I wrote a short piece (appended) called 'The Fossil Tooth of the MCA' some time ago, and since I wrote it Mr Justice Charles has <u>ruled</u> on the Briggs case. I made a couple of comments on the ruling <u>here</u> and <u>here</u>.

Mr Justice Charles explained the situation of Mr Briggs:

'The decision I have to make is whether a part of the current treatment of Mr Paul Briggs, namely clinically assisted nutrition and hydration (CANH), should be continued. Mr Briggs is in a minimally conscious state (MCS). This is the result of the serious and permanent brain damage he suffered as the victim of a traffic accident on 3 July 2015.'

So, this is the type of situation which I discussed in 'the fossil tooth':

'Simple, if a person creates an Advance Decision, and then goes from mentally capable to something similar to comatose: all you need to do, is ask yourself 'when the ADRT was created, had the person thought about the present situation ?'.'

Eventually, Mr Justice Charles decided that withdrawal of CANH would be in Mr Briggs' best interests, using a line of reasoning which seems to me to be the same as one I had previously published:

'Mr Justice Charles wrote in 62 ii:

- '62 But, in my view when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self-determination which an individual with capacity can lawfully resolve and determine by giving or refusing consent to available treatment regimes:
- ii) if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life."

I had written in my previously <u>published</u> analysis of the MCA (within the PDF file which you can download):

'I also wrote in that downloadable PDF:

'A genuine section 4 best interests decision, involves 'working out the patient's likely wishes' - there must be some degree of uncertainty about those wishes (a degree of uncertainty entirely absent for 1). Whoever is considering the best interests test, the fundamental struggle is in persuading oneself that this uncertainty is small enough, to believe that the patient would have refused CPR for the particular CPA in question.''

But I was glancing at the Briggs ruling yesterday, and I stumbled across this section:

'67 Also, if the court was to find that the relevant person would have made such an advance decision that would be relevant to, but not determinative of, what his or her attitude (wishes and feelings) would now be and so the decision they would make now, if they were able to do so. This is because that decision could not have been made in light of the evidence and argument put before the court. And unless there was evidence that the relevant person had considered and decided to make an advance decision in terms that were known (so, as mentioned in argument if Mr Briggs had had his accident travelling to sign an applicable advance decision) it is unlikely that there would be evidence about a detailed consideration of the factors that the relevant person would have had regard to in making that choice. '

This is typical of the sort of thing you will find in court cases – judges 'naturally' look at things from their perspective of making rulings in cases which reach a court. Doctors naturally look at the MCA 'from their working perspective'.

But – from my patient, relative, family carer or friend perspective – and, crucially bearing in mind how I got involved in all of this

'... my observation that 'medical academic debate' almost never addresses the issues which bother me, from my 'live-with relative during end-of-life perspective'. ...

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 paramedics attempt CPR, 'then I'm not happy with the ethics of 999'.

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'.'

my position is we surely cannot have an intention that most decisions made during end-of-life situations, will be made by our courts. But it is definitely true that the clinical situation can change very quickly during end-of-life, and that the communication chain (my term for 'who says what to whom, when, and how who said what to whom is subsequently passed on to the people who were not there but who need to know') is potentially very complex, and that despite this complexity, decisions must be made and often very quickly.

Mr Justice Charles in his section 67 is touching on this from his position as a judge – he is writing about 'what the judge can be sure of when the judge is making a ruling' - but usually during end-of-life at home, we have different people who all know and understand different things. But I stand firm in what I wrote above:

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.

The Fossil Tooth of the MCA is section 25(4)(c)

Dinosaurs are often 'reconstructed' from a handful of bones – or sometimes, 'from a single tooth'. The 'idea' is that bones and teeth have to 'fit function': you do not need sharp and powerful teeth, if your diet is blackberries.

The 'fossil tooth' of the Mental Capacity Act, is section 25(4)(c) – and the words we need to think about to see how much of our 'dinosaur' we can reconstruct (in other words, what we can learn about the MCA from that small collection of words) are these:

'An advance decision is not applicable to the treatment in question if there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.'

Those words describe 'Informed Consent' - you do not really need to read section 3 of the Act, if you take on board that an Advance Decision is the projection forwards into anticipated mental incapacity of the patient's decision, and that the patient's decision can only be challenged 'if there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them'.

Those words also illustrate an issue with the MCA. It is an inherent problem which has to exist, if your law is Informed consent, and you then try to define the rules for mental incapacity. The easy bit, is to project the autonomy of a mentally-capable person, forwards into a period of mental incapacity which the person had anticipated: that is what the MCA does with its provision for Advance Decisions.

The problem is simple – in our 'fossil tooth' of section 25(4)(c) it is represented by the words 'which would have affected his decision had he anticipated them'. That is POINTING BACK to the person's EARLIER decision-making, when the person WAS mentally-capable.

Simple, if a person creates an Advance Decision, and then goes from mentally capable to something similar to comatose: all you need to do, is ask yourself 'when the ADRT was created, had the person thought about the present situation?'.

But imagine that a person was NEVER mentally capable, or has been mentally incapable for many years – for example, has had severe dementia for a long time. Where is that earlier capacitous mind, which is being pointed at by the fossil tooth of 25(4)(c)?

IT IS NOT THERE – the MCA is very unclear about decision-making in any situation when you are not effectively following the patient's own decision.

Put another way – and this is VERY problematic – the clinicians who 'use the MCA the most in their daily work' are those who work with demented or 'mentally ill' patients AND THE MCA IS NOT AT ALL CLEAR FOR THAT SITUATION. The MCA's 'explanation' of best-interests decision-making, is not really much of an 'explanation' at all (this is inevitable – but, and I get very grumpy indeed about this, PROFESSIONALS SHOULD ADMIT IT).