

Hi Kate,

I'm not sure how comprehensible this will be – lots of detail missed out, as is always the case! From our recent Twitter discussion.

I was harassed by the police for 7 hours when my mum finally died at the end of a 4-day terminal coma: the GP had gone on holiday to Europe, the Surgery Receptionist told me to call 999 and then I found that 999 and I had very different views about whether death from a coma, 45 minutes before the Surgery opened, required me to call somebody immediately my mum died (as opposed to what I did – checking that my mum had indeed died, and calling the Surgery at 9.00 am when I felt sure the GP would be there). That left me enraged, whenever I wasn't either grieving or 'numb', over an entire weekend because my mum died on a Friday, about a week before Christmas 2008.

There is a complication around 'why my mental state was 'damaged'', however. About a day before my mum died, I had found a nursing note which stated that I had refused permission for the nurses to examine my mum at some point during the care – I wasn't happy about that, it hadn't happened and I couldn't understand that note (I eventually figured it out – the nurses thought they had asked me for permission to examine my mum's bottom, but I thought they were asking me would it be difficult if they tried to examine her bottom: I knew that mum, quite heavy and seated, would resist their attempts to examine her bottom, but my answer to that effect was interpreted by them as 'a refusal of permission').

About 4 months after my mum's death, the PCT sent me its report – deeply flawed and almost utterly useless – about why various things had happened: its 'explanation' of the nursing note, was so flawed and impossible that I spent about 3 days trying to work it out for myself, again. But, I did not know WHEN this 'supposed refusal' had occurred – so, trying to work out which nursing visit that note applied to, I had to keep 'mentally running through ALL of the nursing visits'.

Which – at least subconsciously – clearly meant that I had to 'keep running past' a conversation I had with my mum, a day or so before she became comatose.

As I have explained in my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-believe-that-Advance-Decisions-should-be-encouraged-but-that-advance-statements-should-be-discouraged/814/>

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. My brain cannot cope easily with 'recalling' that : you want to 'file and forget' the answer to the question, but not the 'you know I love you' part - that is a tricky thing for your brain to handle. Unfortunately a problem with the medical notes, and a useless subsequent PCT investigation, forced my brain to keep 'running past' that event a few months later - that really damaged my brain, as it happens.

By the time I had managed to work out why the nurses had written that note about 'refusing permission to examine my mum' my psyche had been pretty-much wrecked by its 'subconscious thinking about' that final conversation with my mum.

The one time I tried to explain that conversation 'verbally to the 'NHS'' was at a meeting with my PCT - and I simply COULD NOT GET THE WORDS OUT, I just 'broke down in tears' and moved on to the other issues. In fact, thinking about that even 'tangentially' is making me slightly tearful even as I am typing this now (23<sup>rd</sup> September). For about 2 years, I used to think about that conversation every day - and it always made me tearful. For about a year or so, I found it very difficult to write up the description of that conversation, because I'm not a touch-typist and to type I need to be able to see the keyboard: you cannot see the keyboard, if you are crying a lot!

But - I cannot say that it was the conversation with my mum that left me damaged: it was, I feel sure, that 'running backwards and forwards past the conversation, during those 3 days or so when I was trying to understand the nursing note' that actually caused the damage.

I have, therefore, problems with 'explaining how damaged psychologically I was' and also problems with 'explaining the actual cause(s) of the damage': the former is 'upsetting to describe' and the latter is hugely complex to describe.

Which is why, I go for my rather nerdy deconstructions of guidance, protocols, etc - not to mention, that I'm better at that 'analytical stuff' anyway.

**I think you are admirably brave - or perhaps stupidly self-destructive - to go around the country describing to groups of doctors and nurses 'how upset their behaviour made you feel'.**

Best wishes, Mike

PS I'm pondering whether I might find a use for this piece - 'a use for' in my terms means 'put it somewhere online' - which is why I've done it in PDF format: would you object to my publishing this piece (if you have any objection - and if you would object, however 'mildly, please do let me know - then I will not publish this piece, which was, after all, 'written for you').