End-of-Life and Perspective part 3: Ordering the Caveats

It isn't so much that everyone who has a decent grasp of the complications of end-of-life, cannot see what the problems are: some people and some professionals almost certainly have a very inadequate understanding of the depth of the complexity, especially for EoL at Home, but the problems are relatively easy to see, The problem, is working out where 'sensible balance points are' for competing but valid objectives: this is not necessarily easy anywhere, but there seems to be a particularly serious problem for EoL at Home.

By analogy, we all agree that we do not want people to smuggle dangerous drugs into the country, but we also want innocent travellers to not be harassed: we have not settled on strip-searching every person who is entering the country.

This is from my perspective, deeply problematic for EoL at Home - as I have pointed out:

http://www.bmj.com/content/353/bmj.i2230/rr-7

The reason I am so keen on people sticking to the informed consent described in our English law, is not that I am 'against happy endings', nor am I sanguine about young adults, 'exercising their legal right to kill themselves'. I am so insistent about the application of informed consent, because I became involved not in a general 'ethical debate', but in a debate about end-of-life behaviour. And the ethics which many professionals seem to apply during end-of-life, offend me. I am offended that most guidance seems to imply that if a terminal patient has clearly expressed a refusal of a future treatment to a member of his family, 'somehow this counts less than if he had expressed it to a GP'. I am offended that even if I write a very clearly worded Advance Decision refusing cardiopulmonary resuscitation irrespective of why I arrest, if I arrest at home and the death could not be certified, attending 999 paramedics would be likely to ignore my instruction and would probably attempt CPR. I am offended that for known end-of-life but not yet 'expected' home deaths, the police tend to become involved, and to treat the family as if they are suspects – but I feel sure that deaths which happen in identical clinical situations, but in hospital, do not result in the police attending and interrogating the nursing staff. These things all offend me, and they also 'offend my ethics'. My ethics include things such as 'no accusation without some evidence': people should be assumed honest until proven otherwise; decent end-of-life support for patients requires that clinicians and family carers should be working together; etc. So my ethics, appear to be different from the 'ethics' of 999 paramedics, police officers, etc.

If my [hypothetical] 82 years old, but seemingly 'healthy', father had made it very clear to me that under no circumstances would he want CPR to be attempted, I might not think he was making the 'right decision' but I would respect it because it is his life, and he would experience the consequences if he arrested and CPR was attempted – if he collapses, I tell 999 paramedics that he had made it clear to me that he would never want attempted CPR but the When EoL patients are at home, and capacity has been lost, discussions about 'what should happen' can lead to disputes, for example between a GP and a

family carer. The only thing I am 100% certain of, is that a family carer's 'well, I'm not going to do that, because my dad made it perfectly clear to me he would have refused [that course of action]', is legally (and in my opinion morally) correct. It has to be legally correct: because it follows the fundamental 'a person is sovereign over his or her own body' legal principle. There is no such clarity, once 'professional ethics' [and professional objectives] are applied to disputes between relatives, clinicians and police officers: and while 'arguing the ethics' with a GP is one thing, 'arguing with police officers about ethics' is a wholly unsatisfactory experience (for a live-with relative), immediately after a death, and when 'the police officer is confused'.

It seems to me, that police officers in particular tend to have an inadequate understanding of both how complex and confusing EoL at Home is, in the context of communication, 'the communication chain', and also of decision-making, and that police officers have a very poor understanding of the Mental Capacity Act, which is the part of our law which covers the decision-making for available potentially-clinically-successful interventions.