

EoL and ACP: a fundamental complication, which I hope I explain clearly

Recently Dr Mark Taubert posted some tweets, which while being perhaps wider in scope, to my mind definitely contained 'the way you write is hard to follow'.

As a result I have already written and posted a piece about the Mental Capacity Act (ref 1) which I myself think could usefully be read by every student nurse in England and Wales. I told Mark that I would be writing something about Advance Care Planning (ACP) during End of Life (EoL), and this is that piece. My aim is for Mark to be able to understand this piece – and I'm not sure who might 'usefully read it', although Mark might have a view on that.

I am going to start, by quoting something a doctor has said:

She explained that the time pressures meant that she had to choose between writing notes for each patient or seeing the patients. She said: "I prefer to spend time talking to and helping my patients, than to spend excessive amounts of time on note-keeping"

Now, place yourself in the position of a relative living with a dying loved-one: does that make sense, or not? If the GP visits, and can visit for 15 minutes, do you want the GP to be helping your loved-one, or do you want the GP to be concentrating on writing down what has been done to help your loved-one? Do you want your GP to be spending 3 hours a day consulting with and treating patients, and another 3 hours a day making notes about what happened during the consultations, or would you prefer 5 hours consulting and treating, and 1 hour making notes about the consultations? I think most people – asked the question as I have presented it here – would say 'the doctors should concentrate on seeing [and by implication helping] the patients'.

I am going to make an assertion about the clinical situation of end-of-life, and as it happens Mark (ref 2) has recently contributed a piece which includes the theme of uncertainty of prognosis:

In EoL, sometimes things can happen – clinical deterioration or clinical improvement which wasn't predictable, or a 'clinical development in an unanticipated direction' – which can throw a spanner into 'the best-made plans of mouse or man'.

And **I am going to make an assertion** about the way that decisions are often made during EoL at home:

Often there is no alternative to the decision being made by a group which is a happenstance mixture of patient, family, GP and nurses [depending on who happens to be present] and very often 'common-sense compromises' will be adopted: not 'idealised decision-making' and not 'theoretically-perfect decision-making', but decisions which 'everyone settles for'. It is a case of 'compromising and 'muddling through'' in many situations.

I am stating 'that is the reality of how it works' – that what happens during EoL at Home is hugely complex, and frequently 'the decisions made are the decisions which 'seem sensible' to the people involved'.

In theory, while the patient is capacitous, put loosely 'the patient makes the decision', and if the patient isn't capacitous, the legal situation is much more complex. I also think that it isn't legally possible to 'consent to the ACP': legally it is case of 'ongoing consent [or best-interests decision-making] to each intervention within the 'ACP' **at the time of the intervention**'. For example, 'the ACP' might involve taking blood samples twice a day – but if the patient wants to, a capacitous patient can just decide and say at some point 'I've had enough of these blood samples – you can't take any more blood samples'.

It is very difficult to 'translate' what I have described above, into the 'neatness beloved of the NHS' – into ACP, protocols and guidance.

And attempts to do that – to 'impose neatness onto reality' – often tend to be inadequately thought through. For example, it takes very little thinking, to realise that there is a fundamental difference between 'planning' made while the patient is mentally-capable, compared to 'planning' made after the patient has lost mental capacity. It wouldn't be surprising, to discover that clinicians decided to invent different words for the two situations – that planning made while the patient was capacitous might be talked about as (for example) 'CACP' and planning made after the patient had lost capacity might be talked about as IACP.

But – patients are **not definable** as 'capacitous' and 'incapacitous'. The law defines mental capacity as being both decision and time specific: at any given time, a patient might be capacitous for some decisions but incapacitous for others; and for the same decision, it can be capacitous on one day, and incapacitous on the next day [or vice versa].

Throw in that it will often be uncertain, and perhaps disputed, about whether or not the patient is capacitous for a given decision at a particular time, and I wouldn't be surprised if 'the experts' came up with labels and the like for ACP during EoL, which definitely wouldn't cope with that 'uncertainty around capacity', and definitely with 'paper-work' that doesn't fit with my:

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Now, I think we patients and relatives, want the doctors to help – we want our GPs to use common sense to help, not to try and shoehorn us into 'neat boxes and neat protocols'.

Which – and this is a little 'off theme' in one sense, but central to something we should all be thinking about in another sense – is why I started with:

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In fact, I lied about that – what the doctor actually said was:

She explained that the time pressures at the hospital meant that she had to choose between writing notes for each patient or seeing the patients. She said: "I chose to see the patients, so my note-keeping was sparse".

That can be found in 6.29 (page 171) of the Gosport Hospital Report: it was said to the GMC by Dr Barton, who was defending her behaviour. And – 'if something wrong seems to have happened', **then at that point** 'the note-keeping seems very important'.

A lot of good EoL behaviour, amounts to doing what the patient wants, and for EoL at home there is also quite a lot of 'sensible compromise'.

We patients certainly need to have good doctors and nurses helping us when people are dying – but I do not think we will be helped if we end up with doctors and nurses who spend more time 'trying to comply with guidance when the guidance doesn't fit the reality' as opposed to 'trying to help'.

So, I suppose I have two concerns here: that future ACP guidance will be too simplistic and therefore flawed in terms of its categorisation and demarcation with respect to the legal-complexity of decision-making, and that we might have nurses and doctors who are worried about being later accused of having done something wrong, trying to 'shoe-horn their behaviour into their guidance' instead of sensibly adapting their behaviour so that it fits with the complex reality of EoL at Home.

Ref 1 <https://www.dignityincare.org.uk/Discuss-and-debate/download/324/>

Ref 2 <https://www.bbc.co.uk/news/uk-wales-44904057#>