CPR in the community: further discussion

I was one of the authors of a recently-published paper about cardiopulmonary resuscitation (CPR) in the community – the paper examined the interaction between 999 paramedics and 'family-carers' (the relatives or friends who called 999 – sometimes called 'relatives' both here and in the paper, but not necessarily formally relatives). The title of the paper was 'Family members, ambulance clinicians and attempting CPR in the community: the ethical and legal imperative to reach collaborative consensus at speed' and it was published in the online version of the JME on October 15th 2020 {Cole R, Stone M, Ruck Keene A, et al. J Med Ethics Epub ahead of print: [15 October 2020]. doi:10.1136/medethics-2020-106490}. The main issue we explored, was the reasons why paramedics can legally withhold CPR. Beyond that, the paper is complicated.

The paper can be found here:

https://jme.bmj.com/content/early/2020/10/15/medethics-2020-106490

I have been discussing our paper with various people – it was intended to provoke discussion – and there seem to be differing views on some issues, and in this piece I will present my views on those issues. Prominent among these 'disputed' or 'contentious' issues, are the following three things:

1) Is the DNACPR Justification Hierarchy on pages 30/31 of my PDF here

https://www.dignityincare.org.uk/Discuss-and-debate/download/317/

correct, or flawed? I accept that it is incomplete (for example, the section on Welfare Attorneys needs further explanation – it would be wrong to conclude from what I wrote, that if there are several attorneys with Joint & Several authority over CPR that I am saying they all need to express an agreed decision: if only one attorney is contactable, that attorney's opinion is 'legally binding' {but if there are two such attorneys, and they give conflicting decisions – one saying withhold CPR and the other saying attempt CPR - then I believe that a clinician should attempt CPR}. But I consider it to be legally correct and coherent, as a **justification** hierarchy.

2) Is a verbal refusal of CPR during ongoing contact the most legally-valid reason for DNACPR? In other words, is the ordering for 1 – 3 in my hierarchy correct? There is a view, that a written advance decision (ADRT) sits at the top – I consider that to be incomplete thinking.

3) There is a complex discussion, which hinges on the 'duty of care' which attending paramedics are subject to, and the situation of family-carers who summoned the paramedics: the problem cannot be easily summarised, so if interested you will need to read my analysis.

As 'hints' I will point out that consideration of point 2) above [and 2) is closely entwined with 1)], hinges on the fact that while an ADRT refusing CPR must be written in order to be valid, it is misleading for people to write [as they usually do] that 'a valid and applicable

advance decision refusing CPR is legally-binding'. The complication rests on section 25(4)(c) of the Mental Capacity Act (MCA). And exactly when a person considering attempting CPR, could be as-certain-as-possible that section 25(4)(c) is not a consideration.

The consideration of 3) above, hinges on analysis of the situation **not** starting when a relative has called 999 and paramedics have attended – **but instead starting at the time when the relative is considering whether to call 999 or not** [which I consider we must logically regard as a best-interests decision].

I should also point out, that both of my parents had died before I first read the MCA. And without any knowledge of the MCA, I was firmly of the opinion that it was not for me to decide what my parent wanted: **my role was to to try and support his/her decisions**. So, if it had been made clear to me (as it was while my mum was dying) that a parent did not want CPR, then my role was to make sure that nobody attempted CPR. As it happens, I consider that the MCA supports that position – if my parent has made it crystal clear to me that he or she would never want CPR, then my efforts must be to try and prevent anyone from attempting CPR. At its simplest, in this scenario, the family correctly did not call anyone until the father had died:

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounding by his family.

Posted on Nursing Times online, ca 2012, by someone I think was probably a nurse.

Note: the real-life story posted on Nursing Times, is effectively identical to a scenario I asked about in a survey which I think I sent out before the above was posted on NT – my survey can be found in Appendix 1 and it can also be found online at:

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

Detailed discussion of the issues mentioned above

The scenario we discuss in our paper, involves a wife who phones 999 because her elderly and 'frail' husband has suffered 'a collapse' but not, at the time and in the wife's opinion, a cardiopulmonary arrest (CPA). But by the time the 999 paramedics arrive her husband has arrested. The overall situation is that the husband was sufficiently ill to have discussed his possible death within the family, but not close enough to death for formal NHS end-of-life (EoL) planning to be in place – so there is nothing in the way of 'planning involving a GP' for the paramedics to read. When the paramedics start CPR, the wife tells them 'stop – I know he would not want CPR, we have discussed this'.

In our paper, the wife also says '… and **if I had known his heart had stopped, I would not have called 999**'.

It is easier to discuss a slightly different situation, which our paper implied should be considered. So here, I will be discussing the following scenario.

A family-carer knows that a loved-one would not want CPR. The person (the loved-one) collapses, having been mentally-capable until the collapse, and the family-carer thinks the person's heart has stopped beating, but is not 100% certain. There are no records 'in the NHS documentation' which indicate the person would not want CPR, and the family-carer is aware of that.

You can put relative in the above in place of family-carer – it is not in fact relevant whether the person has been doing any 'caring' - what matters is the person's understanding that CPR would not be wanted by the collapsed loved-one/person/patient.

I will address the issues, in reverse order. So I will start, with no 3).

There is absolutely no question, that once involved 999 paramedics must attempt to act in the patient's best-interests [unless a welfare attorney with authority over best interests is present]. And it has to be their own determination of the patient's best interests: **everyone, paramedics and relatives, who considers themselves to be applying the MCA, must act on their own determination of best interests**. And 999 paramedics perfectly reasonably, wish to act in a way which will not get them into trouble. One of the people I have been discussing these issues with says 'the paramedic has a 'duty of care' - but the relative doesn't' and that is too opaque to be useful: so we need to look into it.

The paramedic can get into trouble, for clinical incompetence: here, most easily explained by saying that if a paramedic attempts CPR and his/her 'clinical technique' is abysmal, that might well be culpable. Whereas a relative who attempts CPR, is extremely unlikely to be criticised for 'performing CPR incompetently'.

The paramedic can get into trouble, for failing to 'offer' CPR if it looks as if CPR has a chance of restoring life – the purpose and expectation of the NHS, is that treatments which can be afforded by the NHS, will be offered to patients.

The paramedic must also correctly apply the law – which in these situations, is the MCA.

So the paramedic, once involved, **has to** apply the MCA.

It is not clear, that the relative has to apply the MCA. It is arguable that the relatives in the stories posted on Nursing Times and discussed in the JME paper and in this piece, **do not** have a legal duty to call 999 at all. However, it is not clear to me that our police understand that, and there is a legal requirement for the relatives to report the death to the coroner.

There is also section 44 of the MCA, which does not [so far as I can see] exempt family-carers from its scope:

44 Ill-treatment or neglect

(1) Subsection (2) applies if a person ("D")—
(a) has the care of a person ("P") who lacks, or whom D reasonably believes to lack, capacity,
(b) is the donee of a lasting power of attorney, or an enduring power of attorney (within the meaning of Schedule 4), created by P, or
(c) is a deputy appointed by the court for P.

(2) D is guilty of an offence if he ill-treats or wilfully neglects P.

(3) A person guilty of an offence under this section is liable—
(a) on summary conviction, to imprisonment for a term not exceeding 12 months or a fine not exceeding the statutory maximum or both;
(b) on conviction on indictment, to imprisonment for a term not exceeding 5 years or a fine or both.

It is not 100% clear to me, that section 44(1)(a) definitely cannot be argued to apply to the relatives in our scenarios.

So, I am much happier with a different explanation for not calling 999: at an everyday level it amounts to 'I was told by my dad to not call anyone until after he had died – so I didn't call anyone until after he had died'. At a legal level, it amounts to 'I am aware of what the MCA says – and the MCA says that I should not have called anyone'. I am avoiding writing 'I am aware of the MCA, and I decided it was in my dad's best interests for me to not call anyone', and it should become clear why later in this piece. However – pragmatically, often 'I decided it would not be in my dad's best interests to call anyone – so I didn't call anyone' would be satisfactory.

The legal defence in the MCA, is provided via section 4(9):

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.

If a person – **note it says 'a person other than the court' which surely covers everyone** - 'satisfies' 4(9) then there are legal protections which can be claimed, as described in section 5 of the MCA:

5 Acts in connection with care or treatment

(1) If a person ("D") does an act in connection with the care or treatment of another person ("P"), the act is one to which this section applies if—
(a) before doing the act, D takes reasonable steps to establish whether P lacks capacity in relation to the matter in question, and
(b) when doing the act, D reasonably believes—
(i) that P lacks capacity in relation to the matter, and
(ii) that it will be in P's best interests for the act to be done.

(2) D does not incur any liability in relation to the act that he would not have incurred if P—
(a) had had capacity to consent in relation to the matter, and
(b) had consented to D's doing the act.

The title of the section, covers both 'care' and 'treatment' - it also uses the word 'Acts' and it looks as if it is providing a defence against intervention without consent. In fact – and this

is important, because our scenarios are looking at the legal justifications when potentially successful CPR is either withheld by a paramedic or relative, or is precluded by a relative not phoning 999 – compliance with section 4 does provide legal protection for the withholding of a treatment. I am not going to prove that here – it takes too long, and a particularly irksome legal issue with the word 'decision' in the context of the MCA is involved.

I will put this here – as opposed to later – but section 5, which explains the legal protections provided by the Act's sections on **Best Interests**, also explains that those protections are not claimable if a valid and applicable Advance Decision (ADRT) applies:

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

It is beyond dispute, that the MCA applies to family-carers. You can work it out either because the Act itself does not state that it does not apply to family-carers, in particular by thinking about section 42 of the Act, or you can read in the 2007 Code of Practice (Introduction, page 2):

… the Act applies more generally to e*veryone* who looks after, or cares for, someone who lacks capacity to make particular decisions for themselves. This includes family carers or other carers.

So: my position is that while legally this seems to be 'an opt-in', a relative standing by a loved-one who has just lost mental capacity by collapsing, **can claim** to be at that point 'looking after' the loved-one. **And having claimed to be doing that, the relative can then claim to have applied section 4 of the MCA and hence the protections in section 5.**

We can now move on, to a discussion of my issues 1) and 2) – is a verbal refusal of CPR ***during a situation of ongoing contact*** the most legal valid of all justifications for withholding potentially-successful CPR, and is the DNACPR Justification Hierarchy I have been publishing since 2014 correct?

This is the hierarchy I assert is correct, when the law and the logic of situations is combined – it was written very much with the interaction between paramedics and relatives in mind.

The DNACPR Justification Hierarchy

1 A face-to-face discussion with a mentally capable patient, which takes place during the clinical events which lead to his CPA, the outcome of which is that the patient issues a DNACPR Instruction which those who were involved in the discussion can interpret correctly.

2 An apparently valid and applicable Advance Decision refusing CPR which has not been discussed with the patient.

3 A DNACPR decision made and communicated by either a single Welfare Attorney (where only one has been appointed), or agreed and communicated by all Welfare Attorneys
(Note: for non life-sustaining treatments, a Court Deputy can fit here between 3 and 4 – see section 20(5) of the Act)).

4 A DNACPR decision made by any person who is sufficiently informed of the patient‘s clinical situation and likely wishes, to enable that person to defensibly consider section 4 of the MCA.

5 A DNACPR action, which is based upon information supporting the reasonable belief that something within categories 1 to 4 makes DNACPR the best available behaviour.

6 If none of the above apply, but it is clear that attempted CPR would be clinically futile, then DNACPR.

7 If none of 1 to 6 apply, CPR should be attempted.

I will first point out, that no 6 – not attempting CPR because it seems clear that CPR could not restore life – is not a justification within the MCA: it stems from the idea that treatments which could not be clinically successful, need not be offered. So logically justification no 6 can be placed either where I have placed it, or else as no 1 in a hierarchy: doctors tend to put that justification at the top of the list.

Secondly, I will point out that I assert the above is correct as a justification hierarchy. If you read my numbers 1 and 2, you will see that I do not state that the verbal refusal of CPR during a situation of ongoing contact is a valid Advance Decision – it clearly isn’t a valid ADRT. And, I specified in my no 2 that an apparently valid ADRT has been read, but [because the patient has already lost mental capacity] the ADRT has not been discussed with the patient [and cannot be discussed with the patient] when the patient arrests.

We need – *when looking at **justification** for withholding CPR* – to consider that although an advance decision to refuse CPR must be written in order for it to be valid (section 25(6), a written ADRT can be verbally retracted at any time while the person is still capacitous (sections 24(3) and 24(5))

(3) P may withdraw or alter an advance decision at any time when he has capacity to do so.

(4) A withdrawal (including a partial withdrawal) need not be in writing.

and the description of the treatment on a written ADRT can use the patient’s own words (24(2)

(2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman’s terms.

And crucially, if the written ADRT is valid, it can be considered inapplicable if section 25(4)(c) is believed to apply

(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.**

If I have listened to a person explaining to me, during a lengthy conversation about CPR, that he/she is refusing CPR then I can ask during the conversation if there are any situations when the person would accept CPR – and I can also check that the person understands the clinical outcomes of attempted CPR. *So if that has been done, and the person then has a cardiopulmonary arrest before I have walked away from the person*, **then I cannot involve the doubts within either 25(4)(c) or within 24(2)**.

When you put all of these things together, the discussion about CPR promptly followed by the person's arrest definitely makes that refusal more legally-binding, than simply reading a valid ADRT and considering its applicability.

I have been told, that in legal terms the verbal refusal leaves the listener with a best-interests decision to make – but the person who insists on that, also agrees with me that it would be unacceptably perverse to decide that attempted CPR would be in the person's best interests, if after the person had spent 30 minutes making it clear he was refusing CPR he promptly arrested and you then decided to attempt CPR. I would think of this in terms of 'if the conversation had been filmed and recorded, would a doctor who had been involved and then decided to attempt CPR, fancy his/her chances in the ensuing court action?.

Myself, I insist that the situation in my justification no 1 is part of patient autonomy, and should not correctly be thought of as being part of best interests – but, all I wrote in my hierarchy is that (however else you describe it) it is the strongest of all justifications for withholding CPR.

I will point out, that it is not possible to refuse CPR while CPR is being considered – if the patient has arrested, the patient is unconscious. The closest it is possible to get, to a 'contemporaneous refusal' for CPR, is the situation I have described: a conversation when the patient explains his refusal of CPR, followed by an arrest before you have left his presence and when he has never retracted his refusal. And if we look in section 6 of the MCA, we can find (26(1))

(1) If P has made an advance decision which is—

(a) valid, and

(b) applicable to a treatment,

the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.

There is a problem, with the MCA's adoption of Best Interests instead of Substituted Judgement: in a nutshell, substituted judgement involves working out 'what the capacitous person would have decided, and doing that' whereas best interests involves working out what the capacitous person would have decided, then incorporating that understanding into a best-interests framework. For interventions which are not life-sustaining, it is effectively impossible to clearly explain 'best interests' - although I have attempted to do that in this piece:

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

I have posted a thread which lists some court rulings, with links to them, here:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/SOME-COURT-CASES-RELEVANT-TO-THE-MENTAL-CAPACITY-ACT-and-to-BEST-INTERESTS-DECISION-MAKING/907/

I thought about how to reconcile section 1(5) of the MCA with the rest of section 4, in the context of a best-interests decision to withhold potentially-clinically-successful CPR and I had concluded – as readers will discern from my DNACPR Justification Hierarchy which I have been publishing since 2014 – that the justification had to amount to being convinced that the person would have refused CPR him/her-self. Subsequently Mr Justice Charles, when deciding in the Briggs ruling that CANH could be withdrawn on best-interests grounds, published the same 'reasoning'.

Mr Justice Charles wrote this:

But, in my view when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self-determination which an individual with capacity can lawfully resolve and determine by giving or refusing consent to available treatment regimes:

i) the decision maker and so a judge must be wary of giving weight to what he thinks is prudent or what he would want for himself or his family, or what he thinks most people would or should want, and

ii) if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.

In an earlier piece by Mr Justice Hayden, it was explained very lucidly that, to use my phrase here, 'close friends possess an understanding beyond simply having listened':

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.

If we concentrate on the ruling by Mr Justice Charles, we can see that for life-sustaining interventions – so for the withholding of CPR which might succeed in restarting the heart – **what he describes is a two-step process**:

A) If what the person would have decided is understood well-enough, then the person's 'worked out' decision should be applied: which would be either no CPR, or attempt CPR, depending on what the individual in arrest would have decided, and

B) If what the person would have decided is not understood with sufficient certainty, then the fall-back position is to attempt to preserve life – so it is to attempt CPR.

It is not easy to explain – without saying 'read Briggs' - exactly what level of certainty is necessary, in order to apply A). I think that nobody involved in a best-interests determination would consider that 'slightly more likely to have refused CPR than to have accepted CPR' would satisfy the wording of '*with sufficient certainty'* used by Mr Justice Charles. And Mr Justice Hayden used ' *none of his friends are left in any doubt what he would want in his present situation'* which again cannot be rigidly true: no doubt at all, is too high a bar for this determination

But I am sure of two things: the required level of certainty described by Mr Justice Charles, is lower than the level of certainty possessed by the listener in situation 1 in my DNACPR Justification Hierarchy.

And I am sure of a second thing: we can, because of the Briggs ruling, explain in simple terms when CPR can be legally withheld on best-interests grounds. And, in everyday language, it can be stated as:

'We should not attempt CPR, if we know that your dad would not have wanted us to attempt CPR'.

A Hell-Hole to be avoided – at all costs!

In the scenario we presented in our JME paper, it ended with the paramedics starting CPR and the relatives 'shouting 'stop that – he would not have wanted you to attempt CPR!''.

Ever since I read the 2007 version of the joint guidance around CPR, published by the BMA, RCN and RC(UK), and came across the following, I have been forcefully saying 'NO – that isn't what the MCA says, and it is offensive to family-carers!'.

9.2 Adults who lack capacity, have neither an attorney nor an advance decision but do have family or friends

In these circumstances, it should be made clear to those close to the patient that their role is not to take decisions on behalf of the patient, but to help the healthcare team to make an appropriate decision in the patient's best interests. Relatives and others close to the patient should be assured that their views on what the patient would want will be taken into account in decision-making but that they cannot insist on treatment or non-treatment.

This is the hell-hole, which if entered, probably would lead to relatives shouting at paramedics:

Relative to paramedic: 'Why did you just ask me, if my dad would have wanted CPR?'

Paramedic to relative: ‘Because we should not attempt CPR, if we are certain that your dad would not have wanted CPR’.

Relative to paramedic: ‘I’ve just told you that my dad would not want CPR – and I am certain of that, because I have been talking to my dad for the last year while he has been ill. How can you – who has never met my dad – be ‘certain’ about whether he would want CPR!?’.

I would be shouting at paramedics in this situation, if they implied that they understood what I perhaps did understand – whether my dad would have wanted, or refused, CPR.

I will also point out, going back to that section in the CPR Guidance from 2007: **if I am at home with a parent who arrests, and I can perform CPR having been taught CPR as first-aid, that I decide whether or not to attempt CPR.**

That 2007 CPR guidance also said this in its Main Messages section:

If a patient with capacity refuses CPR, or a patient lacking capacity has a valid and applicable advance decision refusing CPR, this should be respected.

That is what I wrote as my justifications 1 and 2 in my DNACPR Justification Hierarchy [and as it happens, also in the same order].

Which gets us to justification 3 – 5 in my hierarchy.

Nobody disputes the ordering of my 3 and 4.

But my introduction of number 5, is ‘trickier’.

It is absolutely true, that section 4 of the MCA allows a paramedic, attending a collapsed lone jogger who has arrested, to attempt CPR. And, that is defensible as a best-interests decision. But – it is a best-interests decision, made on the basis of Mr Justice Charle’s ‘B’: it is CPR **based on not understanding** what the collapsed individual would have decided.

In the scenarios I have discussed here, and in the JME paper, it is reasonably likely that the relative who called 999 **understands enough** to form an opinion about CPR on the basis of Mr Justice Charle’s ‘A’.

If two children of a collapsed parent are present, and one says ‘he would want CPR’ while the other says ‘he would not want CPR’ then assuming both are trying to be honest, that disagreement I can live with – but I cannot accept a paramedic saying to a relative what amounts to ‘I understand whether your husband would want CPR better than you do’.

As it happens, it is possible to explain what the paramedics should do, without even the assumption that the relatives are aware of the MCA at all – my analysis is here:

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/

I have also done a couple of surveys on Twitter. These surveys seem to indicate that most people think along the same lines as I do – and not along the lines of what the BMA, etc, write about best-interests decision-making and the role of relatives in it.

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

https://twitter.com/MikeStone2_EoL/status/919195401898680321

An 82 years old man is diagnosed as terminal. He and his 79 years old wife ‘invite clinicians to help while he dies’. Does that invitation of itself, imply that if he loses the ability to make his own decisions, he wants the clinicians, and not his wife, to make them?

Yes it does 8%
No it does not 92%

Total votes cast 79

As I think I have argued, in situations such as this

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn‘t want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounding by his family.

the correct ‘answer’ is as given by some of the people in answer to my survey in Appendix 1:

He should do what his father asked him to do

Respect father’s wishes,

respect his fathers wishes and not phone 999

Written by Mike Stone, November 2020.

I often give an e-mail address, but during this pandemic my e-mail access is less simple than it used to be, and I am easier to contact via Twitter

@MikeStone2_EoL

Appendix 1

Some years ago – about 2011/12 – I sent a survey out to PCTs and NHS Trusts.

One of the survey questions, was very relevant to this piece, and I show what I asked and the answers I received.

Scenario: 'Father and Son'

A father is living at home, with only one family carer, who is his son. This is supposed to be an EoLC situation, so the father is expected to die within at most a year (determined, I assume, by divination). The father has been seeing his GP and is, therefore, 'sort of aware' of treatment options and outcomes. The father has not refused CPR, and is not considered to be sufficiently 'near death' for his death to be considered 'expected', or for a 'clinical' (i.e. for CPR to be predicted to fail) DNAR order to be in place: so there cannot be a DNAR 'Instruction' in place. The expectations for a CPA could range from 'unlikely' to 'almost sufficiently likely, for the situation to be an 'expected death''. The father is in some sort of discomfort, which he considers to be severe. Either pain, or something else, such as struggling to breathe. This could be either continuous or episodic in nature.

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'.

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

Q2 As Q1, but with 'should' replaced with 'would' (in other words, Q1 is asking for your opinion of the 'theoretically and morally correct' behaviour – by contrast, Q2 is asking you for an opinion, as to how you think 'sons' would actually behave in that situation).

COMMENT: this scenario leaves open the question of whether, if the son lets his dad die in peace and then afterwards calls out the GP, the GP would certify the death: but I can see no reason why patients and their relatives should be aware of post-mortem procedures.

Answers to Q1 (the answers are exactly as the respondents wrote in their replies to me).

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

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

Paramedic no 1: *Preferably make a quick note in care package AND/OR do not call 999.*

Paramedic no 2: *Respect father's wishes, in the event and contact and discuss with GP ASAP, call 999.*

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 2: *respect his fathers wishes and not phone 999.*

Nurse no 3: *Either ask his father to document his wishes in some form, or if possible contact the out of hours GP, and see if that would be an appropriate course of action.*

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.*

Answers to Q2

GP: *I think some would and others wouldn't.*

Consultant Doctor: *As for 1.*

Paramedic no 1: *Most people will call GP/District Nurse/Macmillan Nurse for advice, and invariably be told to call 999.*

Paramedic no 2: *Respect his wishes, not call 999 but still contact GP for advice.*

Nurse no 1: *From my experience most would call 999 because of the moral and ethically duty not to let someone they loved die with an attempt to save their life. The son has to live the rest of their lives with the knowledge that if they didn't act "what if" and can severely affect their grief process unless they felt the action produced more good than harm (their father would be at peace rather than suffering).*

Nurse no 2: *As above.*

Nurse no 3: *He will probably ring 999, having recently done some teaching about end of life with the local ambulance service, this is a situation which arises on a regular basis.*

Nurse no 4: I *think the son would dial 999 as he would want his dad to have every chance at life, also he may panic at seeing his dad die. This nurse also wrote the following, after my 'comment' on her reply: 'You cannot assume that dad dies in peace, also there could*

be guilt at the "what if" as dad may be successfully resuscitated and have time to put his affairs in order and see family before he dies.'

SURVEY ENDS

I received 8 replies in total to my survey: 6 quite quickly, and 2 more after 6 months from a PCT which told me it had mislaid my e-mail and re-found it.

So in total I have got replies from 2 Paramedics, a GP, a Consultant in Palliative Care and 4 nurses: two of the nurses work in the same PCT, and both paramedics worked in the same PCT (a different PCT from the nurses). Although small, this sample is large enough, and diverse enough (both in role and answers supplied) to be 'informative'.

If you read the answers, it strikes me that:

The two doctors follow the 'the patient's decision should be respected' principle;

The two 999 paramedics do not really 'want to be involved' in this situation;

The four nurses give **very inconsistent** responses: I have a particular problem with the answers to question 1 given by nurses 1 and 4 because, to put it bluntly:

If when a patient expresses a refusal of treatment face-to-face to a doctor, the doctor must not apply the treatment – then why, when the patient expresses a refusal of treatment face-to-face to a family carer, isn't the family carer in the same situation of 'I must not allow the treatment'?

According to me: **it doesn't matter that a family carer isn't 'a professional' - this is the father's decision to make, and once he has made it and expressed it, it doesn't matter who hears it**. The problem – well, both of the doctors seemed to agree with me

He should do what his father asked him to do.

but some nurses write things like

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"

I refuse to accept this 'distrust of family carers' mindset from professionals. I have been involved in one of those 'I want to be left to die now' conversations, with my mother – **and I can tell you:'once you have been told, you definitely know!**'.