These are a series of Twitter direct messages which a palliative care specialist doctor with experience both in hospitals and in community palliative care and I were exchanging recently, on the topic of the behaviour around end-of-life. I would point in particular to the final message from the doctor to me, because it is wonderfully accurate and concise, as a description of many 'problematic issues'.

Mike Stone to the Doctor:

I'm interested that you've told me, that you [a doctor] often write things aimed at patients and families - because 'I [a lay person] spend most of my time writing for clinicians'. And - in that context - as I've been pointing out for years, there are 2 steps. The first step, is that 'the conversations take place, so we can understand what the patient has decided or would probably want to happen'. The second step, is turning the understanding acquired by the participants in the conversations, into actions. We all know, that currently 'step 1 all-too-often doesn't happen'. But, as I keep pointing out [to 'an NHS not keen on being told'], the current guidance/protocol around EoL, and especially if patients are at home, isn't satisfactory for the achievement of step 2, even if step 1 does happen.

Doctor to Mike Stone:

I agree!

Mike Stone to Doctor:

It is the way that 'a conversation between a patient and a family carer, at home' doesn't seem to 'count' unless it has been 'turned into documentation' that is my main issue, having been on the listening end of such a conversation. Put simply: 'the 'system' seems unable to accept that relatives can listen, and the professionals cannot, if only the relatives were present to be told'. Of course - it is further confused by misrepresentation of what the MCA says. Yesterday I was reading both the RCP report - which correctly points out that an ADRT refusing CPR is legally-binding, but a DNACPR is not legally-binding - and also a CPR document from BUHCW document for its staff, which states 'The standard for documenting those (CPR) decisions is the DNACPR form.'. There are in my view some problems with over-reliance on ACP (which has obvious, and as-yet 'unanswered', complications during EoL

https://www.dignityincare.org.uk/Discuss-and-debate/download/325/ )

and there are also issues with CPR: I like CPR, because it is simpler to analyse. Not because i'm

Mike Stone to Doctor:

Pressed return for a new line - again! Anyway - as I was saying, I like to analyse CPR, because the analysis is simpler: the prognosis if CPR is performed is so uncertain, that asking a doctor will not make you any better informed, and if CPR is not attempted you will die - MUCH SIMPLER than most possible medical interventions, to analyse. It isn't that I'm bothered about CPR, and not bothered about 'care' - I do CPR, because it is the intervention which most easily allows for the MCA to be analysed and correctly described. I'm about to go offline for a bit.

Doctor to Mike Stone:

When people are dying, they need to have an understanding of what is likely to happen, so that they CAN plan ahead, and decide (for example) whether home is suitable; whether somewhere else is preferable; what kind of support they might want; and to have conversations with families about love, appreciation and reconciliation (which are far more enjoyable than ACP!) rather than leaving it too late.

The documentation thing will always be an issue, because organisational governance will always require first attenders at home to 'follow instructions' unless they are very senior practitioners. So if paramedics and I both arrived at a house where a patient was close to death and the family explained that this was an anticipated event, but they had asked 999 for help because of unexpected pain or a symptom not previously anticipated, then the ambulance crew would almost certainly be obliged to begin 'death-aversion' care in the absence of any ADRT/DNACPR order/Emergency Health Care Plan etc, whatever the family members might say, whereas I would be able to sit down, get everyone a cup of tea, and discuss how to manage symptoms and keep the dying person as distress-free as possible; prescribe new drugs or use any 'as required' drugs in the house for a purpose not on their drug prescribing sheet (for example: morphine might be available, and prescribed on the drug sheet 'for pain.' I would be able to use that morphine for breathlessness i.e. off prescription, whereas the paramedics might not).

In the end, the person's rights under the MCA often get overwhelmed by self-protection policies of care organisations. This is a societal problem brought upon us by an increasingly litigious tendency in society, and it's hugely regrettable on many fronts.

It may take some prosecutions for Battery because clinicians over-rode patients' wishes as expressed by family before we can change organisational instructions to their outreach staff.

I hear what you say and understand that you are challenging that automatic 'I'm the clinician

here, so I'll decide' attitude. Having been the relative explaining to out-of-hours GP & others that my own beloved relative preferred to remain at home even if she were to die, rather than to go back into hospital again, without the EHCP or ADRT to support me, I know how very hard it was to enable them to follow her wishes when she wasn't awake enough to express them. I guess I'm in the 'fortunate' position of seeing it from both sides, as a clinician and a palliative care person, and also as a relative of elderly and deteriorating relatives who accept dying as a natural end to life and have no wish to be interfered with en route to death.

This is going to be a 'long game.'

Keep making your points.

The system is very slow to change, because it's so complicated to align all the different care areas and the necessary bureaucracy that trains, appraises, governs and holds us to account. But change will happen. I am working for it, you are working for it, and many others likewise.

Mike Stone to Doctor:

I'll read that properly - but you are spot on with 'In the end, the person's rights under the MCA often get overwhelmed by self-protection policies of care organisations.'. Ever since I told Tessa Ing ca 2013 'I increasingly find myself writing about the conflict between the MCA and 'safeguarding', I've been banging on about that one. More fundamentally - and 'organisations' are likely to be 'institutionally incapable' of coping with this one - it seems to me that in many CPA-at-Home situations, the decisions of family-carers must be compliant with MCA 4, whereas the attending 999 staff are logically-incapable of satisfying MCA 4(9). That leads to the issue of 'how do you get 999 staff to follow a best-interests decision which they themselves cannot defensibly make?' and that is why I'm in such dispute with the RC(UK)/ReSPECT etc https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-issue-with-ReSPECT-which-I-will-be-pointing-out-to-the-Public-Guardian/960/ I have just read your DM properly - yes, I could have written that, although my style is different: I'm sure Bee Wee could also have written that. We all (I probably shouldn't have used 'all' there - 'most of the people I discuss EoL with in depth') understand the problems - there are some perspective differences about 'balance points' [largely on the 'trusting the family-carers' aspect of any guidance], but mainly while I know where 'This is going to be a 'long game.' comes from, I want more rapid change. Which is another reason, why I tend to use the 'what you are doing is illegal' approach - I believe the way to change professional behave fastest, is to get the professionals to see 'unless we change, we could very well end up being prosecuted!' https://www.bmj.com/content/352/bmj.i26/rr-2 Even that approach is difficult: quite a lot of clinicians will not understand the legal arguments, because they haven't even read the MCA. When I was discussing whether a 999 paramedic could defensibly claim to have satisfied MCA 4(9) on Twitter, with a 999 paramedic (I pointed to 4(6) - and it is obvious, that no 999

paramedic could properly CONSIDER all of those factors, during 'an emergency') he tweeted back 'no - in my opinion 999 paramedics couldn't claim to have complied with 4(9) - but most 999 paramedics have never heard of 4(9)'.