

**TRANSCRIPT OF EVIDENCE FROM DR.
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FOR ETHICS IN MEDICINE, UNIVERSITY OF
BRISTOL AND DR MARTIN CURTICE,
CONSULTANT IN OLD AGE PSYCHIATRY AT
HOLYHILL UNIT, BIRMINGHAM**

**Wednesday 20 April 2011
2.45pm, at Demos**

Baroness Barbara Young (BY): What I propose, since we've got a bit more time on our hands, and Elaine has now passed me the poison chalice of chairing, is that we take you sequentially rather than as a sort of bulk buy. I mean, feel free to sit there and feel free to chip in, but we'll take you in turns. So it will be useful if you were to tell us who you are first of all and then we'll know who to take in turn.

Dr Richard Huxtable (RH): Hi I'm Richard Huxtable, Senior Lecturer and Deputy Director for the Centre for Ethics in Medicine at the University of Bristol.

Dr Martin Curtice (MC): Martin Curtice, Consultant in Old Age Psychiatry in Birmingham and Vice Chairman for the Special Committee on Human Rights at the College of Psychiatrists.

BY: If we may start with Dr Huxtable. Thank you very much for coming along today. The DPP policy, the current position of the DPP policy, do you think that that has helped or hindered the current situation?

RH: I should say at the outset as well, I work with other organisations and committees and the evidence that I'm going to give is my own personal evidence and therefore shouldn't be seen as representative of them.

BY: Sorry, I should have said – is there a preliminary statement you want to make before we begin?

RH: There are, but I can...

BY: No, feel free, do start with that.

RH: Thank you. By virtue of the position I described, I'm in the Centre for Ethics in Medicine which is within the School of Social and Community Medicine in Bristol. It means that by background I'm a lawyer, within an ethics unit, within a medical school. And I think all three of those come to bear on the position I've nowadays reached on assisted dying. And that is a distinctive, some would say unusual, position insofar as that I'm essentially a defender of the

middle ground – I think the law roughly, but only roughly, is in the right place, although I would argue that it does need tidying up.

So in terms of being in the right place I think the law adopts a nuanced compromise where it recognises that we are talking about prohibiting intentional killing or ending of life, but also dealing compassionately with those who do end lives in the situations you're addressing. I would also emphasise none the less, the law, as it stands, including the DPP policy as it stands, needs tidying up. I think the DPP policy goes in the right direction, but it alights at the wrong stop, and my reason for thinking this is that the DPP policy does convey this compromise, and I can expand on that later if you like, but I think there's still a considerable degree of lack of clarity, uncertainty and unpredictability which are the sort of thing we can legitimately expect of law; so there's more that the law can do in telling people what are the dos and don'ts in this area.

Having said that, I think the law goes in the right direction but we need to clarify that direction; and that direction does feel roughly like the law is roughly occupying the middle ground at present. I've argued this in the academic press. Where I would want to push those arguments is by going at least one step beyond the DPP policy and explicitly creating a legal category of assisted dying, mercy killing, call it what you will, and that would involve creating a specific offence, which could also be available as a partial defence to other charges like murder, manslaughter and the like.

My reason for thinking that is that I think that the law, in going in that sort of direction, would split the difference between the three main groups of arguments we hear from the ethicists out there in relation to this issue. So first of all on the prohibitive side obviously, we have the appeal to the so-called intrinsic value of life, the idea that life itself is valuable and should not intentionally be brought to an end. On the more permissive side, of course, we've got the arguments that appeal to instead the instrumental value of life, in the sense that we refer to suffering and the like; so in that account we're not saying life itself is valuable, but rather that life of a sufficiently good quality is valuable. In other words life is an

instrumental vehicle to other goods; if that vehicle is substantially broken maybe it's time to abandon it.

But thirdly, and perhaps most prominently nowadays, we talk about the self-determined value of life whereby it's over to me to decide what counts for me or what doesn't count for me in terms of making life worth living or not. And I think - and as I say I've been writing about this and thinking about this for some years and talking with patients and professionals, both health and legal professionals - there's something of value in all three of those accounts. So we do want a legal system that says no to intentional killing, at least by and large, we also want make all efforts we can to eradicate suffering. We also of course want to respect what people want to do, what values and beliefs they wish to live by.

The problem I think, hence me arriving at this middle ground, is that there are also deficiencies with all three of those accounts as well. So on the prohibitive side, the intrinsic value of life side of things, there are some pretty fine lines drawn there and increasingly it's seen as quite a theological construct; and so one can immediately say, well, if I don't come from that faith-based perspective of, the sanctity of life, lets say, or I have no faith, then why should I buy into this set of beliefs? So that would be one set of problems.

But I would also argue that there are problems with the more permissive arguments based on the instrumental value of life and the self-determined value of life; so these appeals to suffering and autonomy if you will. In terms of the suffering one, I've written in some papers with a colleague, Dr. Michael Möller, that suffering can be seen as a very subjective matter. If, when we're talking about assisted dying, and this starts to bring us into the territory of today's discussion particularly, we are appealing to let's say a health professional to assist in that dying, then they need to at least sympathise with the quality of life judgement that the patient has reached. There needs to be some way of speaking to that health professional if they're going to have a reason for acting. And I would suggest, it might be only an incremental matter, but if you start there, with the allegedly subjective value of suffering, it's not such

an extreme step to start talking about objectifying suffering and judging the value of other people's lives.

So that would be one cluster of problems here; but I recognise of course that more often in this debate we're talking about the self-determined value of life, so autonomy and people's own accounts of what matters and doesn't matter to them in terms of quality of life. There I'm particularly struck by a Dutch case in terms of exposing the logic of what we are talking about – this was the controversial Dutch case of Brongersma in which an elderly gentleman was helped to die by his GP on the grounds of existential suffering or that he was 'tired of life'. The Dutch have attempted to draw a boundary there and say this is not permissible behaviour, but I think logically, in terms of the appeal to autonomy, we can't rule that out. So how one is going to draw these boundaries is going to be very difficult at the outset.

So this leaves me in no man's land momentarily insofar as I'm saying there's something of value in all of this, but equally I want to throw it all away, it would sound like. But I don't want to throw it all away, I want to signal that there is something in merit in all of these perspectives; so that's why I arrived at a position where it's a compromise insofar as people gain and lose and simultaneously on both sides of debate. And in terms of both sides of the debate, I think it's too often cast in terms of permission / prohibition, or justification / no justification. I would argue for going in the middle and talking about concepts like *excuse*. So that is why I would come up with a specific offence and defence of assisted dying or some similar synonym.

BY: So in terms of the practical changes you would want to see to the legislative system as a result of that, what would they be?

RH: It would arguably be along the lines of something proposed, or at least discussed rather, by the Law Commission around six or seven years ago, where they talked about creating a specific, mercy killing I think was the label I think they used at that point in time, offence, and as I say, also defence. So we'd still be talking about investigating deaths that we can apply the label euthanasia /

assisted suicide / assisted dying too, by they would be dealt with as a specific legal category; so recognising that this is not to be treated as murder as such, but is still to be treated as a criminal matter, but dealt with more passionately and leniently. And I would say my position really is a clarification and a tidying up of what's been going on, I would suggest, for decades, insofar as we know that a lot of people who come before the courts, often lay people, relatives, will be passed down with probation, counselling, largely non-imprisonment; so we're not talking about these sorts of cases. So I'm just saying, let's acknowledge this is what we're doing, let's tidy up what we're doing and bring it out into the open.

BY: Ian...

Lord Ian Blair (IB): I find this really interesting and I want to just put a couple of challenges back to you; the first seems to be, and we just heard from a witness that the fear is prosecution. And at the back of the fear of prosecution, of course, is imprisonment; that's the key component here. While it is true, just an example, one of the categories that your offence of assisted dying might look like, would be infanticide where it's still infanticide, very normally treated by the courts as infanticide within the first year by the mother, that is the classic position. That is normally treated by counselling and by psychiatric treatment, by probation; it still carries a criminal penalty, including imprisonment. And I take it that you're not suggesting that an assisted dying offence would not lead to imprisonment?

RH: No I would leave that open...

IB: No, it either is imprisonable, it doesn't mean it has to be imprisonable, but it would have a maximum penalty of imprisonment. In which case, practically, it doesn't take us that much further away – it takes us away, further, because you are not facing life imprisonment for murder, but you are still facing, in the situation in which Mrs Broad found herself, you are still not only facing investigation – which is inevitable, we all agree that investigation is inevitable – the key component is what is the

penalty. And if the penalty can still be imprisonment, then that I think...

RH: But I would emphasise the can be. Essentially on my reading of the prosecutions that we can see, at least publicly available, it seems that the judges are already constructing a paradigm case of mercy killing or assisting in suicide. And in that paradigm case, and we can argue about what would count as a paradigm case, actually it's not imprisonment. Where prison seems to have been used, and a case like Mrs McShane in the late 1970s might be an example, is where there seem to be contaminating factors that suggest that this is something rather different from a characteristic assisted dying or assisted suicide. In that case, it was the fact that she seemed to have mixed motives in what she was doing or why she was doing it, there seemed to be a financial motivation behind it.

So I do emphasise, and I've emphasised this elsewhere in what I've written as well, that where this arrives me is an uncomfortable position, and I acknowledge that it is an uncomfortable position, but it's a compromise precisely because we feel the pull of these conflicting values.

BY: Denise...

DP: Can I just come back to that really. A lot of the models that we've looked at around assisted dying, there's a really heavy emphasis on the fact that this is the person's decision. You talked about the Netherlands where this is clearly an issue of medical consent between the doctor and patient, and then things go ahead. But the concept of mercy killing gives an impression that somebody else makes a decision about the quality of your life, which you may not share. And from the evidence that we have received, that's what some groups fear most; that the life of a person with a disability, which to them is very valuable and they can contribute, others might judge from their perspective, an able person's perspective, as being miserable, non-contributory and not useful. And therefore if that person was to make a decision about you that might not be in your interests, because you don't want that to happen to you.

And so, which is where we get into the area of safeguards, that this clearly has to be the person coming to that conclusion about their life and their life circumstances, rather than other people's judgements.

In the model that you've described, how does your middle way negotiate out from that so that those people who feel that they are in a vulnerable position don't come under undue pressure? One witness we heard representing a disability group said 'an opportunity could become an obligation', because you're made to feel that your contribution, your life, is not of equal value, and others may make that decision about you. How does your middle way go with that?

RH: I would say in terms of the offence I'm trying to craft, that the voluntary instances, so the instances led by the patient, would be the paradigm case to which I'm referring, such that, and with reference back to Lord Blair's question, you would keep, let's say, a maximum of life imprisonment available if, on investigation you find that this is not what the patient wanted, or the patient wasn't consulted, or the patient couldn't be consulted. So then we'd be into murkier territory where the discretion opens up for the judge and they might say this is beyond the pale.

Drawing the line that tells us where the pale is, I agree, is a very difficult one, particularly as I'm struck in terms of, and this is a problem I think shared with more permissive attempts to reform the law, to embrace legalisation or decriminalisation of assisted dying, there's all the other law that we have in terms of respect for autonomy, and I note, for example, references amongst the law Lords to the right to make decisions for any reason whatsoever, rational, irrational or on at least one famous occasion, for no reasons given at all. So one could engage with what we mean by respect for autonomy in present English law, and also what it would mean, both in the model I'm discussing, but also in more permissive attempts.

IB: If you've got a situation where investigation had shown that patient hadn't consented, hadn't wanted etc, you wouldn't have a charge of assisted dying, would you, you'd have a charge of murder?

RH: Well I'm very sympathetic to that, that this category of involuntary euthanasia, which is occasionally glistened in the literature, is one that is always very quickly dealt with as, this straightforward murder. But, with respect, I suggest that that begs the question insofar as presently, as we stand, all instances of euthanasia, whether voluntary, involuntary or non-voluntary, all count as murder.

IB: I understand the point you're making. I'm just trying to say I don't think an assisted dying offence could possibly contain life imprisonment, as an example, because it would already be being treated as murder under the law, in that sense.

Dr Carole Dacombe (CD): I wanted to explore two things with you. One is that as you know the DPP guidance actually does draw a distinction between the assistance of a health or social care professional versus the compassionate companion, friend, spouse, etc. So would you actually see there being a difference in this offence of compassionate killing? Would you discriminate between compassionate killing carried out by a professional as opposed to an amateur?

RH: I personally wouldn't. I'm struck by the way that the DPP guidance has evolved into its current final form, where it seems to be much more prohibitive of health professionals becoming involved...

CD: Well indeed, and we actually have heard evidence of medical legal advisors, indemnity organisations, who are now positively advising medics to avoid these topics, these discussions, the potential supportive actions, because of the DPP guidance.

RH: What strikes me about that, and again, my social science colleagues would say that this is not the most rigorous sample I'm basing this observation on, but in terms of the media reports I've seen of trials to date, it's quite striking that actually, the law has

been very lenient in its application to health professionals wherever such allegations have been made in the past. And this strikes me as quite a sea change, at least in the signal that is being sent, insofar as those prosecutions that you do glimpse have, with only with one exception that I can recall, have involved members of the public, as opposed to a health professional. There was only one doctor I can recall who was convicted of attempted murder for the types of behaviour we're talking about today.

So, in terms of crafting any new law, I should emphasise of course these are arguments I'm advancing, if ever any arguments went further and gained any currency then it would be open for extensive debate as to what such an offence might look like, the sort of debate, in fact, that the Law Commission were looking to initiate back in 2004/5. I would suggest that you would leave it as an open category and make it applicable to anyone and then contaminating factors be dealt with at the level of sentencing, if conviction results.

CD: OK, so let me just challenge you a bit about this compassionate killing, given that it has the word compassionate in it. Where is the compassion in causing a great deal of pre-death anxiety on the part of the person who is seeking the killing, the person who is being expected to do the killing, when they know that what will follow is a really stringent investigation with the risk of a prosecution, when we do know that there is some evidence that says the bereavement process for those who are bereaved after assisted dying, is, to some extent, actually improved by the knowledge that the person who has died has achieved what they wished, in the manner in which they wished it to be achieved, and therefore they feel a sense of rightness, albeit they feel a sense of loss. Where's the compassion?

RH: I would unkindly and unfairly, and rhetorically to be honest, reply with the question, why would this model be any less compassionate than the prohibition on murder that we currently have, and those investigations that we currently have? At least if we're talking about charges of murder, wherever they result in a conviction for a lesser offence, the lesser offence has been voluntary manslaughter by virtue of diminished responsibility. Well, I don't know if that is the most compassionate message to be sending to

those people who do feel, in extreme circumstances, that they wish to assist their loved ones to die.

CD: So the relative loss of compassion that you're new proposed offence brings with it, you believe is the necessary compromise in order to avoid the risks that you would see attached to true assisted dying?

RH: In a word, yes.

CD: OK.

BY: Stephen...

Dr. Stephen Duckworth (SD): Yes, just to move slightly on a tangent away from what we've been talking about in relation to prosecution, you are helping us to understand this issue around autonomy, and the concept that autonomy can be influenced by the environment in which we live. For example, we're seeing severe cutbacks in public sector funding, retrenchment of funds available for community voluntary sector organisations that have been there for many years and might not exist in the future to support fairly vulnerable people to live as optimal life as they can. In an environment where those, both statutory and voluntary community services are being withdrawn, will people not be forced into making autonomous choices dictated more by the economic environment in which we exist rather than the reality of their experience, that could be otherwise if we had a different economic climate?

RH: I agree that context must matter in terms of autonomy and there's been an unkindly, again I would say, a tendency occasionally to caricature autonomy as 'I want I get', but of course autonomy properly understood will mean there are lots of 'I's all rubbing up against each other, who must be ensuring they are respectful of one another. And I don't think I could say much more than that in response to, of course, circumstances within the society within which one is, will influence the range of choices available to one.

BY: Sam...

Professor Sam Ahmedzai (SA): You started off speaking very clearly about quality of life and you talked about self-determined quality of life. Is it always a qualitative, subjective issue, or do you think, in the bigger picture, there might be some more objective way of looking at what a person is going through?

RH: There will be measures out there, but I just don't know whether our tools are going to be good enough for saying these are, this is the threshold quality of life below which we can say assisted dying is permissible. So I recognise, and I should emphasise that I am not medically trained so I can't make direct reference to the types of tools that are out there, but of course there are tools for gauging ability / disability and pain, of course they're available, but whether they do the theoretical work we want them to do in this situation? Pass.

SA: So at the moment it really comes down to a person's own self-determined and communicated perspective. What if the person can't communicate? They can observe, but they can't communicate. Do they have any particular rights?

RH: Do they have any? Sorry –

SA: Do they have any particular rights? I mean, we can see what they're going through, but they cannot communicate to us; it could be the nature of their illness.

RH: Of course, yes, absolutely, I would agree, yes, clearly rights.

SA: So they don't actually have to have expressed it themselves. Can it be a judgement taken on behalf of that person?

RH: Then we're in the realms of surrogate decision-making, and this starts to take us down the line to which I referred earlier, where we start with me saying this is bad for me, I appeal to you to help me. You then start thinking, well, should I help you? And one of the questions you have to ask yourself is, is this a sufficiently poor quality of life to warrant me stepping in, to then be judging others with that quality of life and it starts to go further. Whether, I think you expose an interesting dimension to this debate, insofar as if one

contemplates legalising assisted dying, on the grounds of appeals to individual judgements about suffering and quality of life and the like, for now, then what it is to preclude us from talking about advance directives and/or handing over the decision-making responsibility to our loved ones, at the point at which we might not be competent to decide for ourselves?

SA: We were talking about safeguards earlier in the day – what kind of safeguards do you think might be worth putting in so that you didn't allow that to happen? For instance, somebody could be making an ad-hoc decision / a surrogate decision without necessarily understanding the implications. How could you protect against that?

RH: I found myself scribbling furiously on the train and coming to no firm conclusion. I can quite clearly see the principles one would need in terms of protecting the individual and ensuring it's what they genuinely want and arguably what they need - and I think that's probably the more difficult one - but then there's the whole question of protecting others as well. So I, would I want to frame the law? No I wouldn't.

Sir Graeme Catto (GC): Just one question and a comment. You referred earlier on to courts being supportive of a patient's right to choose. But am I not right in thinking that it's a patient's right to choose not to have treatment? They haven't yet been supportive of a patient's right to choose to opt out of life, or to choose a positive form of treatment.

RH: I was referring to the right to refuse, yes. Sorry if I wasn't clear. Yes, I do mean the right to refuse.

GC: I think I'm right in saying the most recent case in Scotland, where there was an assisted suicide, the relative immediately confessed to the police what had happened, the prosecution at that time had no option but to charge for attempted murder with a mandatory life sentence, because the person had already admitted what had happened. And the judge, in his wisdom, got out of it by finding the person guilty of culpable homicide, given that the

balance of his mind was disturbed, but there was absolutely no shred of evidence whatsoever that the balance of his mind was disturbed, but it was to get off the end of the pin that Ian was talking about earlier. The law in England and in Scotland just might benefit from some greater clarity on these issues.

RH: I quite agree. This is a fudge, and in my terms, in terms of extolling the virtues of compromise, however uncomfortable, I would suggest that it's a benign fudge and it's one that I'm very familiar with from English law where even the judges have written about this in a series of papers from the mid to late 70s, about there being complicity, essentially, between prosecuting council and the judges in ensuring that the 'right result' is reached. In other words, not a finding of mandatory life penalty, or a finding of murder.

GC: I suppose the issue for me, and perhaps for all of us, is whether that fudge is where we want to be? Or whether is it a fudge that you think is necessary because the law at the time, it's the best you can do with a difficult law?

RH: This is why I feel that my argument is, in a sense for an academic lawyer, it's controversial because it's so conservative, with a small c, in the sense that I'm actually saying we're roughly in the right place, let's just tidy up where we are. And it's not much more ambitious than that.

BY: Could I challenge that gently, perhaps not even gently? Perhaps I'm wrong, correct me if I'm misinterpreting you, but you're basically saying that the patient and whoever helps them should make the decision according to their a) personal ethics and b) interpretation of the law and the DPP guidance, but that the individual - the patient who has sought support - once gone, has got to leave whoever supported them to the, to some complicity between the prosecutor and the judge. That doesn't feel like a bundle of laughs to me, if I was a terminally ill patient looking to bump myself off.

RH: But I'm suggesting that's where we presently are. I would suggest if we move to openly embrace this as a legal category, it's

not so much a trap. Of course, it's still a difficult situation because the patient will still know there is a considerable risk that their loved one will be found guilty of this new offence. But there is an openness to that rather than reliance on prosecutorial discretion...

BY: But why should we put up with that? It doesn't seem a very satisfactory situation.

RH: As I say, I reached that because I felt that the arguments on both sides seemed in such fine balance, and it's quite familiar to me that people will strongly extol the virtues of one or other side of this debate, but I found myself increasingly in these debates which I often have with health and legal professionals and with my students, I would myself be going back and forth, and I've been doing that for a long time. And I found myself increasingly thinking, the reason I'm going back and forth, and the sheer tenacity of the arguments on both sides is because both sides of this debate have got something to say.

But as I say, it's a compromise insofar as we can gain because we give something to both sides, but we lose because of course both sides lose part of what they want, which is either prohibition or permission depending on where you stand.

SD: Can I push you on that, because as a scientist, surely you weigh up the evidence and look at the balance of where the evidence lies? And you would have analysed that in some degree of detail. What evidence is there on both sides and what is the balance between the evidence of the arguments both for and against a change in the legislation on assisted dying? How weighty is that evidence?

RH: I think on the pro side, obviously the biggest evidence we've got is the sheer wealth of support that seems to be out there. And there's been difficulty in the past with some of the surveys and opinion polls that have been conducted, but they seem to be more robust now and there clearly is a lot of public support there. So to disregard the autonomous views of a large number of the public would be abhorrent. So on that side there's that cluster of arguments, in addition to these general philosophical arguments, if

you will, about respecting autonomy and the subjectivity of suffering.

On the anti side I think there is still something in this intrinsic value of life tradition, insofar as, as I say, if law, any law, is to do anything it's probably going to need to prohibit intentional ending of life. Now we are obviously talking about exceptions to that general principle, so one then is into murky philosophical territory in terms of whether the main principle still stands. But of course the other side of this debate, and one that is very difficult because the evidence to which you refer is heavily contested, is of course evidence from jurisdictions that have taken the step. And I appreciate that that evidence is contested, but I still find myself with considerable disquiet, so mindful of these strong arguments for, on that side I'm still concerned about steps that have been taken in the Netherlands, for example. So the fact that the Netherlands finds itself at this point, where existential suffering is even being contemplated...

SD: But rejected...

RH: - but rejected, but the doctor in question to the best of my knowledge, not imprisoned or subject to any criminal censor as such. So I would ask what message is being sent there? We've got these very firm criteria for what's permissible but if you step outside then that's not too bad. I would argue that more robust policing would be more respectful of the principle that's at stake. And of course there's also, although this too I would emphasise is very contested in itself, the moves along the lines of the Groningen Protocol, by which neo-natal euthanasia is endorsed. I query, not being a sociologist or knowing this area in any great detail, I would emphasise that, whether they would be at that point if the earlier step that hadn't been taken, but I'm aware that I'm on slightly slippery territory, so I would pause there.

But its those sorts of arguments, there's a sheer wealth of support, but also elements that give us reason to pause, which is why I find that I'm in this tricky position where everyone takes me on from both sides.

BY: Any further questions? No? Can we leave you where we are at the moment, and thank you very much, and do stay. Perhaps we could move on to Dr Curtice, who's a consultant in old age psychiatry. Welcome, there are some pretty key issues in your particular area of expertise that we have already touched on this morning, including the whole issue of the particular challenges to any change in the law that are represented for older people. I wonder if there's anything you want to begin with by way of a statement, or whether you want to just pick that up as a question.

Dr Martin Curtice (MC): If I could, just a brief statement just to bring things together, and again, my views today are my own views and not part of any association. I sit on the Special Committee for Human Rights at the college and my background, I'm just a jobbing old age psychiatrist, so I do this day in day out. I literally use the Mental Capacity Act every day. This is something I use day in day out, and it was interesting to hear the patient representative earlier. These are the things, speak with my colleagues, we use day in, day out. I've not yet met a colleague, who until any legislation is brought forward, who've said they would go with it or do it, so it's quite interesting from a lot of my colleagues.

Just three aspects that I wanted to comment on. The human rights aspect – there was actually a case in Switzerland in January this year – my background is also, I've got a Masters in law, I got a Distinction in Mental Health Law, and that's where I've taken all my research and academic interests from, but I'm just a jobbing psychiatrist. The case in Switzerland gave us a point where we're at with regard to assisted dying in Europe, as they see it. And there's no consensus in Europe as yet, they give each contracting state to the convention quite a wide margin of appreciation. So they sort of say, well, every state's different; you do what you want to do. So they're giving quite a wide margin of appreciation currently.

But the case in January that the court ruled on was about a chap with bipolar disorder and he wanted to end his life in a dignified manner, and he went and asked 170 psychiatrists who refused to write him a prescription. He then said to the state, well that's against my Article 8 rights, (to make a choice about when I die) and

they said no and the court ruled saying what the state did was absolutely fine because they went by their law.

So what it does do, this case, it affirms the right of an individual when to end their life with capacity is an aspect of right to private life, whereas I think the previous Pretty cases, the English courts weren't so sure about that. But the European courts are saying it is part of Article 8 now. And assisted dying, they also said in this case, is a balance between Article 2 rights, the right to life, competing with Article 8 rights, the right to a private life and your own autonomous decision-making. But they also do say, they advocate psychiatric assessment as part of any process. They're very well aware of liberal approaches needing to be underpinned by safeguards and they specifically mention that. And they also say it is important to distinguish between the desire to die as an expression of a treatable mental disorder – I know this is slightly going about assisted dying for people with mental disorder - but also the desire to die of a person making a capacitous and autonomous decision is still to be upheld.

So that's just a little bit of human rights context, and that's from January this year, so it's, sort of, up and running. My views on assessment of capacity, just in no particular order, obviously the starting point would be of presumed capacity under the Mental Capacity Act. You could under new legislation have a different test; you wouldn't have to use the Mental Capacity Act, although the biggest change in our legislation recently is the Deprivation of Liberty Safeguards (DOLS), and that's still working it's way out, it's a little bit grey, but it's new legislation that will evolve over time.

But that, as its bedrock, has the Mental Capacity Act, so that would be the starting point. I think in real terms if it were to be incorporated under assisted dying legislation, you could literally have a checklist. You could be quite specific about the issues to discuss. I was looking at the Oregon [legislation], they're almost like the forerunners of this, they've been doing it for 13, 14 years, and their psychiatric form you have to fill in hasn't really got it, it's just got a bit of space for a narrative. It doesn't say have you checked

this, this and this, feasible alternatives and suchlike, risks / benefits.

I think that an important risk that a patient would need to understand is that you don't always die when you ingest stuff, and they've had three cases, out of 525 in Oregon up to the end of last year, where the patient didn't die; they woke up 60 / 80 hours later, and died several days or even 2 weeks or 3 months later. So I think that's an important aspect that patients need to know. But you can build things like that in if you have a list; you could build things like that in quite easily. You could, I do work as a CQC, as a second opinion proof doctor, for people under the Mental Health Act...

IB: Could you explain that?

MC: A second opinion proof doctor for the Care Quality Commission, sorry. What that provides is people who are detained under the Mental Health Act, have various levels of safeguards. One of the safeguards is, at about three months after you've been detained, and if you lack capacity to consent to treatment, an independent doctor will come in and review the treatment plan proposed. So say I can refer it to the CQC; I've got a patient and I have to by law, if I think they're lacking capacity, ask for a second opinion from an independent doctor who'll come in, and sign things off or check the treatment plan.

And the test of capacity under the Mental Health Act is different. All I have to assess is that the patient understands the nature, purpose and likely effects of the treatment, which is a little bit different to the understand, retain, weigh and communicate, although we're advised and we routinely use both, but under the Mental Health Act the actual test is a lot simpler in many respects, it's quite specific. Whether you could develop something similar, I don't know, but it's just a thought, it doesn't have to be implicitly the Mental Capacity Act, although that's the logical choice.

And just lastly about the role of psychiatrists, and the lady earlier was speaking about depression, obviously there's a big overlap between depression and terminal illness and chronic physical

disorders, that's taken. There is an editorial in the British Journal of Psychiatry in February this year advocating that we should be part of this conversation, but also we will probably be inevitably an 'agent' of any process that's enacted. An interesting thing about depression is that in Oregon, again, it's not mandatory, interestingly, to have a psychiatric assessment. So the patient will go to their physician; if the physician suspects a psychological or psychiatric element, they then refer them. So it's not a mandatory thing, and interestingly out of the 65 cases last year only one person was referred for psychiatric assessment, and overall in the 13 / 14 years they've only referred 39, so 7.5 per cent of patients get a psychiatric assessment.

I suspect there's a lot of palliative care doctors who are very good at this and probably wouldn't need it, but the issue is that there's also evidence coming out of Oregon that there are people being given prescriptions for barbiturates who suffer from major depression; there's another study which suggests that three out of 18 who went on to kill themselves had a major depression. Now major depression in itself, if you apply the Mental Capacity Act, does not automatically mean you lack capacity, but it's highly likely to influence your decision-making.

I have a patient at the moment who a few weeks ago declined ECT, mild to moderately depressed, has subsequently had a relapse and is now psychotically depressed, who clearly, his psychosis is part of his depression, is affecting his decision-making. So that's the sort of group you would want to look out for as part of the process, and again if you look at the DOLS safeguards they have a mental state assessment as part of it, so you could build it in. So I think that's about where I'm at really, with those three areas, just for interest.

BY: Thank you very much.

EM: Could I leap in, because I've already said I'm going to go soon, but I've just got one brief question. Just so we clarify for people that the mental health legislation of course completely cuts across capacity legislation in the sense that it's to do with risk, the risk base, the new mental health legislation set aside the notion that we

would have a capacity-based act. So we have these two pieces of legislation that sit side by side, of which the Bournemouth legislation has been added on to the capacity legislation, and sits rather unhappily within the mental health legislation. I'm hoping I'm clarifying rather than making things more confusing for people, but perhaps I'm not. I just wanted to add, I don't know if you would agree, that the mental health legislation, which is extremely relevant for assessing depression and how emotions affect capacity and so on, it runs along parallel lines to mental capacity legislation, which is entirely different. Because our mental health legislation comes from 500 years of legislation, our mental capacity legislation comes from a more modern framework, would that be...?

MC: Absolutely, yes. So they sort of –

EM: And that's my parting shot, actually!

MC: They sort of touch each other, and in reality you have to think of both things. I mean, you could be detained under the Mental Health Act but physical treatment is essentially under the Mental Capacity Act...

EM: And actually it's a lesser test, the mental health legislation is a much lesser test of capacity.

CD: But as I found out on Monday, quite tricky to sometimes arrive at a decision. It's quite relevant to point out I think that in everyday general medicine, whether it's caring for the elderly, general medicine, palliative medicine, has to assess capacity. The issue of capacity, and a person's ability to alter their state of capacity temporarily or permanently, it is a day-to-day event, isn't it, in medicine. So it's clearly easier to talk about that than it is to talk about mental health legislation, because it's a day-to-day part of medical and nursing practice.

MC: You're absolutely right, it's a fluid concept and it certainly can change.

BY: Can we move you on to a slightly different area, which is the issue of older people and a change in the law. If there were to be

changes in the law, and obviously it depends on the changes, but if, for example, there were to be changes along the lines of the Joffe Bill, what are the particular ramifications, do you think, for older people?

MC: I think, I mean, if you apply Lord Joffe's legislation, I don't see a big issue, obviously the older person's going to get higher rates of cancer and stuff, and if you look at Oregon and Washington, 80 per cent of people who have assisted dying have got a cancer of some sort. I think in the last couple of years older people have been mentioning to me now and again, 'oh I wish I could have a way out.' And obviously I've got to be very neutral on the subject, but it's an increasing thing that they don't ask me about, they just mention. Increasingly I hear from relatives who have people who are in severe dementia states who are bedbound and mute etc, that their loved one really would not have liked this and is there is any way to cease their life, they would like that. But that's not a representative thing, that's just an anecdotal thing.

But I think the law would apply equally. I don't see particular, in any new legislation, I can't see it being any big issue for older people, apart from if you had living wills, advance directives, if that was catered for. And also lasting power of attorneys as well, because you can also now devolve decision making to an attorney for health and welfare decisions and whether that might be incorporated or tested out at some point under a lasting power of attorney under any new legislation would be interesting to see.

BY: And you don't feel that the higher predisposition of older folks to being depressed adds a complication at all?

MC: Yes, I can see, yes. I do this every day so I'm less worried about it, I mean, the average age of people, you're right, who do end their lives in Oregon - Oregon's really good because they have annual reports, the actual average median age is 72 - so you're right, it's the older person. I think it's more conceptually easier to understand for a physical disorder rather than just to say I'm not looking forward to when I'm 107 and I've lost my autonomy, and this, that and the other, I want to end it now. I can see it conceptually much easier in

any person, irrespective of age, having a terminal illness. And I wouldn't even go so far as to say, if you have a chronic psychiatric disorder, and I've seen many, many patients saying it's chronic, it's unbearable etc, but I think conceptually, in my personal view, that's slightly a step too far.

IB: Can I just ask a practical question? My question, really, is the question of coercion. It is more likely, excluding people with learning disabilities...to what degree is it easy for someone with your professional skill to understand whether what the patient is putting forward is their own opinion or the opinions that they are being, if you like, coerced is a big word, but led to? How easy is that?

MC: It can be quite difficult, and again, some research has suggested that people like myself find it difficult to make an assessment from just a one-off, meeting somebody on a one-off. History and context is everything, when you discuss this, absolutely everything. The more collateral history you can get...I know this thought that people who are in a care home, feel a burden to their families to the care home, money, etc., they can have that of their own volition. It's very difficult. I had a case a while back of a chap who was being financially abused by his carer who was his friend and we just didn't know, we'd met with the carer loads of times; if you want to be devious about it, you can be.

In general terms if you are aware and try and be alert and aware for it and about it then that helps tremendously. Context and history and getting collateral history is important. The person can obviously say, 'I don't want you to talk to anybody else'; they can say, 'you have to respect my confidentiality' if you thought they were making a reasonable decision. But it can be quite difficult; it can be difficult.

BY: Carole...

CD: We hear quite a bit about the issues generally, in society at the moment, of achieving adequate total care, shall we say - social and health care for people with chronic health needs. Do you see much

evidence of fear and anxiety in, particularly, the older population and patients, about whether their care needs will be adequately met?

MC: Well, I'll be honest, I know the social care budget is going to treble to £50-odd billion in due course, and the number of people with dementia in the country is going to hit a million in 10 / 12 years. I'll be honest, it's not something...I'm aware of it in wider terms, but it's not an issue that...

CD: It's not impacting on your day-to-day work?

MC: No.

CD: OK. I also just wanted to raise the issue, we know that the legislation that was previously suggested by Lord Joffe, and his more recent increased safeguards that he's recommended for any further legislation, do very much hold the line that, perhaps unfortunately, in order to be safe, it has to be just for people who have capacity at the time the process is followed through, and therefore he doesn't see it as something that necessarily can be anticipated beforehand, written into an advanced request (as opposed to an advanced decision to refuse treatment) or presumably, therefore, not written into what somebody with an LPA for health and social welfare decisions could enact on behalf of somebody. Do you think that's unfair? Do you think that's discriminating against the large body of people who are developing and are going to develop dementia in our society?

MC: Advance directives, I find, I've not come across a lot of them really, and in a sense you're right, they're advanced refusals. LPAs, I think somebody will, because it's interesting that they've come in a couple of years ago, and I've just done a review paper on it, and there's an increasing amount of case law from the Court of Protection on the wording of the documents, and they've revised the documents because they were too wordy and unwieldy and had a massive change. I think somebody would stick it in, because you put in the conditions.

I had a patient a few months ago whose son had made an LPA for health and welfare, and I said right well, your father's not in capacity now, I need to speak to you about certain medical decisions we need to make. And he said, well, I don't want to and...

CD: ...you accepted it!

MC: ...you should read the small print because I'm obliged to ask you and seek your opinion. I think under the conditions you can put some conditions on the form. Whether that would be acceptable by the Court of Protection...

CD: My point was that obviously Lord Joffe is suggesting that one of the safeguards has to be that the individual person has to have capacity at the time of seeking and proceeding with assisted dying, and therefore that would preclude that process of an LPA from being used to support...

MC: If you incorporated that into the legislation then yes. But if it wasn't I could quite see people trying it out, for sure.

SA: Can I come to the biology of ageing please? It's been hinted that there is more depression in old age, is that right?

MC: The rates per 100,000 are slightly higher, yes. And the rates of ECT that we use to treat depression, which is usually severe depression, are slightly higher in the older population than the younger population.

SA: And of course we can differentiate between old, older and very old, is there a kind of scale that as you get older and older, you will have a naturally higher propensity towards depression?

MC: I'm not sure of the exact numbers, but I know it keeps me very busy!

SA: With depression would come certain symptoms that would make it quite difficult to differentiate from physical changes going on as well I guess?

MC: The thing about old age psychiatry is that it's about physical symptoms interacting with psychiatric symptoms, which is for people like me, that's why we like it. But certainly people can present depression with physical symptoms and within older people that's not uncommon. You can present with pure physical symptoms when in actual fact is a depressive disorder that's underlying it, or...

SA: Well can I ask you about that, about physical symptoms? To what extent does the ability to suffer physical symptoms change, as people get older? I'm aware, for example, the data shows that older people report pain less. Are they actually experiencing pain less or is it just that we don't ask them? Because that's the conclusion from epidemiological studies: they have lower doses of painkillers, they report pain less – is that based on anything?

MC: I don't know specifically. I can think of –I cover 60 odd in-patients, there are a lot of them on pain relief, predominately for arthritic conditions. Again, I've got a skewed population I guess, I'm seeing a lot of people who are psychiatrically but also physically unwell. I'm not sure in broad terms.

SA: So in biological terms, are older people capable of suffering as much as younger people? There's no evidence that they intrinsically suffer less because of changes biologically, that go on with ageing?

MC: No I think its more to do with personality and coping mechanisms and strategies, and depending on...it's a whole host of things; it could be social, it depends how well socially supported they are, their family network, all sorts of things, how much they can or can't do still. It's difficult to pin down exactly but of course they can still suffer, for sure.

BY: Graeme, and then Denise.

GC: Yes, just two quick questions. The DPP guidelines suggest that healthcare professionals who get involved with assisted dying are more likely to be prosecuted than others, and we've heard evidence from some of the medical defence organisations, that they've been advising doctors not to enter into any discussions at all with

patients about end of life issues or assisted suicide. Has that impacted on your practice, at all? Or have you heard this brought up by any of your colleagues, with regard to patients facing end-of-life issues?

MC: No, I've not heard any colleagues mention it to me. As part of my role I provide, I help the team provide palliative care and end-of-life care to older people with chronic mental disorder in my unit, so we're quite used to talking about the Supportive Care Pathway or the Liverpool Care Pathway or whatever pathway people employ. It's quite normal for us to talk about it to patients and families.

As I said earlier, there are just some patients, I'm talking maybe a handful, who just give more of a throwaway comment about Dignitas etc, not anything meaningful, but I just hit a neutral note. I say, well I can't comment.

GC: On an individual case basis, these are anecdotes. I want to ask another related question, and that is that every day in your practice, patients are making major decisions on events that are life or death, such as consenting to or refusing treatment. Do you think that if there were to be legislation for assisted suicide, that the test for capacity would be higher in that situations than it would be for a common or garden, but still serious situations that are made in everyday clinical practice?

MC: I think if you use, say you didn't go through another new test but you used the Mental Capacity Act, and the Sections 1,2,3,4 there of the Mental Capacity Act, I think you would have to have a high threshold, I think almost automatically due to the seriousness of the decision being made. But one of the things that the editorial in the British Journal of Psychiatry mentions was about how high you would the put the bar, and somebody who is sympathetic to the person's degree of suffering or situation may inadvertently reduce that bar a little bit or be more sympathetic to it, and somebody who's completely opposed to it may set the bar higher.

But I think intrinsically, if you bolstered the, not so much the test of capacity, but if you had certain absolute bits that you were to test

for everybody, you would improve consistency; you would actually try and engage the patient in looking at alternatives. It's not just about 'I'm going to take this tablet and die', it's about making it more of a discussion. It needs to be pretty high, I think. The test of capacity for marriage and engaging in sexual relations is very low, technically, in legal terms, but it needs to be much, much higher I think. This is a serious decision and ultimately somebody's life is on the line.

GC: I noticed your comments on Oregon and the fact that psychiatric opinions are sought relatively infrequently. Yet in the current proposals from Lord Joffe, there's no requirement for psychiatric appeal unless there are concerns about capacity. And that leads again onto the Capacity Act, where there's a presumption in favour of capacity unless there's some evidence against. Is that compatible with your views, or do you think that there should there be a formal psychological or psychiatric assessment, were there to be legislation in favour of assisted dying?

MC: I do, I alluded to it earlier. In Oregon they've got a system where it's just referred to as and when. But you're doing it for that small number of people who have a major mental disorder that you could do something with, that is influencing their decision making abilities. I think it could be enacted.

The numbers of psychiatric referrals in Oregon are decreasing year by year, but they've got evidence to show that they're giving medication out to people who clearly have major depressive disorders. It doesn't automatically mean they lack capacity, but that should be something that can be potentially treatable. I agree with the patient representative earlier, absolutely, these people get sad, helpless, hopeless, but in psychiatric terms there is a way to measure mild, moderate.

GC: Would you suggest that were legislation to be enacted in this country, there ought to be a specific requirement for a psychiatric assessment? Unlike a requirement for major surgery, some patients who for major surgery with very limited likelihood of success, but

they make that decision without a psychiatric assessment for the most part. This would be specifically different.

MC: I think there's evidence from Oregon; they're suggesting that it could be rates of 1 in 5 patients. Again, the last annual report suggests that in 20 per cent of patients, there is a depressive disorder - I don't know if that's mild, moderate or severe - and in each of those cases the physician did not prescribe in Oregon. So there's clearly some evidence. I think there's ongoing research. I'm saying that I accept your point about surgery, but I'm saying for this group of patients there is evidence that there is a significant component of depression. I bet you that wouldn't be the same for people going for routine major surgery, I don't know. But all I can comment on is that in this group: there are rates of depression there and the evidence is suggesting...

BY: Conscious of time, but one last point from Stephen.

SD: When I was a medical student 30 years ago, I was taught, I won't say by who, but I was taught that there was what's now known as institutionalised discrimination in the medical profession, in terms of diagnosis as applied to different ethnic minority groups in relation to their mental health experience. For example, you'd get an over-diagnosis of schizophrenia in young black men. Is that still the case?

MC: In that specific example, I believe that to be the case. I'm not a general adult psychiatrist, but I believe there are over-representations in those groups.

SD: So applying that to mental capacity, is there a danger that mental capacity amongst different minority groups which are becoming more increasingly majority groups within the country, that they be served less favourably by judgements under the Mental Capacity Act?

MC: I wouldn't think so, I've not really thought of it. It's about application; if you apply the Mental Capacity Act and for example that person's not fluent in English - and I had a mental health tribunal recently where the person spoke a bit of English but it

wasn't their main language and there was a translator - if you apply the Mental Health Act then it shouldn't be discriminatory. Whether the people doing it do so properly, I don't know. And whether certain ethnic groups, for whatever cultural or religious reasons, do see this as good legislation or bad legislation, I don't know.

BY: Can we bring Denise in?

DP: I Just want to make a social care comment and then come on to a question, because I can see another Martin sitting at the back and he doesn't know I've got to go before he comes and answers questions. One, it's a minority of people that receive state funded social care; it's a very small minority of people who receive state funded social care. Yes, there have gone huge resources in a line in a budget book. It is un-ring fenced in local authorities who have to make 30 per cent of cuts over the next three years, frontloaded. Adult social care is the largest controllable budget of any council; they can't make the cuts without taking a lot out of that social care budget. Martin's grinning at the back, I just wanted to put that on the table, because there was the comment about social care resources.

We know that older people are discriminated against in the NHS; as the co-Chair of the NSF for Older People I have some knowledge of what that is. And people who come into contact with specialist services, like your own, get a better, more understanding deal. Does that mean there should be different sorts of safeguards for older people in other parts of the health service not in touch with specialist care if there were to be assisted dying in law? Because they quite often miss-out in proper cardiology care because it's not seen as necessary; miss-out on depression being picked up because it's not seen as a necessary, it's seen by physicians who aren't specialists as a consequence of old age, and therefore a request for an assisted death from somebody on a general ward, say, is a consequence of old age. Does that lead to specific safeguards for older people from the general melee?

MC: I understand what you're saying, but I don't see if we were to enact legislation you would make...I don't think that you could; you

couldn't positively discriminate on behalf of an older person. If they asked, again, they should be dealt with equally as somebody who is younger. Whether you can legislate for that, I don't know. Whether you should put in big red exclamation marks within any legislation for somebody who is over 65.

But I think that could become, you would probably have some code of practice or guidelines, those sort of things are built into the Mental Health Act and the Mental Capacity Act, a code of practice; that would be your vehicle, but I don't think you can make it-

DP: You can't legislate.

MC: No, I don't think so, no.

BY: Conscience of time, can we thank you both for the evidence you've given. If there's anything you would want to add, can you send it through to us? But thank you both very much for your incredibly wide-ranging and useful experience. Thank you.