End-of-Life and Perspective part 2: I was there

I perceive a serious problem with End-of-Life at Home, because, to put it bluntly, it seems to me that many professionals consider it legitimate to question the honesty and integrity of family-carers and relatives – to go beyond the general logic of 'not everyone is honest and trustworthy' (Harold Shipman, anyone? Hillsborough?) to the idea that 'we can't trust relatives until they have proven their honesty'.

That isn't acceptable, from where I'm standing: because as I pointed out in my piece

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Mikes-Cheeky-Blog-the-Mental-Capacity-Act-inevitable-unknowns-and-safeguarding./991/

GETTING FROM 'we have no way of being sure of that' to 'so we are not going to believe what the relative WHO WAS PRESENT tells us' is from my perspective OFFENSIVE and UNREASONABLE.

Some police officers take bribes – but that doesn't result in all police officers being permanently suspended on suspicion of having taken a bribe, does it? There should be some actual evidence of wrong-doing, before accusations of dishonesty and nefariousness are made/implied against the family-carers of end-of-life patients.

Some years ago, somebody posted this during a discussion on Nursing Times [online]:

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.

In my opinion – from my perspective as a family-carer for my own parents when they were dying – the relatives were completely right to not call anyone until after the father had died: he told them to do that, it was his decision, it is his life and his family should do what he has told them to do. See the two Twitter Polls which you can find on page 17 of my PDF at

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

However, if you read current 'guidance and protocols' for end-of-life at home, it seems clear to me that 'the system wouldn't be entirely happy with only being involved after the father had died'.

It is a very similar situation, to something that I had included in a survey a few years

ago – you can find the survey question and responses at

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

In my survey I asked about this scenario:

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'.

I then asked two questions:

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.

Most people agree, that if the son phones anyone immediately his dad collapses, he is likely to end up with the attendance of 999.

But answers to my question 1 were distinctly mixed:

Answers to Q1

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.*

The answers I agree with in there, are the answers from the two doctors: they are short and *He should do what his father asked him to do* and *Wait and call GP later to certify the death* seem to sum it up: it is father's decision to make, other people should follow the father's decision. Nurse no 2 gave the same answer.

But – I have very serious objections to the answers from nurses 1 and 4: the son, and the family in that post on Nursing Times, don't need 'evidence' **because they were there.**

It isn't the fault of family-carers during EoL at Home, that sometimes the patient tells them things – in this case gives them an instruction – when there are not any clinicians present to hear it: if we heard it, then the patient loses consciousness before the instruction has found its way into 'the records' THEN WE STILL HEARD IT!

I had that type of conversation with my dying mother – see pages 24 and 25 in

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

and I can assure you: you cannot ignore an instruction of that type from a dying loved-one, and once you have been told, then 'you have been told'!