

Three Deaths, some details and some questions.

I was sent a direct message on Twitter a few days ago by a doctor, and it told me something that I had not been aware of – how unusual it is for people to die, while they are talking to you. The doctor wrote:

' My reference to your Dad was about his sudden realisation, during his last illness, that he was suddenly fading as his heart stopped or as his blood pressure suddenly fell. I can't find now the place where you told me your very moving story (so I really hope I've got that right). Most people are deeply comatose before the last few heart beats, so his experience (and yours alongside him) is really unusual, based on my clinical experience'

I had explained in my tweet, that my dad had died while my mum and I were talking to him: how my dad had said 'Oh – I feel funny – hold me' after, I feel sure, his heart had already stopped beating. What I take from that, is it doesn't necessarily hurt when at the end of a long illness, and weeks of struggling to stay alive, your heart eventually gives up the struggle and stops – my dad only noticed 'a funny feeling', he didn't mention 'a sudden pain'.

When I tweeted about this – I wanted to know if most people are indeed comatose before their hearts finally stop - a different doctor tweeted back something like 'if not comatose, then very often deeply asleep': and, this other doctor asked me 'what do you mean by coma?'.

My mum, was what I describe as 'peacefully terminally comatose' for the final 4 days of her life: she showed no signs of life at all beyond breathing, was motionless, showed no reaction at all when being turned or washed, etc.

But – I'm not sure the doctor's 'what do you mean by coma' question, is the most crucial for this situation of what my former contact at the Department of Health used to call 'the dying phase'. If another of the people who I swap tweets with sees 'coma' I suspect she tends to think 'what type of 'coma'?', but I think that is over-complicating the question for 'dying'.

I was using 'coma' to mean 'apparently not engaged with the world and is going to stay like that until the death' – whereas 'deeply asleep' for me doesn't imply 'couldn't be woken up'.

If I'm boring readers so far – I will, I hope, 'get to somewhere 'interesting' quite soon.

I give brief details of the deaths of my dad, my mum and a friend on the next page.

I think a 'better question' is not 'sleep versus coma' but, instead, is 'will your loved-one ever again be able to 'meaningfully talk to you'?'

NOTE: I am using 'talk' very loosely here.

My Friend's Death

My friend died about 10 years ago, in a care home. He knew he was going to die.

For perhaps the final 2 weeks of his life, he was 'detached from the world'. In the penultimate week of his life, he was clearly in great pain, but he was still talking – in the sense of he would have 'delirious conversations with himself'.

During the final week of his life, based on my visits, his only vocalisations were 'screams of pain'. **Awful to hear** screams of pain.

My Dad's Death

My dad died about 20 years ago, at home and less than an hour after arriving home from about 6-weeks in hospital.

My dad was dying from congestive heart failure, and he had come very close to death in the hospital: he died at home, while my mum and I were with him, and while we were talking to each other.

My dad only ever seemed to accept that he was 'very poorly' – he never said 'I know I'm dying'.

My Mum's Death

My mum died at home about 10 years ago, about 9 months after my friend had died.

My mum went from still talking, through a period of something like a day or so when she wasn't talking but was still communicating (nodding yes, gesturing, etc), to being 'peacefully terminally comatose' for the final 4 days of her life.

I knew that my mum wanted to die, and to die at home, because she told me.

There wasn't one of those 'saying your goodbyes' conversations with my dad, but my mum and I clearly both knew he was dying – **you can't 'impose'** that 'goodbye' conversation on a person who only ever mentions 'being very poorly'. But it didn't matter – I don't think my mum or I ever felt 'we never said goodbye to dad'.

With my mum, I definitely and explicitly had 'the goodbye conversation' but, despite it being obvious that she was dying, it was pretty-much at the last-possible moment. I was prompted to ask her, when my mum refused to take some prescribed items – it will probably be useful for me to reproduce my description which I have already previously published:

My mum was the precise opposite, to 'the 'ideal' EoL patient': she was a 'doctor dodger' and before I involved her GP a week or so before my mum actually died, she had most recently visited her GP about 30 years previously. My mum wouldn't involve her GP 'while she was dying' – when my mum couldn't stand up one day, I involved a cousin and we phoned her GP (and 999 because the GP would not be coming until the afternoon) essentially without my mum's permission: which, according to my own 'ethics' was wrong – it should have been my mum's decision, not mine.

So, by the time the GP and subsequently the District Nurses became involved, my mum was already close to death – and, although I feel sure that my mum could still talk at that time, she

wasn't talking (it seems to me, that she was deciding not to talk). But my mum made it very clear, to the GP, that she didn't want to go to hospital. I am almost certain – but based on observation of her decisions, as opposed to directly asking her – that my mum's number 1 priority was to die at home (my dad had died at home).

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 – this is my write-up from an earlier piece:

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'.

That was the last thing she ever said to me.

To explain 'when I was sure my mum was 'with me' I asked ': my mum was having episodes of dementia by then. The nature of these 'episodes' still puzzles me – it didn't seem to be what I had assumed ('in the present but with gaps in memory'), instead it was if at various times she thought she was a teenager still living at her parent's home, or that she was 70 and my dad was still alive. As if 'when her mind awoke, it searched its memories, and 'booted into the past''. So, before asking I made sure that 'the mum I was talking to' was the mum aged 86 – I needed to get answers from 'a mum in the present' and not from a mum who was living in a past world. COMMENT: I could see this 'sometimes it is the mum of now – but at other times, my mum isn't in the now': **I can't see how a nurse, or GP, could have 'seen that in the way that it was obvious to me [because I knew my own mother]'**.

Now, **for my mum's death:**

- 1) Before she became 'peacefully terminally comatose' I knew my mum wanted to die - **because she had told me;**
- 2) During the day before she became 'comatose' it was clear that my mum had a pain in her head – that did bother me, but once comatose there was no indication of any pain or discomfort at all;
- 3) When my mum was comatose, I assumed she couldn't 'hear the world': a couple of years after she had died, I read something which implies that it is within the realms of possibility that although comatose, people can hear, etc – I wish I had known that at the time;

4) I absolutely was reconciled to my mum's death – and I absolutely was not prepared for what happened after her death (which I will return to, later).

My 'feelings' when my mum was dying, were effectively '**she died when she entered** her peaceful terminal coma' and you can add in that I knew she wanted to die, and that she did not seem to be in any pain.

If my friend had been dying at home – with a week of 'no interaction with the world but a lot of screaming in pain' - then I have no idea how a relative could cope with that.

Even for a lengthy period of 'painless dying beyond interaction with the world', I suspect that if you have not 'said your goodbyes' and if you are less-than-certain that your loved-one wants to die, that period would be different for a relative, than it was for me when my mum was dying.

I also learnt, that when my dad was very ill in hospital for those 6 weeks, I was noticeably 'stressed' **all the time when I wasn't in hospital visiting**: when I wasn't visiting, my resting heart-rate was 100+ all the time. Presumably 'because when you are not there, you can't be sure your loved-one hasn't died'.

That wasn't true when my mum was terminally comatose at home – presumably, before 'has she died?' became a subconscious 'issue', I would have walked into the room and checked. I was so tired, that I needed to concentrate to walk in a straight line, by the time my mum died, but there wasn't 'the stress of not knowing'.

After my mum died.

What happened on the day of my mum's death, is why I am now involved in debate about end-of-life behaviour – you will find it described [in my piece here](#).

Because my mum died about 45 minutes before her GP Surgery opened, I decided to wait until its opening time to call her GP: the GP had taken the day off, I was told by the Surgery Receptionist to call 999, and I ended with a paramedic and police officers, and **a deeply unsatisfactory** 7 hours after my mum's death. Aside from 'no joined-up record keeping', it was clear to me that none of the 999 staff seemed to understand why I hadn't felt the need to call someone, immediately my mum died – and for my part, I definitely couldn't see the point of calling someone immediately my mum died. I was discussing this with a Police Inspector some months later, and he said 'I know death from a coma still comes as a shock to the relatives'. When I asked him 'how do you know?', he said 'friends have told me' but, when further questioned, he said the comatose loved-ones of his friends, had all died in hospital. As I've just pointed out – 'the stress of not knowing' seems to me to be significant during EoL, and in the context of 'knowing' it is obvious that 'hospital and home are different'.

In fact, it seems to be 'even worse than' the lack of understanding about dying at home: it seems that people without personal experience of caring at home for a dying loved-one, still 'believe they can predict how they would react and behave'.

Then, I found a clear lack of understanding between myself and the police/paramedic – **the most ‘fundamental’ issue seemed to be**

‘The 999 Services couldn’t understand why I had not felt the need to phone someone immediately my mum died – I couldn’t see why I would feel the need to do anything immediately, when my mum finally died at the end of a 4-day terminal coma, and when my arrangement was to phone the GP at her surgery’ (to be clear – I absolutely agree, that some relatives would 'feel a need to phone someone immediately': but we are not all the same, and in that situation there is absolutely no logical reason why a relative should have to phone someone immediately: to start with, why would you potentially involve a cover GP, if by waiting for 45 minutes you could instead get the GP who had been caring for your mum?).

Note: there is something ‘deeply unhelpful’ here, so far as my limited investigations after my mum’s death imply. I asked about 7 people – 5 friends and relatives, an undertaker, and the police detective sergeant who had been questioning/annoying me for much of the day my mum died. When he was driving me back home – having been forcibly-decamped to a police station between about 9-30am and 4pm – I decided to question him. I wanted to know why he thought I would have felt the need to call someone, immediately my mum died. He was clearly a clever chap – **but, eventually, all he could come up with was ‘I don’t know why – I just think I would want to call someone’.**

Of the 7 people I asked, all of them came up with the same response – which amounted to ‘I just think I would want to call someone immediately’ except for the undertaker. **None of them had been a family carer for a comatose dying patient in their own homes.**

Much later – between 6 months and a year after my mum’s death, I had a meeting with the detective inspector who was in charge of the police station, from which ‘my police’ had come. I had an interesting conversation, about ‘death from coma’ with him. Setting aside the use of the word ‘shock’ here, he said ‘I know that death from a coma, still comes as a shock to the relatives’. I asked ‘how do you know that’ and he said ‘I’ve been told that, by friends who have had loved-ones die from comas’. I asked ‘where did they die’ and the answer was ‘all in hospital’. I pointed out that ‘hospital isn’t home – very different’.

The differences I perceive between Clinicians and Relatives.

I'm not sure of the position of most relatives, so to an extent this is my own position, when I was a family-carer for my own dying parents. In one sense – in the legal sense – it doesn't really matter, because the issue there is 'are people following the law or not' irrespective of wider considerations – [see my problems with 'ReSPECT'](#) to understand that issue.

Loosely, when I look at protocols, papers written by clinicians, what doctors tweet and what they tweet about, etc, I see this type of difference – I'm using 'relative' to include 'friends' and I use family-carer to mean someone who is either sharing a home with a dying loved-one, or who has a very similar level of ongoing day-to-day contact with a dying loved one. I'm going to use clinicians as my heading, but there are some differences between doctors and nurses, and my observations are more about doctors.

Clinicians

Discuss whether CPR could still be clinically successful a lot

Imply that the senior clinician is the most important decision-maker

Focus heavily on records and the process of record keeping/dissemination

Think the most important distinction is the professional or lay distinction: so stress the MDT concept with 'MDT composed or only the professionals' and devalue 'who has been in ongoing contact with the patient'

'Like' arranged 'MDT Meetings'

Relatives/Family-Carers

Want to understand if their loved-one would want CPR to be attempted

Believe that their loved-one is the most important decision-maker

Focus on the understanding of what their dying loved-one wants to happen

Think the important distinction is 'has this person been listening to the dying patient or not?' - and that leads to [my CCT](#) (Core Care Team) alternative to the MDT.

Discussions happen between whoever is present in the home, at the time

I suppose my theme is that I believe the relatives see 'listening to my dying loved-one' as the most important thing, with of course 'then doing what my loved-one wants us to do'.

But 'the system' seems to think 'if we clinicians were not there to hear – then 'the listening doesn't really count''. **VERY OFFENSIVE!**

I can absolutely tell you – **conversations such as the one I had with my mother, described on page 3, cannot be forgotten by the relative who is involved.**

I don't care that a clinician wasn't present – I was, and I damn well heard!

It is probably obvious, that my position for end-of-life at home, is that the clinicians are overly-influenced by the things they themselves most-easily understand – the clinical situation – and that the guidance and protocols written by clinicians, incorrectly de-emphasises the thing that family-carers understand better than the HCPs: the individuality of the particular patient, within the clinical situation.

Outside of end-of-life, David Gilbert has been working on similar themes. David has pioneered the Patient Director role, and if you read [his piece here](#) it is clear that we are writing along very similar lines. If you [go to David on Twitter](#) and browse his tweets, then you will be able to find his writing about the development of his patient director role, concept or whatever you care to describe the approach as.

My first impression, looking at David's work, is that it isn't quite the same in respect of how greater patient and family-carer involvement should work, compared to my own Core Care Team model for end-of-life at home. **I essentially described my CCT model by means of just three rules:**

The way the MDT 'concept' works, is fairly well understood by clinicians in theory, even if in practice implementation is variable. So I will concentrate on the 'mechanism' implied by the CCT concept. It basically only involves a few 'directives', with the members of the CCT being told to follow these principles, and to create for each patient and LWR(s), on an ad hoc basis, 'whatever works best for you as a group' (this does not exclude things such as EPaCCS - it merely relegates the significance of such formalised records):

- 1) Everyone in the CCT, and the patient, must attempt to keep talking to each other, sufficiently that nobody is deprived of any information that person would 'reasonably need to know' - so the stress is on 'keep talking to each other, as openly as possible, because if you don't talk, then confusion and false assumptions can easily be the result'.
- 2) This does not preclude record-keeping, but it downgrades written records to a status secondary to an explanation of a record, given by anyone within the CCT who says 'that actually means'. So, the second implication is that everyone outside of the CCT, must be instructed to believe what anyone within the CCT is saying, as the default position: paramedics must be told to believe what LWRs are telling them, even if the information is not supported by records (because a patient-relative conversation, can have taken place but not yet been recorded: there is also an issue, in that currently the NHS seems determined to only allow specified professionals to up-date records, and you cannot write something down in real-time, if you are not present !).
- 3) The professionals must, if they think a relative has done, or said, something 'strange, confusing or wrong', ask the relative why it was done or said. And the professionals must tell the LWRs 'to ask us to explain why we are doing things, that seem wrong or inappropriate to you'.

NOTE: LWR means Live-With Relative and it is my term for the people who are sharing a home with the dying person – do not take 'relative' as excluding close friends, etc, from my term LWR.

CONCLUSIONS

When 'the rules for' dying at home, are created by groups of professionals and those professionals have only 'canvassed' patients, relatives and family-carers, then the resulting protocols and guidance are not perspective-balanced. I can't say where correct perspective-balance would be – but, I do assert that it is in a different position to the balance of protocols created when only professionals are at the table.

Also, while you can find discussions of the things I have been writing about in this piece, you will find that discussion in the wider writings of doctors, nurses, etc: it seems to largely disappear, by the time you get to a protocol or flowchart [at least for EoL at Home, and for decision-making in 'emergency situations'. As an example, the behaviour of the family here, as posted on Nursing Times by someone a few years ago, looks absolutely correct to me – but it isn't obviously correct, if you read EoL Protocols (see [here](#) and [here](#)):

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 surrounded by his family.

Why, is the transition-point before which a dying loved-one and friends and family can still 'say their goodbyes', and the time after which saying those goodbyes has become impossible, any less important than the transition-point at which future CPR changes from having a chance of being clinically-successful, to almost certainly being clinically-unsuccessful?

Why is what a GP has placed on an electronic database, more significant than what a patient explained to a family-carer, two hours before the patient collapsed, and if the conversation has not yet found its way via the GP into the 'official records'?

Why do clinically-authored protocols at the very least strongly imply that the senior clinician makes the important decisions, and also that family-carers are 'somehow semi-passive bystanders', when [neither the law](#) (the MCA) nor my surveys on Twitter (see the Appendix) support that assertion?

Written by Mike Stone September 2018.

e-mail mhsatstokelib@yahoo.co.uk

Twitter [@MikeStone2_EoL](https://twitter.com/MikeStone2_EoL)

APPENDIX: two of my Twitter Polls.

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

In an earlier poll on Twitter, I had asked a related question:

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

Both Polls, and much more, can be found in my lengthy PDF 'Mike's Little Book of Thoughts about End-of-Life v2' [which can be downloaded here.](#)