

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

1

MCF: Right, here we are the legal bit. The draft guidance on end of life treatment and care, I think rightly places an emphasis on the impact of human rights in this, what seems to me, very difficult area of medical practise and what do I know about it but that's how it strikes me as a lawyer. At the Human Rights Act as we know have now, has now been in operation for nearly nine years and of course inevitably our understanding of its implications for this part of medical practise is going to be greater than it was when the current existing GMC guidance was published. So what I am going to try to do in my fifteen minutes is to give you a sort of over view of the most significant ways in which the Human Rights Act has had an impact on end of life decisions and indeed the interface between Human Rights and well established ethical principles in this area. To kick off with the basics you all know this I am sure Human Rights Act works by compelling public authorities to act compatibly with

Human Rights that is to say the human rights in the European Convention on Human Rights and of course NHS bodies are public authorities for this purpose so there is no doubt that health professionals need to respect the relevant human rights in this context. And the Convention Rights that seem to me to be particularly important are the right to life in article two and also the right to respect for private life in article eight. And this is of course where you sometimes get a conflict between the principle of the sanctity of human life, the right to life on the one hand and the right to private life, respect for private life or personal autonomy guaranteed by article eight on the other. This slide just shows you the sort of escape clause under article eight which basically means when there is a sufficient general interest to allow an interference with respect for private life that will be permissible. But focusing on article two which has to be it seems to me the key provision here that is recognised, not

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

3

surprisingly as one of the most fundamental human rights of the convention. And on the face of it the first sentence of that article, everyone's life shall be protected by law might be taken to indicate pretty much an absolute obligation to protect life at all cost. But that isn't of course the case. In fact the Strasbourg court has so far given article two a fairly limited role in relation to medical treatment. Just to set it in context the Strasbourg court has said well there is a sort of high level general positive obligation to compel hospitals to have appropriate measures designed to protect patients lives and also to set up a judicial system that ensures that the cause of death of patients in hospital care can be investigated and those responsible can be held accountable. But that's a very high level obligation it doesn't actually affect clinicians as it were at the coal face and their individual decisions so that individual errors of judgement even

when they may lead to death have not been held to involve a violation of the right to life under article two. Recently though the House of Lords has actually held that a special operational obligation to protect life can arise under article two in particular circumstances specifically where a mental health patient is detained under the mental health act and is at real and immediate risk of suicide. In that situation if clinicians don't do what is reasonable to deal with such a real and immediate risk there may actually be a violation of article two which is quite a development, a sort of derived from the well established care law that where prisoners are at risk of suicide the state has a special operational obligation in relation to them. So that's now been extended in the Savage case to as I say detained patients under the Mental Health Legislation. And one of the interesting questions left open by the House of Lords in the Savage case is whether that sort of obligation could actually extend to

voluntary mental health patients too. Now so far we haven't really had a suggestion that that specific operational obligation under article two should extend to any patient in hospital whether private or public but watch this space. Certainly as matters stand as I've said the general obligation is really at the higher level of the state to ensure if you like sufficient regulation and control and accountability. But of course that's not to say that article two and human rights generally don't have a role to play in end of life decisions. The European Commission of Human Rights has specifically held some time ago that article two permits what it has called passive euthanasia, that is to say the withdrawal of life sustaining treatment in certain circumstances. And that reflects of course the well known, well established position at common law as set out in the Bland case with which I am sure many of you will be very familiar. But its worth I think just remembering where we at in 1993 when the House of

Lords took that ground breaking decision in the case of Bland. Anthony Bland was a victim of the Hillsborough Disaster who'd ended up in a persistent vegetative state. Everyone agreed, the clinicians and his family, that there was no hope of any improvement or recovery in his case. He himself had given no indication as to whether he, what he would want to happen if he ended up in PVS but his father thought that he probably wouldn't want to be left like that. So the trust applied to court with the support of the family to seek declarations that it was lawful to withdraw life sustaining treatments including ventilation and artificial nutrition and hydration. And at that time early 90's the argument on behalf of the official solicitor, James Mumby QC as he then was, was quite stark in the sense that as guardian ad litem he submitted that the proposed action of withdrawing life sustaining treatment and care would be murder, there we are. He said regardless of it being done for the best

of motives with family support it would be murder and he said and I am quoting here from his submissions, history teaches that dangers can grow from small beginnings and the best of intentions. Well that, that probably is right. Anyhow against that you had the arguments in particular of the Amicus Curia in the Bland case referring to the right of self determination and personal autonomy the sort of concepts that you now have reflected and indeed then had reflected in article eight of the Human Rights Convention. And the whole idea that you had to balance those interests stroke rights against the principle of the sanctity of life. And ultimately that idea of the balancing exercise as it seems to me was reflected in the House of Lords decision. Lord Goh expressly referred in the House of the Lords to article two of the Convention although of course at that time we didn't even have the Human Rights Act and he said that article encapsulated that fundamental principle of the sanctity of life but

sometimes it had to yield to the principle of self determination. So what the House of Lords made very clear was this idea that a competent patient of course can refuse life sustaining treatment however unreasonably and indeed where an incompetent patient has previously indicated what he or she would want in that respect that also needs to be respected. But going further than that the House of Lords thought that there had to be a way in which the principle of self determination could be respected in relation to an incompetent patient such as Anthony Bland who wasn't able to say what he wanted at that time but who might actually have wanted life sustaining treatment and care to be withdrawn. And so of course you get to the fundamental principle that in such circumstances, such treatment and care can be withdrawn if in the best interests of the patient. But Lord Goth thought giving a leading judgement it was very important to stress the crucial distinction between a doctor

who decides to withdraw life sustaining treatment on the one hand lawful, perfectly lawful in certain circumstances and on the other hand administering a lethal drug in order to bring a patient's life to the end, the latter being unlawful euthanasia. Now on what basis does that distinction really rest you might ask between what is lawful withdrawing treatment and clearly unlawful, the lethal injection on the other hand. One might have thought based on the Bland decision that there was in a sense quite a simple distinction based on an omission I.e. withdrawing treatment counting as an omission lawful, not murder or doing something active, giving an injection, positive act, unlawful. But Lord Goff in Bland was more nuanced than that and said that in the end the reason for the difference I.e. between lawful and unlawful is that whereas the law considers that discontinuance of life support may be consistent with the doctor's duty of care for his patient. It does not for reasons

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

10

of policy considers, consider that it forms any part of his duty to give his patient a lethal injection to put him out of his agony. So it all sort of rests on what the law for reasons of policy sees as the duty of a doctor and the relevant question to ask is not whether its in the best interests of the patient to die but whether its in his best interest that life should be prolonged by the continuance of whatever relevant medical treatment or care. Now this very difficult area was then revisited by the Court of Appeal more recently after the Human Rights Act in 2005 in the Burke decision which was a direct challenge to the GMC's guidance on all of this where Mr Burke who had Spino Cerebella Ataxia was worried that at some point in the course of his illness clinicians would decide to withdraw artificial nutrition and hydration or ANH and so he challenged the guidance on that basis. The Court of Appeal upheld the GMC guidance and said well it didn't indicate at all that someone like Mr Burke would

**Developing GMC guidance on End of Life Care
Consultative Conference
*Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

11

end up in that situation. The court first of all very very strongly supported the idea of self determination and personal autonomy, the idea that patients who are competent have an absolute right to refuse treatment. But also said that so far as ANH is concerned once a patient is in hospital of course there is a positive duty to provide care and a fundamental aspect of that duty to provide care is to take reasonable steps to keep the patient alive. So where ANH is necessary to keep a patient alive the duty of care will normally require doctors to do just that. Although it wouldn't override a competent person's wishes to the contrary. Of course there would be exceptions as recognised in Bland, the refusal of the competent person or indeed, where in relation to an incompetent patient, it's in his or her best interest for ANH not to be given. But importantly for someone like Mr Burke who said that he wanted to be kept alive by ANH the Court of Appeal said well if a doctor deliberately decided not to give

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

12

ANH in those circumstances with the intention of terminating the patient's life that would give the doctor no answer to a charge of murder. And indeed the court said that such conduct i.e. if you then withdrew ANH would involve a breach of article two of the Human Rights Convention. A pretty strong statement there and you may think that really then looking at the Burke decision there isn't much room for that distinction that sort of had emerged in the Bland case between an omission I.e. the withdrawal of treatment and commission or a positive act, the lethal injection. Where it all really seems to rest is in this idea of what is the doctor's duty prima facie to keep the patient alive unless he or she doesn't want to. Well so much in the brief time we have for that hugely difficult area of withdrawal of treatment. I think I should just mention where we're at on euthanasia if you like actions designed to bring life to an end for the best of motives which of course is an extremely

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

13

topical thing. In a sense the starting point here is the Pretty case. Pretty against the DPP which went to the House of Lords back in 2001 where Mrs Pretty who had Motor Neurone Disease wanted the DPP to undertake that he wouldn't prosecute her husband if he assisted her in suicide. And she relied specifically on articles two and eight of the Human Rights Convention but the House of Lords held that none of those provided effectively a right to life or a right to assisted suicide. The case went to the Strasbourg court which agreed with the House of Lords although for slightly different reasons saying that article two really couldn't be interpreted as providing a right to death or a right to choose death rather than life. However, the court didn't rule out the possibility that article eight might come into play here talking about respect for human dignity and human freedom being crucial under the Convention and how quality of life could be of importance under article eight. At the end of the day

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

14

the Strasbourg court said the ban on assisted suicide in the UK was justified under article eight but as I say it did leave open the possibility for further argument under article eight in that respect. And of course in the domestic courts we've had more recently the Purdy case. Purdy against DPP where the Court of Appeal effectively said it was bound by the House of Lords in the Pretty case to rule that article eight couldn't help Mrs Purdy who said that she wanted the DPP to promulgate a policy that would make it clear when someone who assisted in suicide would be prosecuted. Now as I am sure many of you will know the Purdy case is being heard on appeal in the House of Lords this very week so it will be very interesting to see what the House of Lords as our final Court of Appeal will say about that. I am very much running out of time so all I wanted to mention finally is the role of article 14 of the Convention which is all about equal treatment in the enjoyment of Convention Rights it really serves to

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

15

reinforce or compliment other equality obligations that exist in specific legislation such as the Race Relations Act and the Disability Discrimination Act and of course it is important to ensure that there is equal treatment in relation to health care and in particular in relation to end of life decisions. It doesn't always mean treating everyone in the same way but it means sensibly and rationally treating those who should be treated in the same way in such a way as the Court of Appeal said in Burke for example the GMC's guidance expressly and rightly warned against treating the life of a disabled person as in any way less valuable than anyone else's. Obvious one may think but nevertheless stressed by the Court of Appeal. I think where I end up as a lawyer after all of this is to feel that one can take some comfort from the fact that the Human Rights Act rather than radically changing medical law and practise in this area has provided important support and reinforcement for principles that were

**Developing GMC guidance on End of Life Care
Consultative Conference**

***Interface between human rights, the law and
ethics in end of life decision making***

Monica Carss-Frisk QC

16

already there at common law and as I
understand it well established ethical
principles and principles of good
practice. Thank you very much.