interests determinations, require the person who is making the determination to 'apply' s4(6) of the MCA:

[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.

It is clearly 'challenging' to consider those things while a person is in cardiopulmonary arrest – in fact, I will argue that in reality those things **cannot** be considered during an arrest. And even at a glance, it is obvious that of the GP, district nurse and the family-carer, **the person most-likely to understand the things in s4(6) is the family-carer.**

For CPR, only if a Welfare Attorney (appointed under the LPA) had authority over CPR and was present, would we have a person who could forbid others from attempting CPR – this comes from s(6)(6) of the MCA:

[6](6) Section 5 does not authorise a person to do an act which conflicts with a decision made, within the scope of his authority and in accordance with this Part, by—

- (a) a donee of a lasting power of attorney granted by P, or
- (b) a deputy appointed for P by the court.

Section (b) doesn't apply, because court deputies cannot be given authority over life-sustaining treatments.

Note, that the welfare attorney can decide and state that attempting CPR would not be in the patient's best interests, irrespective of whether or not the attorney could actually perform CPR: you can form a defensible best-interests position about an intervention, even if you could not yourself perform the intervention.

Suppose, that you are a welfare attorney, with best-interests authority over CPR, and you are present at the time your loved-one's heart stops, and you are making a best-interests decision. For simplicity, make the people present a GP, a district nurse and

a family-carer who is also a welfare attorney with authority over CPR. You have to apply section 4 of the MCA, to arrive at a best-interests decision about CPR. Section 4 includes a lot of things in 4(6) which you are supposed to try and consider – but it does **not** include ‘someone else’s recommendation’. The clinicians might be able to provide useful information about the clinical situation (although for CPR, they cannot really tell you much about what the clinical situation would be if CPR did restart the patient’s heart), and the clinicians might feel able to suggest what they think would be in the patient’s best interests. If they were present, other family-carers and relatives might well be able to state what they thought would be in the patient’s best interests. Personally – and bearing in mind that a decision about CPR has to be made almost instantly (the patient starts to suffer irreversible and cumulative brain damage after about two minutes of no blood circulation) – I might ask other relatives for their views about best interests, but I wouldn’t ask the clinicians.

If we remove ‘the urgency’ then in my view, the best-interests process involves many people who are in discussion, some of whom consider they are only able to provide information and that they themselves could not arrive at a genuine best-interests position, and some of whom who could each say ‘I think I have arrived at a legally-satisfactory best-interests position’. Each group, can include clinicians and relatives, friends: a nurse might say ‘... he said to me, one day last week, ...’ but that nurse might not feel sufficiently involved and well-informed to say ‘I think it would be in his best interests to ...’. But a GP, or a nurse whose involvement had been more extensive, might feel able to say ‘I think it would be in his best interests to’, and I think often family-carers and others ‘close to the patient’ would feel able to say [assuming they understood the MCA] ‘I think it would be in his best interests to ...’. **You don’t need to be a clinician to form a defensible best-interests position – you only need to be sufficiently well-informed to apply section 4 of the MCA correctly:**

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

As a welfare attorney with authority over the best-interests determination – which, when made by an attorney would technically be a decision (see ref 6: only Judges, Welfare Attorneys and Court Deputies can technically ‘make a decision’ under the MCA – everyone else can only make a best-interests determination. See footnote.) – **I would be asking for information from the clinicians who were involved at the time: so, I would be paying very little attention to the ‘recommendation’ on a ReSPECT form.** And, as a general point, section 4(6) of the MCA tells me to consider ‘the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity)’ - **so, I am pointed**

FOOTNOTE: This – which I consider to be totally unnecessary and a fault of the Act – is why, should any reader be wondering, that I am using the phrase ‘best-interests position’.

**to things written by, and signed by, the now-incapacitous person.** The MCA does not, point me at things written by clinicians, after the clinicians have talked to the person: quite why ReSPECT is stubbornly refusing to allow patients to complete and then sign section 3 of the ReSPECT form, is both mysterious and at-odds-with MCA 4(6).

If, as I have pointed out, a person considering best interests 'in the now' is supposed to consider the best available information at the time, and a clinician's 'recommendations' made in the past are not particularly significant, then we must wonder – why is the ReSPECT form presented as a 'recommendation'? Why, is the form not presented as **information**? Why is the ReSPECT form, not presented as a description of 'what **WE** would do if a clinical event happened as we write this form'? In the context of CPR, as I've pointed out, if a suitably-empowered welfare attorney is involved, then the attorney can forbid CPR, whatever anyone else thinks would be in the patient's best interests. If there isn't an attorney involved, then different individuals can defensibly make differing best-interests determinations about CPR: some people considering that attempted CPR would be in the patient's best interests, and some people considering that withholding CPR would be in the patient's best interests.

## **The problems of Absence, Uncertainty and Knowledge versus Records**

A main thrust of the MCA, seems to be to enable capacitous patients to make their own decisions, and to project into anticipated future incapacity 'their own control'. A person might believe, that by creating a written Advance Decision refusing CPR, CPR would not be attempted. And that by appointing a welfare attorney with authority over CPR, the attorney would make any necessary best-interests decision about CPR in the future [if an ADRT was not applicable]. In reality, this isn't true. ADRTs are often 'challenged' rather than being followed – section 25(4)(c) can easily be misused:

[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.

And the authority of welfare attorneys, is frequently 'ignored'. I consider the ReSPECT form, to be 'sinful' in this context: clearly if a person appointed a welfare attorney and wanted the attorney to make any best-interests decision about CPR if present 'in the now', then the person would want any 'anticipatory best-interests 'recommendation' recorded on a form' (such as on the ReSPECT form) to be made and signed by the attorney.

I read guidance, which suggests that at the time of a cardiopulmonary arrest, before accepting the authority of a welfare attorney 999 paramedics must check the validity of LPA documentation. All a patient/donor and attorney could reasonably do, would be to alert 'the NHS' to the existence of the LPA – most obviously, by telling the patient's GP about the LPA when it is created. Then, having done that, I would expect any attending 999 paramedics to accept my position as an attorney, as soon as I handed the LPA documentation to them - 'my authority should be immediate'.

For CPR at home, it isn't clear that either a written Advance Decision, or the appointing of a family-carer or relative as a welfare attorney with authority over CPR, will always be successful in 'asserting the patient's control over CPR'. Especially, in the context of CPR not being started by 999 paramedics.

Capacitous patients, can make, express and change their decisions whenever they choose too – **so listening to the patient is absolutely crucial**. Family-carers who are living with a terminally-diagnosed loved-one, are able to listen to the loved-one/patient more comprehensively than anyone else – for the simple reason, that 'they are almost-always present'. This – a situation which I describe as '**ongoing contact**' – is why the family-carer can be 'as certain as it is possible to be' of the things I put on page 1, in green text. Even if a patient is inside a hospital for a longish continuous time, the nurses work in shifts: they are not 'as continuously present' as are family-carers [and other people] who are sharing a home with the patient.

In my opinion, ReSPECT is not respecting this ability of family-carers to listen. Putting undue emphasis on 'care plans' is not respecting the right of a capacitous person to make his or her decisions in real-time, and to change his or her mind during the progression of end-of-life. Having forms, such as the ReSPECT form, which only carry the signatures of clinicians, is not respecting the complexity of decision-making during end-of-life – see reference 7:

Ref 7: <https://www.bmj.com/content/352/bmj.i26/rr-5>

As I pointed out in reference 7:

*The recent ruling by Mr Justice MacDonald (see ref 3) has made it clear that mentally-capable patients make their own decisions, which are not then to be questioned by others, and I have pointed out above that sometimes it is legally clear*

*that a welfare attorney [or, but never for CPR, a court deputy] is the decision maker. The Winspear ruling starts its point 4 with 'Although the precise terms of that conversation are a matter of dispute,' and exactly who said what during Tracey, is very uncertain indeed. The ECTP prototype does mention conversations between clinicians, patients and relatives - but it does not suggest that such records of conversations, should be 'signed off' by 'all sides': the ECTP wants only clinicians to sign. Similarly, the ECTP does not seem to want attorneys and deputies to sign to confirm their decisions - again, it wants the clinicians to do the 'signing off'.*

*This is both legally dubious - people should sign for whatever they are responsible for, so a clinician signs for a clinical prediction, a welfare attorney signs to 'authenticate' his/her own best-interests decision, etc - and anachronistic. This type of 'clinical control' of 'patient records' reinforces inappropriate distinctions between clinicians and involved laymen, it potentially introduces 'bias', and it definitely does not promote the necessary cooperation and integration between the clinicians, family, friends, and if they are present attorneys and deputies, which decent 'joined-up' care requires.*

*Once, husbands 'owned their wives' - but no longer: and clinicians do not 'own their patients'. Until patient records contain within them the 'right' signatures (at the very least, the possibility of the right signatures being present: I accept that it might be difficult for patients and family members to sign such documents, but they should definitely not be prohibited from signing them) - signatures based on authority, responsibility and involvement, and not simply on whoever happens to be 'the senior clinician' - there will in my opinion never be satisfactory integration between the many people who are typically involved in supporting, and caring for, patients.*

*The complexity of best-interests decision-making, and my mother's death (see ref 4), convince me that we should be pushing for patient-expressed decisions made in advance: so it is Advance Decisions which need to be promoted. But there seems to be an agenda to encourage patients to create 'written advance statements', which – unlike a written advance decision – cannot 'just be followed in an emergency'. In contrast to this push to promote the essentially 'very challenging in application' 'written advance statement', nobody seems to be trying to address the problem I mentioned in reference 5 of a patient at home expressing a decision to only a family carer.*

*I am not reluctant to state, and the perceptive reader might have discerned this, that I am very annoyed by this situation.*

If you read what 'the system' writes about End-of-Life-at-Home, then it looks as if the system 'is claiming the GP is in charge' – this is not respecting the legal situation of the GP being unable to 'order family-carers about', see reference 8:

Reference 8: <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-am-trying-to-persuade-the-Royal-College-of-General-Practitioners-to-change-what-it-writes-about-relatives-when-patients-are-dying/1129/>



It is not respecting common sense, to have systems which in effect apply ‘we couldn’t have been there to observe what happened, or to listen to what was said, but although you were there we are going to discount what you tell us because we were not present’. That **definitely looks like** ‘we just don’t trust relatives and family-carers’.

## The Elephant in the CPR Room

There is a HUGE elephant in the room, for CPR. It doesn’t hinge on whether we regard the withholding of CPR as being justified on patient-autonomy grounds, or on best-interests grounds (something I have discussed at length in my writing, for example in reference 6) – it hinges on the issue of ‘sufficient certainty’, and **how a person can possess sufficient certainty**.

When we move the logic of Mr Justice Charles’ ‘Briggs’ ruling to CPR, it is clear that the problem with scenarios such as those I discuss in my writing – see reference 9 – **is the absence of time**:

Ref 9: <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/>

**Whether you consider that CPR is being withheld ‘because of patient autonomy’, or because of a best-interests determination, there is a simple truth: the decision CANNOT IN REALITY BE MADE DURING A CARDIOPULMONARY ARREST.**

**You need to already know, at the time the loved-one/patient arrests: you need to know ‘My dad definitely doesn’t want CPR’, or you need to have already worked-through a best-interests determination.**

This is only possible if you have been ‘in a situation of ongoing contact’. Although it is clear, that family-carers, relatives and others ‘close to the patient’ are much better-placed than clinicians to apply section 4 of the MCA, *you simply can’t do it during an arrest*.

In my Father and Son scenario, the father has explicitly told his son:

*‘One evening, the father initiates a conversation with ‘Son, I’m really struggling here. I really can’t put up with this. Would it upset you, if I’m just allowed to die, if you think*

*I have stopped breathing?'. It could end with 'We'll sort this out with the GP tomorrow, but if I die before then, don't phone 999.'*

When my own mother was dying, and she refused to take some prescribed medications, I needed to ask – see reference 10:

Ref 10: <https://www.dignityincare.org.uk/Discuss-and-debate/download/315/>

The GP prescribed some energy drinks and some medication for a skin infection on my mum's legs, but my mum wouldn't take them – at this point you need to read the conversation I pointed at earlier:

Dr Smith, the GP, prescribed some antibiotics and energy drinks, but my mum wouldn't take them. While Dr Smith had been trying to examine her, my mum had been pushing Dr Smith away and saying 'don't want no more'. Some time later (i.e. a couple of hours later the same evening) it struck me that 'don't want no more' might mean LIFE, instead of 'being examined/messed about', something I needed to be sure of. So when I was sure my mum was 'with me' I asked twice. That evening I said 'Do you know that you won't get better unless you take the drinks and medicines' and the following morning I said 'If you don't take the drinks and medicine you will go to sleep and not wake up again. Is that what you want ?' My mum wasn't speaking by then - she was nodding and mumbling. But I was bending down in front of her, and having nodded 'yes' to that final question she looked me in the eyes, smiled, and SAID 'you know I love you'.

You need to be 'certain' that withholding CPR is the right thing to do, and of course that includes being sure that your loved-one has not had a very-recent change of mind about CPR. A 'suddenly-introduced' clinician, such as a 999 paramedic or a doctor who is covering a lot of hospital patients at 2am on a Sunday morning, doesn't possess that certainty: and none of the documentation (except for an ADRT refusing CPR – and see page 6), or 'care plans', sits above the MCA's best-interests process – it is the correct application of the MCA which provides the necessary legal-protections for individuals who are involved with potentially-life-sustaining CPR. 'The system' has been trying to resolve the complexity of this with 'planning ahead and documentation' but often the documentation 'lacks sufficient legal force', and the simple fact that 'ongoing presence is up-to-date – whereas documentation is potentially out-of-date' is de-emphasised by the 'NHS approach'. There is also the problem, of some people simply refusing to 'discuss dying': my father, never admitted that he was dying, only ever admitting to being 'really poorly'.

I am hugely annoyed, that we family-carers are being disrespected by clinicians and a system which seems to think we shouldn't be trusted, and that even when we are trusted, somehow 'our role is to help the professionals'. I am also hugely annoyed,

that patients and family-carers are being told things which are misleading and sometimes downright wrong, about their situations in an EoL/MCA/CPR context – see reference 11:

Ref 11: <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-dont-believe-family-carers-and-relatives-are-being-told-the-truth-about-how-the-law-applies-to-them./1134/>

## How Can We Change Things?

The 'we' means patients, family-carers, relatives and close friends. And, unfortunately, it seems that 'they' – 'they' meaning clinicians and the system – will not willingly change their attitude, so we will probably need to be much more assertive. **We need to challenge things which are wrong.**

I'll give a few examples.

If a husband and father is comatose in hospital, and his family are summoned to the hospital to discuss what should happen next, then if a doctor says 'You need to help me to work out what is in his best interests' we should forcefully counter with 'Sorry – we all need to discuss things, so that we can each work out what is in his best interests'.

If a ReSPECT form is being completed for a capacitous patient, the patient should insist on completing and then signing section 3 him/herself. And if the patient is incapacitous, and a welfare attorney or court deputy would have legal authority over a decision made 'in the now', the attorney or deputy should challenge the signatures on section 4 of the form – pointing out 'if this looks like an anticipatory best-interests recommendation, then I should be making and signing that, if it would be my decision to make if the event happened now'.

Family-carers in particular, should be aware of the legal situation of relatives during EoL - <https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/DNACPR-at-Home-and-a-Twitter-thread-what-is-the-legal-situation-for-relatives/1110/> - and if it is suggested they have done something wrong, we should ask 'which law are you suggesting I have broken?'.

Now, TO BE CRYSTAL CLEAR. I am NOT trying to set relatives and clinicians at war with each other, during end-of-life. I want clinicians and relatives to be valuing and respecting what each is 'bringing to the table', **and to properly work together** in supporting dying loved-ones/patients. But EoL-at-Home in particular, can become extremely complex – and it is intolerable, to add to the distress of a loved-one's dying and death, an attitude of 'we don't trust you, and we are under-valuing your input and role'. So if 'we' need to challenge 'them', in order to force a change in

professional mindsets from 'us & them' to 'us & us', then that is what we need to do: sadly!

The most-certain way of preventing attempted CPR, is to explain to whoever is caring for you that if your heart stops then you don't want CPR to be attempted – and for the person doing the caring to do what you wanted them to do.

Basically, that is my Father and Son scenario (reference 2 and see page 9), with the son doing what his dad wants, and not calling anyone until after his dad has died. As soon as you involve anyone else, the chance of CPR being attempted increases.

I asked two questions about the scenario, the first being:

Q1 What 'should' the son do, if he thinks his dad has stopped breathing, before anyone else has been told of the conversation?

The answers I agree with, were from a GP, a Consultant Doctor and a nurse:

GP: He should do what his father asked him to do.

Consultant Doctor: Wait and call GP later to certify the death.

Nurse no 2: respect his fathers wishes and not phone 999.

Two answers which I strongly disagree with, were from nurses:

Nurse no 1: If an Advance Decision to Refuse Treatment (ADRT) has not been made and the father has not verbalized his wishes to a professional involved in his care then the son would have to call 999 as his conversation with his father has not been witnessed and not evidenced as "in his best interests"

Nurse no 4: He should dial 999 as there is nothing formal that acknowledges his dads wishes. If he does nothing he will be in trouble as it will be classed as neglect also dad may have been having a bad day and if resuscitated may go on to live the rest of his life pain free, with dignity and in control by completing an advanced directive.

BUT – it would be great, if the son could phone 999 to confirm that his dad's heart had stopped beating without then risking that 999 paramedics would attempt CPR if

his heart wasn't beating: **'your' 'care planning, documentation, etc, pushes some very-challenging decision-making onto us family-carers. As I keep pointing out: the family-carers and relatives understand 'what dad would have wanted' and the clinicians understand the clinical situation – and application of the MCA's principles REQUIRES BOTH THINGS.**

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