

The Question we Cannot Ask – and the Answer we Cannot Ignore

I usually 'debate the Mental Capacity Act' from the perspective of a patient or family carer, but without introducing my personal experience: but I will introduce my own experience here.

Mr Justice Hayden has written:

55. I must record that the Official Solicitor's lawyers appear not to share my analysis of the cogency and strength of TH's wishes regarding his treatment. I confess that I have found this surprising. If I may say so, they have not absorbed the full force of Baroness Hale's judgment in *Aintree* and the emphasis placed on a 'holistic' evaluation when assessing both 'wishes and feelings' and 'best interests'. They have, in my view, whilst providing great assistance to this court in ensuring that it has the best available medical evidence before it, focused in a rather concrete manner on individual sentences or remarks. To regard the evidence I have heard as merely indicating that TH does not like hospitals as was submitted, simply does not do justice to the subtlety, ambit and integrity of the evidence which, in my judgment, has clearly illuminated TH's wishes and feelings in the way I have set out.

There is a question WHICH 'WE CANNOT ASK' during end-of-life – it is:

'WOULD YOU NOW PREFER TO BE DEAD?'

When my mum was dying, I was her family carer. I asked her 'that question' because I was forced to – my asking of the question (bold) is at the end of what follows in italics:

My mum almost never went to her GP (she had previously most recently seen her GP about 30 years before her death), wouldn't even take an aspirin for a headache, and she wouldn't call her GP as she got older and iller: eventually one day she couldn't stand up, I enlisted the help of a cousin, and we called her GP out (she was already 'very poorly' by then: however, this situation isn't easy for a relative, because in the same way that doctors cannot force patients to seek treatment, relatives cannot force people to involve a doctor: in any event, I could see that my mum was dying from old age, which is incurable, I'm pretty sure she also knew that, and her main determination was to die at home). The GP couldn't come until the afternoon, so we also called out a 999 paramedic (who couldn't do anything at all, as my mum 'refused to be touched').

*Her GP, prescribed some antibiotics and energy drinks, but my mum wouldn't take them. While the GP had been trying to examine her, my mum had been pushing the GP 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'.

To explain 'with me' in the above: my mum was suffering from some type of 'dementia' but it was very variable – it was as if she was sometimes 'living in the past' but at different times in the past. Sometimes what she said implied that she believed she was still a teenager, at other times it seemed that she 'was 70 and not 86'. I needed to be sure that 'it was the mum of 86 who understood her present situation' who I was talking to, before asking that question – hence 'when I was sure my mum was 'with me' I asked'.

Now, that conversation was on Friday evening and Saturday morning: by the next time any clinicians visited, the following Monday, my mum had 'become comatose'. So, it wouldn't have been possible for her GP to ask my mum 'about that conversation'.

BUT I KNEW – it was clear to me, that my mum would not have consented to any intervention which would extend her life, or prevent her death. So, although I did not explicitly ask, I 'knew my mum would refuse attempted cardiopulmonary resuscitation (CPR)'.

I'm generalising without proof, here, from my personal to 'a generality':

THE RELATIVE OF A DYING LOVED-ONE CANNOT IGNORE THAT ANSWER

You will notice that I did not ask my mum 'do you want to die' or 'what specific treatments would you refuse' - I asked 'If you don't take the drinks and medicine you will go to sleep and not wake up again. Is that what you want ?'.

As an aside – I have just discovered [because I am currently crying] that typing this explanation STILL brings tears to my eyes, 9 years after it happened (although I can see through these tears – for about a year after my mum's death, I found it very difficult to type that piece, because 'the tears were a flood and I couldn't see the keyboard' and I'm not a touch-typist). Further to the aside – it isn't the conversation of itself which 'makes me cry so much when I recall it', it was something the PCT forced me to do, which in my view damaged my mind [too lengthy to explain here – and also unnecessary].

Currently, 'the professionals' seem to think that 'somehow that conversation doesn't count because there were no clinicians present': **I'M SORRY, BUT TO QUOTE A FAMOUS RESPONSE 'I DON'T GIVE A DAMN'.**

As the relative and family-carer of a dying loved-one, my responsibility is to do what my loved-one wants – I 'take my instructions' from my loved-one, I don't take instructions from clinicians for things such as the above.

Of course, 'I would now prefer to be dead' isn't an instruction – and the legally-binding instructions which patients can give to clinicians, take the form of refusals of treatment.

So, we now move to another 'question which cannot be asked', the answer to which, if it is a refusal, is indeed a legally-binding instruction:

'If your heart stops, would you want us to try and re-start it or not?'

Loosely – and there is 'terminological complexity here which I'm ignoring' - 'are you Do Not Attempt Cardiopulmonary Resuscitation?' ('are you DNACPR?').

Doctors freely admit, how 'awkward' it is to ask patients, even in hospital, about DNACPR.

When NHS England, a few years ago, tried to prompt GPs to discover if their elderly patients would refuse or accept attempted CPR, parts of the media reported this as 'GPs told to ask elderly patients 'do you want to die'', and other people said 'Now the NHS is giving up on the elderly'.

THESE QUESTIONS ARE INCREDIBLY HARD TO ASK – but if a family carer asks and receives the answers, or if the dying loved-one explains the answer without being asked, THEN THE FAMILY CARER KNOWS: IT IS OFFENSIVE, ILLOGICAL and UNFAIR for professionals to imply 'IT DOESN'T COUNT BECAUSE WE WERE NOT THERE!'

It is an example of people – in this case 'the system', although sometimes it is patients and relatives - 'having an expectation of knowing something which it is unreasonable to expect to know' [in this case 'somehow 'expecting to have been present' during a conversation they cannot have been present at'].

See also the following, which explain that forbidding attempted CPR if you are at home and not anticipated to die in the very-near future is in practice nigh-on impossible – despite it being clear from sections 24-26 of the MCA that such a refusal should be 'legally-binding':

<http://www.bmj.com/content/356/bmj.j1216/rr-1>

<http://www.bmj.com/content/356/bmj.j1216/rr-4>