

**Developing GMC guidance on End of Life Care  
Consultative Conference  
*Clinician's perspective***

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PBF: Thank you and oh I can't see the clock from here isn't that a pity there we go, no its difficult, I would be grateful if somebody could put a hand up to me when I'm about two minutes from where I should finish thanks. We hear about case law I'm going to speak to you from a very kind of pragmatic point of view about clinical decision making as a clinician and draw on a couple of cases to illustrate the points I want to make. We are here today to discuss this document which is underpinning it all which is this and I'm pleased to see that its termed good practise and it has no higher aspiration on it than that, in other words its not mandatory although it does say in it that if you breach it in a major way you may be up before the GMC. I'm going to talk a little bit about patients and doctors, about control and indeed where control rests at the end of day over giving information and over trust about withdrawing and withholding treatment and obviously end of life decisions. And its I

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think important to remember that we have the Mental Capacity Act which has I personally believe been incredibly helpful for clinicians in giving us a framework and I worry that its been made over complicated when its been taught by various people because actually it does help you understand in advance decision to refuse treatment is not that you can direct somebody to do something to you and of course the best interest decisions come in when somebody lacks capacity for that decision. And I really would emphasise that just as we saw in that scenario the patient for whatever reason couldn't quite get his address out but I think it was fairly convincing that that didn't mean that he lacked capacity for any other decisions that he might be asked to take although there was no assessment that we saw of capacity for each decision. And that's really important. One of the difficulties of course is when does end of life start well if the cynic says it starts when you are born but even when

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people are really ill how often as we as clinicians thought somebody was terminally ill and been proved dramatically and overwhelmingly wrong, we all have patients who we have discharged from follow up because they have done remarkably well and so its very easy to use this term terminally ill but it is not well defined as was given in evidence to the House of Lords select committee that looked at the assisted dying bill by one clinician in relation even to the social security forms that we sign, most of us have lost count of the number that we have signed and the person has outlived their six months allotted slot and then you have to have a very difficult conversation with a patient about actually them no longer really being eligible to carry on getting these benefits. But it's a reality that we cannot predict what's going to happen. So how do I personally approach some of these decisions, well in a way it's the old scale pan in your head where you're weighing up the benefits for that patient

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of that decision against the risks and the burdens of that decision and that isn't the totality its for each decision and then there is the principle of justice as well of course which comes into play when you are in the middle of the night with lots of other patients and you, there is only you around. And in an ideal world we'd all have twenty four hour district nursing but we don't have and the finances of the health care system are going to get worse not better that I am convinced of and so rationing is going to come in more and more. I think that there has been a danger I would have to say a little bit in the way that the guidance is written and it's not to be unduly critical but a sense of control and certainty which doesn't really probably exist in medicine. We cure remarkably little, we alter the disease course remarkably little and yet there is an awful lot of talk about keeping patients alive when actually the disease runs its course and sometimes what we're doing to keep them alive ends up

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shortening their lives. And we live in a society where we I think have become a bit control freakery and not accepted that we all live with uncertainty every day, every minute. Our chief pharmaceutical officer I don't think, I mean it is public knowledge but she went in to work one day to a meeting and the department of health fell down hit her head walking out the steps subdural you know she did not get up that morning expecting that she was going to end up with a burr hole type scenario and yet we don't take that into account. We don't get up every morning saying wow this day is completely full of uncertainty, we get up every day and look at our agenda and pretend that it is but it's the same in clinical decision making. There is also I worry an assumption that somehow before people are so called ill that they have perfect quality of life and that the deficit in their quality of life only comes in when they are ill and yet there are huge numbers of people who have appalling quality of life and sometimes

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their quality of life improves when they do become ill actually and our role as clinicians is to improve whatever we can and help them set hopes and aspirations nearer reality and improve reality so that that deficit in their quality of life narrows. But let's take the sort of scenario that we all come across frequently. Elderly lady living on her own doesn't want any life prolonging treatment, had a good fulfilling life, doesn't want to be a burden, in very severe pain, bed bound, legs swollen can do nothing for herself. The difficulty in there of course is that I hope you can all see there are several things there which are completely remediable and that might improve her decision making underlying that statement of I don't want any life prolonging treatment and can I just ask for a show of hands, how many of you in this room have been in very very severe pain. Yeah OK a few of you, I don't know whether you share my experience but I have to say I would have been prepared to take

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the risk of being killed to get out of that severe pain, it was overwhelming when it happened and I just put that in to illustrate that actually until you get on top of symptom control and get people comfortable their decision making is altered and we know that people with neurological disease for example have altered a decision making capacity because of the drugs they're on. And that goes to the fundamental which I would like to see stressed more in here and that is the duty of diagnosis. And the duty of diagnosis of what all the problems are because unless you get the diagnosis right you won't get the outcome right. And it's very easy to clock into the hopelessness and helplessness and despair that you may feel coming from patients. Sicily Saunders of course put forward the multi faceted concept of total pain and total distress but I think its worth just remembering who steers the consultation and how much of the time is spent talking or listening that emerged earlier on today the

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importance of listening in terms of helping people make decisions that they make rather than have things imposed on them and I really thank the Theatre Company because I think they set the scene beautifully for us earlier on. So fundamental to everything is communication and we have this list of GMC guidance it's all listed in the back of Good Medical Practice and there is lots of guidance there. There isn't actually one about communication skills and I would urge the GMC to look at that next. In Cardiff we've come up with a few kind of ground rules from analysing different consultations that if you stick to you can actually get a bit further. And I would just put them up for you but I am not going to run through them because of lack of time but when you look at consultations that have gone wrong then you often see that. And you need to think where do you lead the patient in the consultation and who is in control because what you do as a clinician leads where they go or their clinical

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state might lead where they go or their drugs might lead where they go if they're distorting thinking. The next one is trust which is a problem, of course people trust their doctors, you get on an aeroplane and you trust the pilot that they are adequately trained and fully up to speed and you trust that you will get there. Sadly this week that didn't happen but actually trust is inherent, it has to be because you're ill and you have to trust the doctor who is there. And so we have to do what we can within our knowledge but I do worry that its very easy to go into an abandon hope mode of thinking when you get to end of life decision making rather than thinking where you are steering the patient with the information you give them and is it information they need might influence it well it does influence their decision making and therefore where they go. And just thinking about which road you might go down with that lady you could say so you want to die and process that request to death and not treat her and

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give her a subliminal message that she would be right that she'd be better off dead or you could go into a diagnostic mode and say what is making today so terrible and what can you do to improve it and work hard to improve her day. And those are the subtleties as clinicians we encounter every day. Stopping an intervention is not necessarily killing a patient at all, sometimes patients die pretty quickly when we stop it, most of the time taking a patient off a ventilator might be deemed to have killed them but it doesn't always, sometimes they start breathing on their own, sometimes patients die when they were going to die anyway and some patients get dramatically better when we stop the treatment that we thought that was prolonging their life. And I do want to just put that perspective in a little bit because I think we agonise over that initial decision instead of being realistic sometimes of our own failures. And that is why it is the intention in doing it that I think is fundamentally

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different and whilst from a legal point of view I can see all the arguments on paper when you've got the patient in front of you whether you intend them to be dead is actually what you're doing with your decision. I've put that up it is very topical all the discussion just simply that actually I have the feeling although I don't know the details of his case that his ventilator could have been stopped in this country and looked after until he died the business of going to Switzerland I think raises bad care issues not issues about autonomy and so on but who was listening to the fact he wanted to come off the ventilator. And the last comment I would like to make about the GMC guidance relates to the family and I do think that it would be important to put the concept of the greater patient in the guidance, everything we do impacts on everybody else. This was a patient I looked after aged thirty six the way that I handled him and his children and his wife went on to have enormous consequences because what I

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predicted as his prognosis was completely wrong as was that of other clinicians we were four of us senior doctors were completely wrong. He was actually desperate to die and wanting no treatment whatsoever but it was eleven years later that his wife had a pancreatic cancer with liver secondary's and died and the way that we had handled him influenced the way that she was able to cope with care and the way that the children coped and we are now at the stage where that seven week old baby has now left school and has set up his own gardening business and that girl who is the daughter got married last week in Italy and the father still alive went in his wheelchair. So the influences of the way that one situation is handled and the decision making on one situation and one patient impacts on the rest of them for the rest of their lives. And I've had many many conversations over the years with these children.

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