

Some years ago – about 2011/12 – I sent a survey out to PCTs and NHS Trusts. Since joining Twitter last year, I have acquired some new ‘paramedic contacts’, and because I think it will help with some current discussions, I am presenting part of my Survey here.

The survey as sent out, included some other questions, but the relevant section, which I will reproduce here, was the scenario I opened with, and the two questions I asked about it. I will now show that section from the survey, as it appeared when I sent it out (in black /blue/green text), with the answers I received shown in brown italic text.

## SURVEY BEGINS

### Survey about ‘The Rules for Death’

#### Background Information

The questions in this ‘survey’ were written by me (Mike Stone) and they are not intended to be a statistically-tested survey – instead, they are intended to be questions which will help to establish how ‘uniform’ the current ‘belief set’ around ‘death’ is across different parts of the country, and between different professional groups within any given PCT’s region.

The questions, if answered, will also help to establish what different people believe, in some of the least clear areas.

The survey’s answers would be fed into a discussion of End-of-Life Care, which is long-running and ongoing within an ad-hoc e-mail discussion group which includes the relevant person at the Department of Health, a Senior Paramedic, a Senior Lecturer who organises Verification of Death courses, the Lead on a CPR/VoD Policy Design Group for a PCT, and myself (I am the ‘amateur’ on this group – I come at this from the perspective of a family carer or relative, or potential patient). Any replies will be forwarded to everyone in the group in their ‘raw’ form (I am assuming there will not be a huge response – if there is, it would make more sense for the replies to be sent to me, and for me to forward them on in bunches: however, I have no idea of the response level in advance). The email address for me, is:

[mhsatstokelib@yahoo.co.uk](mailto:mhsatstokelib@yahoo.co.uk)

and the e-mail addresses for the entire group are;

Addresses were given in the survey, but I have redacted them here (2018 write-up).

#### Purpose of the Specific questions

It has become very clear to the group, that the ‘correct’ behaviour ‘around death’ is influenced by issues of law, ethics, morality, role, personal experience and personal ‘beliefs’ and – **crucially** – ‘perspective’.

Many of these issues are complex and so unclear as to require much ‘clarification’: I myself, am very concerned that there is currently inadequate information about ‘how a person’s perspective influences their beliefs and behaviour’, and until that is better understood, I do not see how ‘compromises which appear sensible from **all** perspectives’ can be achieved. In particular, I am unhappy that the perspectives of patients and relatives, are not currently given an adequate ‘weighting’.

If sufficient people will reply to this survey, I hope their answers will shed some illumination on the above issues.

#### THE SURVEY ITSELF:

This is intended to be completed by the addition of answers to ‘Q1’, ‘Q2’ etc, and to then be saved as a file (please use either .doc or, preferably, to make sure there are no ‘version issues’, .rtf) and then e-mailed back.

There is no question of ‘marking’ going on here – this area is so complicated, that almost no two

people agree about all of the answers – but I do want answers from **individuals**: I wish to know how operational professionals are **interpreting** ‘the rules and guidance’.

Therefore, it would help if whoever is completing the form could include the following information:

I1 Which PCT covers your working area?

I2 What is your role (District Nurse, GP, Paramedic etc)?

I3 How much experience do you have in your role?

I4 Have you undertaken any specialist training which is influencing your answers?

I5 Does your local PCT allow suitably trained nurses to verify ‘expected’ deaths?

The questions, which are intended to shed some light on beliefs, follow, numbered Q1 to Q9.

Some of these are ‘very open questions’ which invite a complex response; others can be answered simply ‘yes’ or ‘no’.

I would appreciate it, if respondents would insert their answers directly after the point at which the question appears – for example:

Q7 Does the term ‘expected death’ mean the same thing, in Newcastle and Bristol ?

Yes, of course it does ! An ‘expected death’ is the same thing as a death with a DNACPR order in place !

I am not giving that as a ‘sample answer’, but merely to illustrate that I would like answers directly after my questions, and that I need to know what people **individually believe**.

## Details of the Respondents

GP: NHS Rotherham, GP, 24 years. I4 = yes, and I5 = yes.

Consultant Doctor: NHS Medway, Consultant in Palliative Medicine, 27 years. I4 = yes, I5 = Yes – after training and if expected death.

Paramedic no 1: Wirral, Paramedic, lots. I4 = no, I5 = no. (please see note below).

Paramedic no 2: Wirral, Paramedic, 19 years. I4 = no, I5 = no.

Nurse no 1: NHS Gloucestershire, EoLC Facilitator, 26 years of nursing (4 years Community Nursing (DN), 11 years Specialist Palliative Care, 5 years GSF/EoLC project work. I4 = Yes – palliative care degree, DN qualification, Masters module in health and social care, I5 = Yes as part of an EoLC Study Day.

Nurse no 2: NHS Gloucestershire, End of Life Care Education Facilitator, Medical nursing background, more recently in last 2 years specifically in end of life care education – care homes and community. I4 = diploma in palliative care, I5 = yes.

Nurse no 3: University Hospitals of Leicester. Palliative Care, Liverpool Care Pathway Facilitator/Macmillan Sister, 5 years. I4 = Completed the OU Death and Dying course, I5 = Not that I am aware of.

Nurse no 4: NHS Rotherham, Commissioning Manager (Registered Nurse), 28 years in NHS. I4 = yes, and I5 = yes.

NOTE: someone on the Wirral, appears to have modified my form before passing it on to the area’s paramedics. For I4 and I5 above, and questions 6 and 9, they inserted ‘yes/no’ boxes, and said ‘circle correct answer’ – I don’t think, that is possible in Word. I have assumed that the option these paramedics made **red**, or added an asterisk to, was the chosen answer.

## 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' behavior – 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

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': '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!**.

I have absolutely no reason to believe, that the 'ways of thinking' the limited responses to my survey hint at, are any different now. The 'mindsets' which are being applied to 'what should the son do?' can be stated, in my opinion, as doctors looking towards respecting the decisions made by patients – I will call this 'looking towards the patient' - nurses 'looking towards the records', and the more thoughtful of 999 paramedics, realising that there is a major problem here, but, in the end, tending towards 'wanting an unreasonable amount of 'certainty' before they will not intervene'.

From my family-carer perspective, I see some mindsets and behaviours which are: *offensive and not perspective balanced; illogical and do not accept reality; are covert; and are deeply problematic for family carers who understand the current situation.*

Before I explain those, I will point out that if the son phones anyone when his father collapses, then unless he manages to get the GP, I think the son will almost certainly be told to phone 999.

### *Offensive and not perspective balanced*

It is deeply offensive, to distrust the word of a family carer without some positive evidence of dishonesty. And it might be argued that the scenario is surely very rare indeed – however, the 'I wouldn't want CPR to be attempted' and 'I want to be dead, now – I've really had enough' type of decision, when expressed by a dying patient, will I think often be prompted by some sort of 'deterioration' which can be quite rapid, and is almost certain to be made at purely the patient's initiation. Whereas 'how could we treat you better?' is a fairly easy question to put to a dying person, almost nobody easily asks 'have you had enough, now?'.

See:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-end-of-life-question-which-cannot-be-asked-and-its-answer-which-cannot-be-ignored/970/>

### *Illogical and do not accept reality*

The reality which is not being accepted, is the sheer complexity and fragmentation of communication during end-of-life at home: only someone present can be part of a conversation, and the GP, and indeed nurses, are not usually in the home, so they are not able to listen to what the patient is saying. The illogical aspect, is that there is no realistic way for the son to prove the conversation took place: I've personally been on the carer side of such a conversation, and I simply don't believe that most relatives would be thinking 'I need to get this conversation into the records immediately' - 'the records' are not uppermost in your mind, when a loved-one has just told you what amounts to 'I'd be better off dead, now'. So this is Catch-22: many healthcare professionals are asking family carers to 'provide impossible-to-provide proofs'.

### *Covert*

The 'covert' aspect of this, is that becoming a family carer during end-of-life, is something which tends to be 'suddenly thrust upon' the dying person's relatives. If you read the

guidance for patients and relatives, you will find that it typically includes the suggestion that the patient 'should explain his/her decisions and wishes to both your clinical team and to your family'. It makes no sense – if a relative reads that – to then have a 'mindset within 999' of 'distrusting relatives by default'.

**It is covert because it will often only be when a relative such as the son in my Father and Son scenario is interacting with the 999 Services, that the relative will become aware of this 'we don't trust you' attitude.**

### *Deeply problematic for family carers who understand the current situation*

What is the son to do, if he is in the [small, I suspect] group of family carers who do understand how clinicians, and especially 999, behave? If not overcome in-the-moment by the 'my dad wants to die, now' understanding, and even if they know about written Advance Decisions, for the same reason of distrust 999 typically 'distrust/discount' an ADRT witnessed by a relative – are you expected to 'drag a stranger off the street, to witness the ADRT'? GPs are not going to be available to 'update records' on a 24/7 basis, either. And, patients who are sufficiently ill as to initiate that conversation, are not necessarily 'in any fit state' to engage with 'NHS record keeping' themselves: Dr Mark Taubert, on Twitter and in answer to 'why do you complete a DNACPR Form, instead of telling the patient to create an Advance Decision refusing CPR?', wrote to the effect of 'often my patients are too ill to write ADRTs – they say to me 'you know I'm refusing CPR, will you please sort that out for me, I don't feel up to it'' (**so – why might a patient, not say much the same to a relative?**).

And, as soon as you have been told, you know: I had the father explaining his refusal of CPR one evening, and the intention being to talk to the GP who was expected to visit the following day, so there could have been a gap of hours between the conversation and the collapse – but, once you know, you know, and it doesn't matter if the arrest is 2 minutes, 2 hours or 2 days after your loved-one made it clear to you, **you know as soon as the conversation has happened.**

Written by Mike Stone January 2018 [and I am still deeply angry about this – I have been ever since I became aware of this 'mindset' some years ago].

[mhsatstokelib@yahoo.co.uk](mailto:mhsatstokelib@yahoo.co.uk)

MikeStone2\_EoL

PS I am much angrier about this – about this mindset – than I am when I frequently come across clinicians incorrectly describing the Mental Capacity Act. I am 'disturbed' by the failure of some obviously very clever doctors, to decipher and describe the MCA correctly – but, in part that is because a 'neutral interpretation' of the MCA, presents deep day-to-day challenges for working clinicians. But the 'we can legitimately disbelieve family carers' (as opposed to 'everyone involved in EoL can legitimately 'keep an eye on' everyone else', which is perfectly reasonable) position is deeply offensive, full stop.