How can change be generated, in the NHS and Social Care: which methods of 'campaigning' work best?

I have previously posted a PDF on Dignity in Care, which is relevant to this piece, and it can be downloaded here:

https://www.dignityincare.org.uk/Discuss-and-debate/download/268/

I have been writing about End-of-Life since about 2010, and even after a decade I am still not sure how to change mindsets, culture, and the associated things such as guidance and protocols in the NHS. I will describe how I have tried to effect change, and my conclusions at present.

I am aware that other lay-campaigners use different methods from mine, but judging by the other lay-campaigners I am in contact with, we all find it very difficult to change things: it is grindingly slow, and frustrating. It is rather like trying to demolish a brick wall by repeatedly running into it – progress is slow, painful, and you might die with the wall still standing. I know that many clinicians are also trying to change things, from 'the inside of the system', and I'm guessing they also often feel rather frustrated.

My own feelings, at the moment, are:

1) The thing which creates the most rapid change, is a court ruling which lines up with the change you want to effect: think 'Tracey', 'Montgomery' or 'Briggs' as examples. However, such court rulings are infrequent, and [while involving a lot of effort on the part of the people who take the case to court] somewhat 'down to luck': a helpful court ruling, is more 'a bonus' than part of a strategy;

2) I don't believe that lay-campaigners can successfully provoke change, on our own: I think we need help from doctors, paramedics, nurses and others who are within the NHS. If we can establish links with clinicians (especially with senior doctors, as consultant doctors do a lot of teaching and mentoring of medical students and junior doctors) and influence those clinicians, they in turn will influence more clinicians. Social Media – personally I have found Twitter very useful – can be used to make contact with professionals.

> As an aside, when I initially make contact with a doctor or nurse, sometimes the doctor or nurse seems to assume that because I am 'a relative', I must be in contact with other relatives: the dreaded '… what do relatives think about this?' question. In fact, until I relatively recently joined Twitter, almost all of my contacts were from the NHS side – doctors, nurses, paramedics and people at the Department of Health. One reason, is that often patients and relatives are hard to contact even if you want to contact them – whereas especially with doctors and academic clinicians, it is much easier to find e-mail addresses to contact them.

3) There are two distinct problems, with the changing of mindsets, culture, protocols and the like. In my experience, most people can see 'an issue' when it is pointed out to them. More problematic, is what I sometimes call 'ordering the caveats': which takes precedence, when two 'issues' which are each valid, conflict with each other. The most problematic conflict is, I suggest, the objective of 'safeguarding' which can conflict with all manner of other valid objectives. It is like the football manager, who announces 'We need to get forward more, and also tighten-up at the back': it is easy to go for all-out attack, and

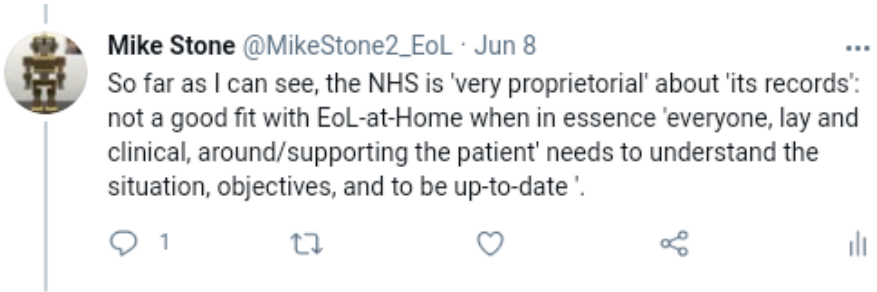
easy to go for an in-depth ‘park-the-bus’ defence, but attacking and defending usually trade-off against each other.

4) Inherent in my 3), is the problem that somehow you need to get everyone involved – not just the professionals but also patients and relatives - ‘at the table’ when guidance and protocols are being created. The approach of ‘consulting the patients and relatives’ doesn’t work, because if the professionals then go away and create guidance on their own (no patients or relatives present at that table) this ‘ordering the caveats’ issue will crop up.

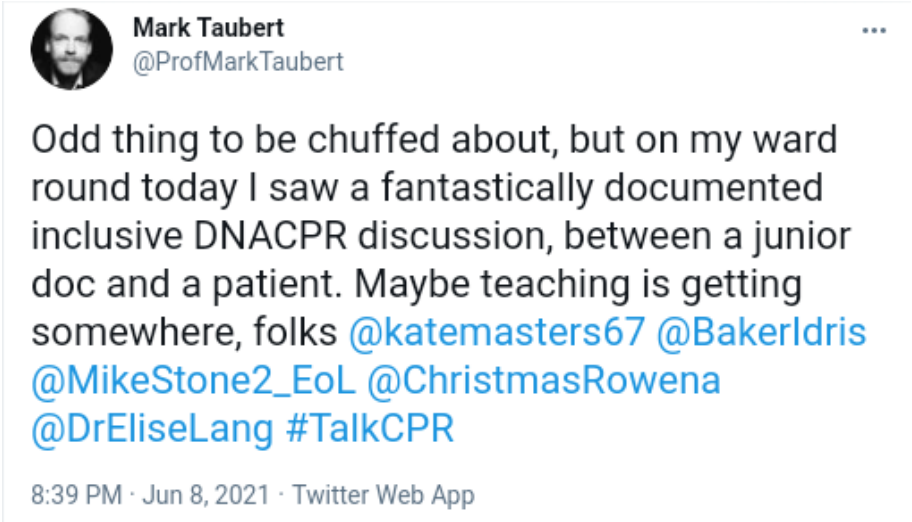
> It is not possible, to work out what the ‘correct’ ordering-of-caveats is. But it is persuasive, to point out that it will vary according to who is sitting round the table. All we can I think claim, is that the decisions would be different if only a group of doctors decided, compared to a group of doctors, family-carers and paramedics deciding (as an example). Different groups will have different background experiences, and often different objectives and priorities.

5) It will help, if we (the public) can ‘educate and inform’ each other: problems better-understood, will attract more attention, and better-informed layfolk are more capable of getting their point across. Again, Social Media is useful for sharing knowledge and understanding.

I recently posted a tweet, stating that the NHS is very ‘proprietorial’ about ‘its records’:



This prompted some discussion on Twitter, loosely about the interactions between patients, relatives and clinicians – it is tricky to ‘follow’ Twitter outside of the platform itself, but these tweets ‘give a taste of’ the discussion:



Joseph Cosgrove @JosephCosgrove7 · Jun 8

Replying to @ProfMarkTaubert @katemasters67 and 4 others

Have been working as a Medical Examiner since Jan & I'm pleased to say I'm seeing more of such things. Compassion & clarity are achievable & on more than one occasion I've seen the words of @drkathrynmannix written by trainees.

1 16

Kathryn Mannix @drkathrynmannix · Jun 8

I am overwhelmed by this.
How lovely to have had the opportunity to influence practice simply by telling stories.

2 13

Kate Masters @katemasters67 · Jun 8

Replying to @ProfMarkTaubert @BakerIdris and 3 others

Not odd at all .. it's uplifting and needs to be shared.

6

clare finnegan @pandaclare · Jun 8

Replying to @ProfMarkTaubert @katemasters67 and 4 others

Some of the best documented discussions I've seen have been by our doctors in training.
Their presence on the wards with inquisitive minds, close working with nursing colleagues & conversations with patients and families is changing the culture slowly.

2 13

Mike Stone @MikeStone2_EoL · 23h

So, is the 'inclusive attitude' 'beaten out of them by 'the system''? or is it really a culture change that is taking place?

2 2

Idris Baker @BakerIdris · 22h

Like Mark and Clare, I think we're seeing things change.

Students, as well as doctors in training.

3

clare finnegan @pandaclare · 20h

Replying to @MikeStone2_EoL @ProfMarkTaubert and 4 others

Hard to know but it feels like a culture change (we do have some experienced colleagues who ate also great role-models!)

2 1

It is being suggested, by doctors and other people who are inside the system, that things – mindsets, culture and therefore behaviour – are changing. But, as Clare Finnegan said in reply to my question, ***hard to know*** *but it feels like a culture change*.

It is really easy, to see how the attitude of those younger doctors, which the group of Tweeters seemed to approve of, might change as they grow older. In essence, if you are criticised by your boss or your managers – who might well be older, and from a generation which had a different mindset – then this pushes you towards changing your behaviour [even if you actually believe your behaviour, which has been criticised, is good behaviour]. I contributed to a paper in the Journal of Medical Ethics recently, which effectively argued that 999 paramedics should place more weight on what relatives are telling them, and less weight on written records. It is easy to see, that any paramedic who does that, and is then criticised by his or her boss, or by a Coroner, might revert to looking at the written records instead of listening to the family-carers.

I find myself at odds with lawyers, on 'mindset'. I have read the Mental Capacity Act, and so have lawyers, but even so my 'eye' [and therefore 'mindset'] is seeking understanding at the time decisions are being made during patient care – whereas lawyers have more of a 'how would things play-out before a judge, in a court?' perspective. I have described such differences in my two pieces:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Can-a-verbal-refusal-of-CPR-be-legally-binding/1072/

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/Is-the-power-of-a-Welfare-Attorney-LPA-largely-an-illusion-a-response-to-39-Essex-Chambers/1103/

There is also a significant complication, in that different groups of professionals have different objectives, and different background experiences. And a further layer of complexity exists around CPR decision-making/decision-recording. The second of the URLs above, describes an issue with decision-making for CPR/DNACPR. And I have analysed a fundamental problem with the documentation of 'DNACPR decisions' in my thread and PDF here:

THREAD: https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/The-documentation-of-DNACPR-decisions./1104/

PDF: https://www.dignityincare.org.uk/Discuss-and-debate/download/435/

I apologise for not trying to summarise the analyses I present in those pieces – it is better to follow the arguments in some detail, as presented if you follow the URLs above.

I think I can see some change in the right direction, but it is slow: I suppose that lay-campaigners, who became involved because we believe we experienced 'bad, unacceptable behaviour', will tend to feel frustrated by 'slow' progress.

Lady Hale, added a sort of 'appendix' to the Montgomery ruling, and rather wonderfully she points out what amounts to '**the law can have changed even before a court ruling makes that obvious**' which, if you are a doctor, is a 'very problematic' situation to apply to your working life (the Montgomery ruling was in 2015 – as one [it seemed annoyed!] doctor

said in a BMJ rapid response, it is not reasonable to expect doctors to work-out what the law is, by reading arguments in legal text books):

107. In the third (2010) edition of their leading work on *Principles of Medical Law*, Andrew Grubb, Judith Laing and Jean McHale confidently announced that a detailed analysis of the different speeches of the House of Lords in *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871 was no longer necessary. A combination of the 2008 Guidance provided by the General Medical Council, the decision of the Court of Appeal in *Pearce v United Bristol Healthcare NHS Trust* [1999] PIQR P 53 and the decision of the House of Lords in *Chester v Afshar* [2005] 1 AC 134 meant that it could now be stated "with a reasonable degree of confidence" that the need for informed consent was firmly part of English law (para 8.70). This case has provided us with the opportunity, not only to confirm that confident statement, but also to make it clear that the same principles apply in Scotland.

116. As NICE (2011) puts it, "Pregnant women should be offered evidence-based information and support to enable them to make informed decisions about their care and treatment" (para 1.1.1.1). Gone are the days when it was thought that, on becoming pregnant, a woman lost, not only her capacity, but also her right to act as a genuinely autonomous human being.

This is probably a good place to draw the piece to a close, because what Lady Hale concludes section 107 with:

'This case has provided us with the opportunity, not only to confirm that confident statement, but also to make it clear that the same principles apply in Scotland'

links nicely with what I wrote on the first page:

'The thing which creates the most rapid change, is a court ruling which lines up with the change you want to effect: think 'Tracey', 'Montgomery' or 'Briggs' as examples. However, such court rulings are infrequent, and [while involving a lot of effort on the part of the people who take the case to court] somewhat 'down to luck': a helpful court ruling, is more 'a bonus' than part of a strategy'

Written by Mike Stone, June 2021

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