

## **What I learnt from the deaths of my parents - 'how I became involved' in EoL debate**

It might be helpful if I explain 'where I'm coming from'. Bee and Mark probably already understand that, but for the benefit of others I'll go over a few things.

Both of my parents died at home, and I was present when they died. I also found a housebound cousin dead in his home, about 7 weeks before my mum died. My position is 'informed by' those three deaths, 'my reactions/feelings', and the behaviour of the professionals who were involved.

I might mention my dad's death, which was about a decade before my mum's, and my cousin's later (depends on how long this piece becomes), but what I learnt from my mum's death is more relevant here, so I'll start with that.

### **My Mum's Death**

I'll start by pointing something out. I do describe my mum's death in some online pieces, but not all that often: unlike many layfolk, I've never really gone in for 'describing my story'. I have published an online piece, which explains why I have tended to avoid 'describing my story':

<https://www.dignityincare.org.uk/Discuss-and-debate/download/299/>

Its 'odd opening' is because it was written to send by e-mail to a 'fellow campaigner' and I published it without modification. I would point you to a conversation I had with my mum, detailed in the piece (in blue text). I will return to that conversation, shortly.

I don't view myself as an 'angry bereaved layman who is trying to get his story across to HCPs' – I see myself as an 'angry bereaved layman who is publishing analyses of EoL behaviour': in other words, I am informed by my own experiences, and my perspective is definitely 'from the lay side', but I see myself as presenting analyses of behaviours, from that perspective.

Some further details of my mum's death are in my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/What-I-Want-to-change-for-end-of-life-behaviour/759/>

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 – 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'.*

*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]'.

The conversation with my mum, was I think on a Friday night and Saturday morning – the GP and the DNs had at that stage each visited once, and they did not visit during the weekend: by the next time the DNs visited, my mum had stopped communicating and certainly by the Tuesday she was comatose (well, I'll describe it as comatose: on a bed, no signs of any interaction, even when being turned, etc). **So the GP and DNs could not have asked my mum, the question I had asked her – but I can assure you that 'having asked and been told, you damn well know!'**

**I just will not have this 'telling a family carer doesn't count' attitude from professionals** – you cannot get an answer if you do not ask, you cannot

listen if you are not there: asking is difficult, and if patients are at home, family carers will often be the people 'who are there'.

Anyway, although the GP knew my mum had forcefully resisted being taken to hospital, I never told the GP of that conversation with my mum: **I saw no need to, because the GP was not making any attempt to move my mum to hospital.** I went along with the energy drinks and prescriptions once my mum was comatose – administered them myself sometimes – but I was aware that they were not going to keep my mum alive: I would have resisted attempts to keep my mum alive, because she had made it clear she wanted to die, so 'I went along with things which were likely to 'keep the DNs in particular, happy' although ethically that is a departure from 'we should have been doing what my mum wanted to happen'. I feel certain that 'going along with ...' is a behaviour during end-of-life, that 'those voluminous pieces of guidance and protocol do **not** properly address'.

During this week-or-so when my mum was dying, and when the GP and DNs had become involved, I never found it difficult to discuss things with the GP, but the DNs were a slightly different story. The GP just answered my questions – she 'verbalised the answer as it formed in her head' and I did the same: we could also 'do that thing where you anticipate the other person's about-to-be-asked question'. The Lead DN in particular, 'very obviously filtered her answers – instead of just verbalising the answer in her head, she added a stage of considering what to say to me': puzzling, and irritating at the time [and in retrospect I'm not certain what was going on – my instinct is 'the GP applied common sense during a complex situation' but the Lead DN was trying to apply 'rules and guidance to a complex situation, which they are a poor fit to'].

In any event, the nurses were 'confused by me' and I was confused by them – not an issue when I was talking to the GP. I'm not sure if that was partly down to me: I'm not sure if most family carers find DNs less confusing than GPs. The GP and all of the nurses were female, so that isn't the reason.

Once my mum had become comatose, I asked the GP what would she like me to do, if my mum died. The GP said 'Call me at the Surgery, or tell the cover GP it was an expected death'. **Note: I said 'if' but we were both perfectly aware that it was 'when' my mum died** – so a question. **If you make a record of the conversation within notes – do you write down a verbatim record of what was said, or do you instead write down 'what we meant?'**

I asked the GP, at the end of one of her visits – and the question and answer were not recorded in the notes, although the Lead DN was present and listened to the conversation between Dr Smith and me.

After being comatose for about 4 days, my mum died at 8-15am on the Friday. I decided to check that my mum had indeed died, before calling anyone (**when I had found my cousin dead, for reasons I still cannot completely rationalise, the 999 operator's 'checking for life' questions really upset me – there was absolutely no way, that I was going to call anyone without being able to curtail any such line of discussion**), so I went and bought a newspaper, then returned and checked that my mum's skin was getting cold (**I have doubts that most family carers could test for death, by feeling for a pulse**).

Then at about 8-55am I phoned the DNs (got their answer-phone and left a message) to tell them my mum had died, I was about to phone the GP, and they need not bother to come that day for their visit. Then I phoned the Surgery - I wasn't sure how long before the 9am opening time the GP would arrive at the Surgery, but she should have been there by then.

The Surgery receptionist told me that Dr Smith wasn't there (she had taken the Friday off as the start of a long-weekend in Europe), and the receptionist told me to call 999. So I called 999. Note: I couldn't understand, why the receptionist told me to call 999 - a phone conversation with Dr Smith about a month later, shed light on that. We had both separately tried to work out why things happened after my mum's death, and we had reached the same conclusions - but, I hadn't been able to work out why the receptionist told me to call 999. So I asked Dr Smith 'why did your receptionist tell me to call 999 - she said the other GP's were all busy, but why didn't she connect me to a GP when one became free?'. Dr Smith said 'I'll get my notes' and returned to the phone to tell me 'she didn't seem entirely clear about what you said to her - she thought you had said that you thought your mum had died, but you weren't sure because you had been out to buy a paper and your hands were cold'. I explained what I had actually said, which would have been 'my mum died about 40 minutes ago, can you send out Dr Smith to certify the death, I know she has died because I went out to buy my paper and she is getting cold' and we both instantly said to each other down the phone 'Ah - not her fault'.

**GP receptionists do not expect to hear a calm relative saying 'my mum died 40 minutes ago' so they simply can't hear it** - and, they can't do what an untrained person might: the receptionist would probably have misheard, and if she says 'did you just tell me, that your mum died 40 minutes ago?' she would probably 'be shouted at down the phone' and, later, told off by the GP. OBVIOUS WITH HINDSIGHT - **as soon as you actually think about it** (I wasn't at my sharpest, in thinking terms, by the time my mum died - I had been sleeping in a chair for about 6 weeks, probably getting about 3 hours of sleep a night by the time my mum died: by the time my mum died, I needed to concentrate to walk in a straight line [literally - if I stopped concentrating, I would collide with door frames, etc]).

So, I phoned 999. I told the 999 operator that I did not think it was an emergency, and that the GP's receptionist had told me to call 999. She sent a 999 ambulance - but she did not tell the crew 'he says it isn't an emergency'.

NOTE: eventually - it would have been sooner, had I not been misled into believing that my PCT would get to the bottom of all of this - I did discuss the events after my mum's death with WMAS, which is why I know what I am describing here (but there are gaps - by the time I was talking directly to WMAS, 'my paramedic' had left WMAS and that meant he couldn't be directly asked why he had done things, etc).

A 999 ambulance screams up, sirens blaring out - then I found myself in conversation (an over-generous description) with a 999 paramedic. Almost the first thing he said was

## **'It was a sudden death, because I was called'**

He very quickly summoned the police, and the paramedic spent a lot of time looking for things such as DNACPR Forms, etc, which were not in the notes. I suspect – and so does the senior WMAS paramedic I subsequently discussed this with – that this paramedic was used to working in Sandwell: Sandwell and Coventry are both in WMAS, but at the time Sandwell did have a 'community EoL death' policy, while Coventry did not.

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'.

**My dad died at home, about 40 minutes after he came home, having been in hospital for the previous 6 weeks. He was very ill in hospital [he wasn't discharged because he had got better – it seems he was**

discharged, because he told his doctors that he wanted to go home] and almost all of the time when I wasn't actually visiting, I was hugely 'stressed (resting heart rate of 100+, from memory). The stress is there because 'if you are not in the hospital, you don't know if your dad has died'. That particular 'not knowing' stress isn't present if someone is terminally comatose at home - before 'has mum died?' began to 'build subconsciously' I would simply walk into the room and check.

Two district nurses - the lead DN and one other - turned up about 10 minutes after the police. While I was talking to a police sergeant, the paramedic asked the lead DN 'was it an expected death?'. The PCT never got to the bottom of what she said: I think she answered 'Yes, but not necessarily today' whereas she 'thought she had said - but apologised if she said something different' - 'Yes it was an expected death'.

When I asked the PCT person who had supposedly 'investigated' 'so - what does the paramedic think the nurse answered?' I was told that the PCT had not asked the paramedic. However, 'Yes, but not necessarily today' is a deeply unsatisfactory reply to 'was it an expected death' (it is an answer that confirms the death was expected, while at the same time making it clear the person answering does not understand what 'expected death' means). I would point out: the paramedic told me 'it isn't an expected death because I was called', he then contradicted himself by asking the DN, and having been told it was an expected death, the paramedic most definitely did not apologise to me.

I could continue, and this whole situation was a 'degenerative negative-feedback loop': I couldn't grasp why, once the lead DN had pointed out that it was an expected death at the end of a 4-day coma, the police did not 'apologise to me and clear off, so that I could get on my grieving' - they, of course, 'viewed my [increasing] irritation with their presence and behaviour as 'suspicious''. But I'm not going to, because what I have covered already, is sufficient to make my point:

*Death at home is hugely complicated - only the people 'on the inside' (the family carers, district nurses and GP) have got even the remotest chance of really understanding any given 'dying and death' - and whereas with hindsight the 999 service staff protest 'but - we didn't know that at the time' and 'the system's 'solution' is 'better records'', **MY ASSERTION is that the situations are often [or at least sometimes] too complicated for 999 staff to properly understand whatever records you have, and I assert that the solution is 'you have to accept that the GP, relatives and nurses are the only people who understand it, and they almost certainly only each understand it in part - the problem is that the 999 services are not being told to believe family carers'.***

I'll finish with one further point - this did not happen, but it might have happened. Because it didn't happen, 'this is how I think I would have felt'.

I wasn't in any way prepared, to effectively be accused by police of murdering my mum after her death. To be taken to a police station: to return home about 7 hours later, to find that the police had searched my home, removed my computers, etc. But, whereas 'shocked by the death' isn't an ideal phrase for the feelings when a loved-one who you know wanted to die, dies at the end of a 4-day coma, I have no doubt that 'you are in a very unusual place, mentally'. In particular - I think you want to 'disengage from the world' on the day of the death [I think that inhibits the laying-down of strong memories of the death itself]. You need to be 'left alone, to do what you instinctively do - whether that is 'rage', sit down drinking tea, go for a long walk or retreat to a dark corner' - because that is an 'inherent protective mechanism we have, by which 'our mind protects itself from future 'traumatic memories''. Being annoyed by the police, for 7 hours, is not at all helpful.

If I had phoned the Surgery, been connected to Dr Smith, and she had said to me 'I've got a very sick patient - can I come out a bit later?', I'm sure I would have said 'fine - but give me a time, because if you are coming at 11am, I'm going out of the house and coming back at 10-45am'.

**I wasn't 'worked up by' my mum's death - but I don't think I would have wanted to stay in the house, between 9 and 11, waiting for the GP to come and certify the death.** The reason I'm explaining this, is that I've wondered what would have happened if I had said that to the GP. We did not have a nurse verification of death policy - so, the option of 'the GP can't come, but the nurses can come without the GP, and the nurses can arrange for the removal of the body, do the paperwork, etc' wasn't available. But - suppose Dr Smith had said 'can I send the DNs round, to wait with you, until I can come out?'. I **would not have wanted that** - if the nurses had been in the house with my mum, I would not have felt happy to leave the house: and as the nurses couldn't do anything useful (no NvoD), I would not have wanted 'the nurses to come, until the GP could come to certify'. I suspect that most NHS policies, if they did consider that situation, would probably suggest 'the nurses should go out until the GP can attend' - **that would have been 'a negative' for me.**

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