

Put concisely:

Claire at about 28minutes into the podcast

You don't know – you're not me – the only way you can know that is by asking me. And talking. And listening.

Me, at the end of my BMJ response

<http://www.bmj.com/content/356/bmj.j876/rr-7>

To Close: (hypothetical)

I have been sharing a home with my now 'dying partner' for 20 years, although my partner has only been 'dying' for about six months. I have talked to my partner a lot during this six months, and during those 20 years. The GP has talked to my partner a little, especially recently. We both talk to the district nurses who have visited a couple of times a week for the last 6 weeks – but they are often different nurses each visit.

My partner has just collapsed. I have called 999 to find out why my partner has collapsed. I am now standing over a 999 paramedic, who is doing something to my unconscious partner. Why on earth, should I accept that this paramedic decides what happens next ?

Comments on the RCP EoLC Podcast by Mike Stone

The podcast webpage is:

<https://ourfuturehealth.rcplondon.ac.uk/podcast/end-of-life-care/>

The speakers are:

A discussion around one of the major difficulties facing physicians, patients and the health care system – end of life care with a panel of;

- Professor Jane Dacre, President of the Royal College of Physicians*
- Professor Bee Wee, NHS End of Life Care Director*
- Dr Amy Proffitt, Consultant in Palliative Medicine at Barts Health and Honorary Secretary to the Association for Palliative Medicine Great Britain and Ireland, and*
- Claire Myerson, patient with metastatic, advanced breast cancer and patient advocate member of charity Breast Cancer Care's ChangeMakers group*

Note: should it in fact be Proffitt with a double t?

I liked the talk, but it was clear to me that three of you were 'thinking like clinicians' whereas I think like a patient, family-carer or Welfare Attorney. Before I get stuck into my fundamental issue - 'the role of family and friends' - I'll make a few general points.

1) Is Amy's name spelt incorrectly (see above) on the RCP page?

2) Jane said that the 'terms' would be explained, but if they were, then I didn't notice where (you talked about ACP – mainly Claire – but you mentioned other terms such as attorneys under the LPA without explanation [see on re Welfare Attorneys])

3) Bee mentioned that she thinks there is a problem because so few people die at home these days (at 14 minutes in) – I couldn't agree more, and my own experience of the behaviour of the 999 Services after my mum's death supports, I think, the assertion that 'most people, including police and even some 999 paramedics, have no understanding of how complex dying-at-home actually is'.

<http://www.bmj.com/content/353/bmj.i3200/rr>

I have written (ref 1) 'at the moment behaviour sets for EoL home death seem to assume an 'idealised model' which is very different from the reality of many EoL home deaths. The guidance and protocols, should be based on the reality of EoL at home, accepting the many complications, and not on 'a guidance-writers' wish-list of how EoL at home should work in a 'perfect and much-simplified world'.

This is made much worse, if police somehow become involved after an 'expected' EoL Home Death, by the fact that the police are deliberately kept away from 'expected death' – so when they do become involved, their 'thinking' is unhelpfully-influenced by their own experience of 'sudden deaths'.

As it happens, the concepts of expected and unexpected death are still being used for Home EoL Death, and that urgently needs to be changed – I've explained how it could [and in my opinion should] be changed at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/275/>

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Markers-and-Timelines-for-End-of-Life-Reconsidered-an-attempt-to-bring-order-to-chaos/785/>

4) The issue of 'the conversations not taking place'. I'm sure that parts of the conversation often do take place: 'the interventions we could offer', 'bereavement care', etc. But, I recently wrote a piece about a part of the conversation that I suspect almost never takes place –

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-end-of-life-question-which-cannot-be-asked-and-its-answer-which-cannot-be-ignored/970/>

At about 19 minutes, Claire explained that her GP doesn't 'know her' while her oncologist does know her. Claire also said support from family and friends depends on their 'attitudes' – however, if you are not in a position to have that engagement with the dying person (if the opportunity to talk, during ongoing contact, never existed) then clearly you cannot 'know the patient as an individual'. At about 29 minutes Claire says some of her family 'have got different views' from her own – this is at the heart of my objections to the way that HCPs describe EoL decision-making (it isn't that what Claire says is disputable – it is the resolution of the many complexities, when the resolution is asserted by the professionals, which is 'biased and illogical'). If the opportunity was there, you can have taken it. That is logically obvious – but I strongly object to what amounts to an attitude of 'relatives cannot listen' which I discern in clinically-authored material, and in clinical

mindsets. This is particularly true for 'dying from 'generalised old age" when it seems obvious that the level of medical intervention which Claire has experienced will probably not take place.

GPs do not have the time to listen:

<http://www.bmj.com/content/355/bmj.i5705/rr-15>

And ReSPECT is asserting that people who had no 'background of contact' should be making best-interests decisions – logically unsupportable, as my scenario at the end of this piece ought to make clear:

<http://www.bmj.com/content/356/bmj.j876/rr-7>

To Close: (hypothetical)

I have been sharing a home with my now 'dying partner' for 20 years, although my partner has only been 'dying' for about six months. I have talked to my partner a lot during this six months, and during those 20 years. The GP has talked to my partner a little, especially recently. We both talk to the district nurses who have visited a couple of times a week for the last 6 weeks – but they are often different nurses each visit.

My partner has just collapsed. I have called 999 to find out why my partner has collapsed. I am now standing over a 999 paramedic, who is doing something to my unconscious partner. Why on earth, should I accept that this paramedic decides what happens next ?

I would point out – and most of my objections to ReSPECT are drawn together in that BMJ response – that ReSPECT [and the RC(UK), which is clearly where ReSPECT is getting its 'legal opinions' from] persistently incorrectly describe the 'consent law' which the MCA describes. And at least one lawyer, who works with the MCA, agrees with me:

https://twitter.com/MikeStone2_EoL/status/906073527236907009

During the past few weeks, I have been entangled in a Twitter thread, within which the most-active of the tweeters come from a group of people who have had 'very bad experiences of deaths'. These individuals make some basic assertions, from which they cannot be shifted:

- * The LCP was created to murder [inconvenient and costly] elderly people
- * The concept of end-of-life care is invalid, and 'EoLC = murder': hence Palliative Care doctors are all murderers

Twitter also makes it clear that there is a lot of misunderstanding around EoL and incapacitous patients more widely: a recurrent theme being that 'next-of-kin' is a concept fundamental to MCA best-interests decision-making [and disturbingly, I see some clinicians introducing NoK when writing about the MCA, as well as lay confusion about this].

Claire made the point that patients are all individuals, in the context of 'do not make assumptions about the hopes of individual patients'. I am not sure if Claire uses hopes, when I use either aims or objectives – more to the point, **we should be** explaining EoL in terms of not 'hopes/aims/wishes' but in terms of **decisions**. And Claire seemed unclear – even, perhaps, in terms of her own 'thinking', about that issue [which would be unexpected unless I'm seeing something which isn't there – Claire seems admirably clear in terms of her 'thinking' during most of the talk].

Claire says 'ask me, don't ask my family' **but she also tells us** that she has appointed two Welfare Attorneys.

The role of a welfare attorney, is not to listen to the patient: **everyone involved, should be listening to the patient** (it is implied that 'some relatives do not listen' - I'll return to that later).

The role of a welfare attorney, is to make and express best-interests decisions: **you appoint an attorney to take-control-of best-interests decision-making**.

And if the patient has 'unambiguously made-and-expressed the necessary decision prior to incapacity', and if there is no reason to believe that the patient has had a change of mind, then there should not be any best-interests decision-making: this seems to be widely misunderstood – not surprising, in view of how badly the MCA seems to be understood – but I explain it at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-SCIE-Robyn-and-Anne-scenario-compared-to-my-Alan-and-Liz-scenario-the-essential-difference-between-informed-consent-and-best-interests/865/>

You – all of you, Claire included, but especially you three clinicians – **talk about 'all of us' but you do NOT seem to mean ALL of us**: you seem to mean 'the patient, the clinical team and 'wider societal organisations'' - you seem to deliberately exclude family carers, other relatives and friends. You appear to be deliberately attempting to exclude, or at least downplay the role of, the family and friends who are immediately-surrounding the patient when the patient is at home: it could be argued that I am 'seeing something not present' but to me, **you appear to asserting that 'the relatives should not be trusted by default' is a legitimate position for the professionals to hold**. To me that is a biased-extrapolation from 'some relatives are nefarious' to 'so we can legitimately assume most relatives are nefarious, without any proof' - so this is similar to the extrapolation those Tweeters are making when they assert 'all palliative care doctors are murderers'. It is a reversal of 'innocent until proven guilty' beyond what I consider to be reasonable: 'everyone should be 'keeping an eye on' everyone else' is entirely reasonable – but doctors, within whose ranks lurked Harold Shipman, should not be asserting that 'relatives are not to be trusted, but of course we doctors are to be trusted'.

My recent tweet at:

https://twitter.com/MikeStone2_EoL/status/974955854448480256

elicited a response from Jim Crawford, an A&E consultant:

Ethically (and I hope legally) if a patient with capacity has expressed that wish to anyone, and that wish is known to the people caring for the patient at the time of cardiac arrest, then starting CPR would be wrong, without having a very, very strong reason for doing so.

It seems crystal clear to me – but apparently not to ReSPECT, **so I would like to know if you (Bee, Jane, Amy and Mark) also see this as 'crystal clear'** – that a refusal of a [future] treatment which has been clearly expressed to a person, is 'legally binding on' that person, irrespective of whether the person is a clinician or a family carer?

As Mr Justice MacDonald explained (see the start of my piece about ACP at <https://www.dignityincare.org.uk/Discuss-and-debate/download/293/>)

C is entitled to make her own decision on that question based on the things that are important to her, in keeping with her own personality and system of values and without conforming to society's expectation of what constitutes the 'normal' decision in this situation (if such a thing exists). As a capacitous individual C is, in respect of her own body and mind, sovereign.

I wasn't proof-reading very well in that PDF – it moved on to explain:

My Own Position when I was a Family Carer for my Dying Parents

1 I would push for any interventions my loved-one wanted

2 I had a deep aversion to 'arguing with my dying loved-one'

3 If my loved-one had lost the capacity to make and express his or her own decisions, I desperately did not want 'the burden' of making life-or-death decisions which would affect my loved-one, so:

3a I tried to make sure that I got the decision from my loved-one if possible, so

3b I spent a lot of time listening, 'enquiring', and 'picking-up-on' the 'wants' of my loved-one

4 Horrible though the burden of making decisions is – see 3 – **one thing would have been even worse**: if I had allowed clinicians to impose on my incapable loved-one, treatments and interventions which I felt sure my loved-one would have refused.

When I re-read that, it isn't clear enough in 3 – I'm saying that 'to avoid having to make decisions after your loved one loses capacity, you are 'listening desperately and urgently' while your loved-one is still capacitous (so 3a and 3b are things you do before your loved-one loses the ability to make his or her own decisions).

Returning to 'the logic'. Some relatives and family carers, probably are not doing what I did – they might 'not be listening', or they might refuse to accept what the patient tells them, and during clinical 'emergencies' some family carers will undoubtedly 'be panicked'. Etc.

But our law – the MCA – has definitely moved away from 'what most patients would choose, and what 'society finds normal and 'acceptable" and it describes a legal framework which hinges on 'patients make decisions based on their individuality'.

And while some relatives might 'struggle with that', it is clear that for many reasons, healthcare professionals and 'planners' also 'struggle with it'.

It really 'throws a spanner in the works of' EoL 'care planning' when patients are in their own homes:

<http://www.bmj.com/content/358/bmj.j3257/rr-4>

And I was recently discussing with a doctor, the situation of a patient in hospital, who explains that 'I definitely refuse attempted CPR from now onwards' to a nurse. The nurse/s are unable to involve a doctor during the next 30 minutes, and then the patient has a cardiopulmonary arrest – the doctor believes that most nurses, would attempt CPR and call the crash team.

See my tweet at:

https://twitter.com/MikeStone2_EoL/status/976091426277740547

The doctor and I, both believe that 'the nurses are assaulting the patient if they attempt CPR' after the patient has told them not to do that.

See also:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/298/>

One of my major issues with ReSPECT, is the assertion that 'the senior clinician signs the ReSPECT Form to 'validate' best-interests decision-making' - **it is not the role of anyone to be 'validating' best-interests decision-making.**

<https://www.dignityincare.org.uk/Discuss-and-debate/download/283/>

Our law has definitely moved to 'informed capacitous patients simply make and express their own decisions, which everyone else should be following'. But – although it could be argued that it is inappropriate 'safeguarding' as opposed to 'lingering clinical paternalism' that is the cause of that legally-flawed 'attitude' so obvious when I read the ReSPECT material – it certainly cannot be argued that clinicians as a group understand the MCA. A doctor whose opinions carry weight [at least with me] has told me that:

'When I explain to nurses that an Advance Decision refusing CPR is legally-binding, but that a DNACPR Form signed only by a doctor is not legally-binding, most of them 'are shocked to be told that'.'

I must admit, that I had worked that out – not by asking nurses, but by reading clinical guidance.

This clearly-discernible 'attitude' of 'relatives and family-carers are not to be trusted' is offensive to family carers – it definitely offends me [and I was harassed for 7 hours after my mother's death in 2008] - and until 'you' change to an inclusive and perspective-balanced mindset (that it is everyone working together to help the dying person) I will keep explaining to laymen 'there is only one thing to do, if the professionals refuse to change their attitudes':

As I explained at the end of my PDF

<https://www.dignityincare.org.uk/Discuss-and-debate/download/289/>

Something which 'rather gives me hope'

I'll finish off now – I could go on (and on, and on, and ...) but by now anybody who isn't already very familiar with the MCA will probably have lost interest, and the people who are deeply interested in the MCA and who are reading this will be few, I suspect.

This is 'the ray of hope'.

The problem, for most family carers, is a combination of two things: one is that the MCA is very difficult to apply if you are a working professional, and the second is that the professionals [incorrectly in my opinion] assert that THEY 'make the decisions'.

If many more people appoint Welfare Attorneys, then this unsatisfactory situation – which amounts to 'we professionals are the experts, and our views are the ones which count' - will be swept away: because it is 100% clear that welfare attorneys are the people 'whose decisions/views count'.

And those welfare attorneys will almost certainly be largely laymen – if I were my father's welfare attorney, why would I 'downplay or disregard' the opinions of my brothers and sisters, etc, and why would I prefer the views of doctors and nurses ?

Written by Mike Stone, November 2016 mhsatstokelib@yahoo.co.uk

So, are you willing to discuss the question I put to you earlier with me?:

I would like to know if you (Bee, Jane, Amy and Mark) also see this as 'crystal clear' – that a refusal of a [future] treatment which has been clearly expressed to a person, is 'legally binding on' that person, irrespective of whether the person is a clinician or a family carer?

I have performed a couple of Twitter Polls, which while limited are worth pondering:

During a discussion on Nursing Times (online) a few years ago, someone – probably a nurse – posted this:

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an

ambulance when he was nearing the end of his life. He died at home surrounded by his family.

Now, I cannot actually 'prove' this – but I am of the view that this is how the vast majority of family carers 'come to terms' with the final stages of a loved-one's dying: we pay great attention to discovering what our loved-one wants to happen, and we support our loved-one's decisions.

I recently carried out a Twitter Poll, and the result seems to be in line with my views:

https://twitter.com/MikeStone2_EoL/status/931819196207509504

I asked this question in my poll, and offered 3 answers: 60 people voted, and I show the results:

A mentally-capable adult is 'dying' ['end-of-life' = 'sometime within predicted final year of life'] at home. Who should the family-carers living with their dying loved-one be taking instructions from? Please retweet - an analysis of answers would be 'interesting'.

From the dying patient 92%
From the GP and nurses 2%
From nobody 6%

Total votes cast 60

In an earlier poll on Twitter, I had asked a related question:

https://twitter.com/MikeStone2_EoL/status/919195401898680321

An 82 years old man is diagnosed as terminal. He and his 79 years old wife 'invite clinicians to help while he dies'. Does that invitation of itself, imply that if he loses the ability to make his own decisions, he wants the clinicians, and not his wife, to make them?

Yes it does 8%
No it does not 92%

Total votes cast 79

Mike Stone

PS Bee's emphasis on the discussions – although she introduces a 'the conversations have therapeutic value' while I write that the conversations are necessary to inform decision-making – is of course completely correct: but when I was discussing EoL with Tessa Ing at the Department of Health between 2009 and 2013, it was already well understood that 'we need the conversations – but they all-too-often don't happen'. Telling terminal patients 'to talk to your clinicians and your family' while at the same time not telling the 999 Services to believe family carers isn't a satisfactory situation: and most relatives are likely to discover 'we are not being believed' **too late**.