

**Developing GMC guidance on End of Life Care  
Consultative Conference  
*Cultural/personal beliefs and decision  
making***

Professor Gurch Randhawa

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PGR: Thank, thank you very much I am conscious that the word diversity has taken on a new meaning since the winners of Britain's Got Talent has been announced so I am not going to do any sort of exercise dance moves just in case anybody is wondering that. I would want to make a very serious preface though before I begin my talk and that is when we talk about culture diversity, faith, beliefs, religion its an incredibly personal journey for all of us so I'm not here to stereotype people and I wouldn't want anybody here also to stereotype the very diverse populations we have in this country. I've split my talk into two, one is to sort of really follow on from the guidance and talk about organ failure and organ donation as a case study and then secondly is to just show you some work that I did about five years ago on South Asian cancer patients whereby they generously told me what it was like to live with cancer in the last few weeks. And also talking to the people who were looking after them and I am going to try

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to stick to time if I can. So just setting the UK context in terms of organ donation for the many people I am conscious are aware of a lot of this data there are over three thousand people in this country who receive an organ transplant which is fantastic in one year. But the more worrying thing is that at least a thousand people die each year waiting for a transplant and we've got about eight thousand people in this country at the moment presently waiting and, and when you look at data related to organ donors, waiting lists and who receives organs you see that there is huge disparity and that's largely to do with issues around diabetes, high blood pressure and how kidney disease is managed. And I guess the really startling statistic for me is that twenty three percent of the kidney waiting list in this country is made up of South Asian communities. They only make up eight percent of the population and they only make up three percent of donors. So there is a huge challenge. And over laid on that

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and I guess this relates partially to end of life care but not solely to end of life care there is currently an ongoing UK potential donor audit which shows that thirty two percent of families refuse to organ donation amongst white families whereas that same refusal rate is seventy four percent amongst non white families. So it's a huge disparity and we need to understand why that is and hopefully work with various communities to address that situation. And I've tried to put this in a simplified form, if you bear with me and look at the columns on the right first in red if you look at the waiting list, this is for kidney transplants in this country you can see that fourteen percent of people who are waiting for a kidney transplant are South Asia. You can also see that six percent of people waiting for a kidney transplant are African Caribbean and the reason that's worrying is like I said that makes up twenty percent of the population in terms of the waiting list but clearly they don't make up twenty

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percent of the UK population. If you then go on to who are recipients the next column of red you can see that Caucasians are eight, eight percent of recipients, eight percent are South Asians and three percent are African Caribbean's. So clearly they're being transplanted in lower proportions. And then when you look at who are the donors you see again there is a huge ethnic disparity. And what that means for people in reality is this and I think Jonathon illustrated this really well in his talk. People are waiting on dialysis and these waiting times only show you the waiting times obviously for the people who have actually received a transplant. Other people either to continue to remain on dialysis or sadly they then receive conservative management and eventually die. So it's a hugely urgent issue. So just in terms of waiting times what does this mean for patients and bearing in mind that a lot of these patients form great bonds with fellow patients on dialysis so they see this,

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they notice this. On average a white patient in this country waits I think that's about two years seven hundred and twenty two days I think, fourteen hundred and ninety six days is about four years so nearly twice as long and the same for black patients. So they will begin to notice that and they begin to sort of ask questions, oh I noticed my friend over there done really well has got a transplant when's my turn, two years on they notice another group of people who have come on dialysis and they have got transplanted and they are still waiting. So for the patient it's hugely distressing and obviously for the family and the wider community it is hugely distressing and we need to tackle that. And for me in terms of what can we do in terms of organ donation we need to think about issues around culture, we need to think about belief and faith systems and I was incredibly privileged to be a member of the organ donation task force as were a couple of other people in the audience and

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it was really really encouraging to see that there was a recommendation to tackle this very issue around how do we promote the concept of organ donation, the concept of gift of life amongst different communities and it was really really encouraging and I think it was sort of quite unique that we were given the resource to actually talk to various people amongst faith and belief groups across the country many of whom are here today. So that's the sort of organ donation context and I just wanted to share with you some quotes about this what people say to me when we've done research around organ donation. And what I want to really focus on is the bottom quote for the rest of the talk but just to tell you and this for me is why people have reluctance around organ donation but also reluctance around end of life care. So this is work we've done with minority ethnic communities in the UK so it talks about people's fears about donating their eyes, about religious leaders giving a

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clear cut opinion, about I don't like the idea of my relatives having to see my body being carved up, I am not sure about life after death but if there is life I want to go complete. Now what's interesting about these quotes is I could overlay these quotes with any study done in any part of the world and they'll be the same. So these, these comments aren't unique to non white populations in the UK and I think that for me is really really important that we, we my opening comment we stereotype and we shouldn't. And this for me is the most powerful comment and I want to show you how we've tried to address this comment. Lots of practitioners say to me well they, meaning South Asian families they look after their own don't they so you know end of life care isn't really an issue and a lot of GP's I talk to they say the same and these are in our research studies. So and obviously there is huge barriers in the community in terms of organ donation, there is obviously confusion about who can donate and who

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can't, there is a huge mistrust and lack of confidence in the medical profession and I think you know we sometimes go around and sort of deny this that within certain populations there is that level of confidence lacking at the moment. There is a very fatalistic view among certain people and like I said this isn't unique to particular ethnic groups you know some people just sort of say well you know God has willed my time has come that's the way I want to deal with it so why should I engage with organ donation and that sort of stuff. There is obviously a reluctance to discuss death, a lot of people don't know why its really important certain minority ethnic groups should come forward as organ donors and people assume cultural and religious objections to organ donation which is why I am so pleased now that the task force is doing some work about correctly those assumptions and I am delighted that so many faith and belief organisations in this country are helping to correct some of those assumptions. And

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it's interesting despite all these barriers as soon as communities find out that there is a huge shortage they all want to help but it's the old adage you know you don't know what you don't know so until you tell someone there is this huge problem they can't really help. So in terms of organ donation the long term solutions are making gifting relevant, getting organ donation rates up, getting referral rates into intensive care units, the same across all ethnic groups, making sure that everybody as a family is, if their dying relative is a potential donor they're all asked you know people sort of say well when I do my research you know well we thought it best not to ask because we're going to say no anyway that, you know that still goes on sadly. And should we also engage with the whole issue about disease prevention and not just organ donation because a lot of communities say to me well all these years nobody has told us we've had a diabetes kidney problem and now they need our organs they're here,

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what's that all about. Hence the lack of trust in the medical profession. So in the short term I think we do need to do a lot of work in terms of end of life care for renal failure patients because clearly for certain ethnic groups that's their reality at the moment because they are not going to get a donation they are going to require end of life care and I am delighted that we've been given a grant to look at this particular issue for the next four years. What I wanted to share with you very quickly was some findings because I guess I am sort of very positive about the GMC guidance in that it talks about equity it talks about beliefs but I think it is very easy to say these things unless you give practitioners some guidance on how to approach it. And what we found when we looked at this, this was based on interviews we carried out with South Asian cancer patients who were in their last few months and weeks was that you know you probably know this better than I, there is a whole history and perception that

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palliative care services is only available if you are white middle class and that may be says something about, especially about how the hospice movement was developed in this country. There is amongst many GP's a reluctance to refer non white patients to palliative care services and there is a lack of information and this what patients say and communication, communication as baroness Finley said you know is a key issue and how do you deal with communication if the person's language isn't, first language isn't English. Services aren't attuned to dietary needs they are not attuned to spiritual needs, we don't sadly collect ethnic monitoring so people tell me oh our services are brilliant and I'm like well prove it you know tell me they're equitable. Well the only way of proving that is if you measure it and sadly we still don't. And there are issues around for example the single equality scheme that may redress this. So for me if I was trying to influence the medical curricula at the moment and trying

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to help practitioners in how do you deal with equity I think about these issues, about try and be aware of taboos and discrimination, think about legislation, be careful about making assumptions, we do this all day you know day in day out we sort of see the way people are dressed or we see you know the skin colour or the way they speak and we make assumptions. And I think we talked about it in the play get to know the patient and the family, think about communication and I know this is really tricky do not use the relatives as interpreters you know. The number of patients we interviewed and practitioners we interviewed in our cancer study who said I know my family member didn't tell me exactly what the doctor said and I'll be facetious to make the point, the doctor spoke for about ten minutes and the person translated that in ten seconds. So they knew there wasn't a direct translation. And there is obviously we need to recognise attitudes towards illness varies from culture to culture, we need to think

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about grief, it does vary and we have you know still a very western medicalised model to grief in this country and we need to be weary you know the world is getting smaller, globalisation is taking place so we need to think about grief models in a non western culture and thinking about faith and environment. I've just left a reading list because people always say to me where can I get more information, that's there and the only thing I wanted to say really at the end was that study that I've just shown you very quickly was done with people, with patients who are no longer with us so for me its hugely humbling and a real privilege that they were able and their families were able to take part in that study five years ago and you know rightly or wrongly with the next study we're about to do with the renal patients who are going to be in their final year of life its going to be the same scenario. But what I will say is the positive that the families have taken out of that study is where that study took

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place palliative care as changed markedly,  
the mindset of practitioners has changed  
markedly. Thank you very, very much.

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