THE FAMILY JUSTICE COUNCIL ANNUAL DEBATE

Motion:

Parental Autonomy in a Child's Best Interest, Should the Courts have the Final Say?

on

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Transcribed from the Audio Recording

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SIR JAMES MUNBY: Thank you all very much for being here. I think the papers you've got include CVs of our speakers and they hardly need introduction, I'm not going to waste your time or embarrass them by going into details. We have quite a good spread across the disciplines, we've got two very distinguished professors, we have and I hope Victoria will forgive me for this, somebody who if she wasn't quite so young would be very distinguished, but it would be unfair to label her with that word, but a very, very eminent barrister who has lots of experience in these cases and in that sense brings that perspective to bear. Last but certainly not least we have Matthew Parris, to describe him as a political journalist, columnist and broadcaster is very seriously to short change him, in other countries he'd probably be considered a public intellectual, but we are enormously grateful for all of them coming to share their thoughts and take up their time with us. The format is, each will speak for about 15 minutes and at about five past six, as long as we keep the time, the event will be thrown open for questions and comments, and that is as important a part of the process as the preceding part, and everybody who speaks will feature on the transcript. So, without more ado, Michael Freeman.

MICHAEL FREEMAN: Can you all hear me through the microphone? Good. Well, 15 minutes to discuss this subject is a tall order, writing a PhD on it would be a lot easier I think, it lends itself to a huge number of different issues. I went through some old papers of mine to see if I had anything on the subject and found I'd written three papers on this 20 or more years ago, but reading on through I discovered that the issues really hadn't changed at all, which means that I didn't have to write another one for today. Initially let me take apart the actual title we're talking about, autonomy in a child's best interest, should the courts have the final say? One could be pedantic about this and say that in the context of the English legal system that no-one ever has the final say because cases fit into a precedent system and get distinguished and explained away and developed in different directions a long time ago, but I don't think that's what I'm supposed to be doing, so I won't do that. But I will ask the question initially, if the courts didn't have the final say, who should have it? I won't develop this in much detail, maybe it's worth just trying to think who else could have the final say apart from the courts. An obvious person to have the final say would be the child himself, but of course most of the children we're going to be talking about are much too young to be able to make decision, but in the light of Gillick and the way in which children's rights has developed we shouldn't rule out the possibility that children could have the final say, particularly when they're a bit older than the ones that have been in most of the cases we've come across so far. Most people, if this question were put to them, would say the family should have the final say, by which they don't mean the family of course they mean the parents, and if we could talk about the parents there's a case for saying that the mother should have the final say rather than the father, if there's a difference between them, for very obvious reasons. The wider family could have the final say, a family group conference could have the final say, one could go on, I've written down about eight out of possible persons who could have the final say, it doesn't include me, but you could indeed do that as well. Social workers could have the final say. I'm not advocating these things I'm just trying to put the possibilities out. So, in saying should courts have the final say, we're not actually saying that only courts could have the final say, and by courts I read the state rather than courts. I read, should it be turned into a public issue rather than a private issue?

Now, let's start off by looking at the most obvious alternative to courts having the final say and that will be easy, leave the final say to parents. What is the problem with that, because that's the way certain things have been going or had been going at one stage? I have written again very recently on the case of Re T, the liver transplant case where you got the Court of Appeal very clearly saying the decision should be the decision of the parents, the mother and the child were one person said Lady Justice Butler-Sloss in Re T. What is the problem with parents having the final say? I think the Charlie Gard case, which I'm not going to be talking about because Victoria's going to be talking about it in some detail, illustrates very clearly why we shouldn't give parents the final say, because parents may think they're doing the best for their child but they're really doing their best for themselves, and they may not be able to separate their own interests from the child's best interests. It may well be the best interest of the child is to die. Let me say in that context, there is now a draft convention which actually gives the child the right to die, and Janusz Korczak, who I hope you've all heard of, should be the bedtime reading of all of you, when he drew up his declaration rights of a child in the 1920s, actually put at the head of the list the child had a right to die, and boy should Korczak have known about it, because he probably saw more children die than anyone in the whole of the last century. So one can't ignore the fact that the child has an important interest in these cases, and I stress this because it's too easy to gloss over the importance of children's rights and I want to try and put them firmly in the forefront of our discussion.

If we're talking about the dignity of children, if we're talking about respect for the rights of children then it becomes very important to see that these children should not be seen as, kind of, pawns, Butler-Sloss called them parcels to be moved around at will. The children need to be seen as persons in their own right and as persons capable of making decisions. Priscilla Alderson in her writing, she's a professor of education but also expert in children's rights, makes the point very strongly that children are capable of participating in decision-making processes about themselves at a very much earlier time than one would think possible. There's a wonderful article by an international journal of children's rights in which she talks about the way in which premature babies as young as six to nine months are capable of influencing the decision-making process. She talks about cases where, for example, when the nurse holds the baby the baby cries, give the baby to the mother and the baby immediately quietens down, now that is a small baby clearly saying something. So I won't make the point any more strongly than I've made it so far, but I would say one should not really rule out the child.

As I said and I'll cite it again, making the parents make the decisions is also not terribly satisfactory, separating their own interests and the interests of the child is something which many parents find it difficult to do. Why then should one move to courts and see the courts having the final say? I think the important points one needs to make initially here are that if you have courts making the decision you have the case argued for on behalf of the child by an expert barrister, you have that case tested out by a barrister on the other side, you have a neutral decision-maker, a judge, who is independent of both the parents and the child and who is capable of making the decision based on the evidence. So what I'm saying is, the difference between parents and a court is one uses their own intuition the other I think uses evidence, one uses reasons, uses a reasoned judgement, delivers a reasoned judgement, has to do so, whereas the parents don't have to give their reasons at all. Thirdly, the decision-maker is totally independent whereas the decision-maker is not independent if it's left to parents to do this.

So those are the two main alternatives to courts. Now, what is the value of courts making these decisions? Courts are confronted in these cases by what has been called a mortal choice, so life or death decision in most of these cases which can't be taken by the patient himself, arguably should devolve on those most intimate to his life not upon doctors or state institutions, but we've seen already that that's not going to work as well as it should. The very first case we had in this country, the only one I'll talk about briefly today was baby Alexandra in 1981, in a sense the decision was a hang-over from an era in which the un-impeached parent held sway where the

courts were convinced by the validity of pseudo-scientific notions like the blood tie and judges could refer to parents' rights as sacrosanct. Baby Alexandra was a case in which the court saved the life essentially of the child, the parents would have allowed her to die. She went into care because of state intervention, and when she was about nine months old her parents saw her in care and saw what a delightful young child she was and said they would like to have her. They wouldn't have been able to have, had it not been for state intervention and a court's decision.

Of course the cost of intervention may be too great, it's said it may undermine family stability and harmony, it may even polarise the family, by intervention the state may achieve nothing valuable and may destroy that which is. Of course we all accept that child rearing is a risk-taking enterprise, everyone has to take risks and you have to accept that if you have to take risks, you can make mistakes, because parental [inaudible] is considered important the argument for confining state intrusion in a family to cases of clear abuse is an obvious point to make, made very strongly in a number of American cases. American cases talk about the private realm of family life into which the state cannot enter. The case of the Amish in America makes the point very clearly. Amish parents wanted their children to leave school at 14 to learn on the farm, home schooling we'd call it today, and the courts said, if these children want to enter certain professions they won't be able to do so if they are deprived of their schooling, and the court intervened in that case.

We have to draw the line somewhere and in this country we have to draw the line at significant harm, but what is significant harm, what does it mean significant? Significant depends very much on context and context includes things like culture and religion and that is why the current debate is going on about male [sex and circumcision]; it's a difficult one to grasp. We've run out of time.

SIR JAMES MUNBY: Now, staying in the academy, Jonathan Herring.

JONATHAN HERRING: Thank you very much and good afternoon everyone. In opposing this motion I shall be arguing that courts do not and should not have the final say in cases where there's a dispute over how children should be treated. Although the motion is broadly worded I've been asked to particularly focus on medical treatment, I think we all have, and so I'll do that. In time honoured fashion I have three key points and my three arguments are self-standing, and so if you agree with any one of them then you should be persuaded that the motion should fail. I'll start by briefly summarising them.

First of all, I will argue that the court does not have the final say because it cannot force doctors or hospitals to provide treatment that the doctors and hospitals have not offered, and there are very good reasons for why that is so. So in short the courts simply do not have the power to have the final say even if they wanted to. Second, I will argue that the law recognises that parents have a discretion over how to raise children. That is important to ensure there is diversity within our culture and it avoids authoritarian government. It also acknowledges that the welfare of children and parents are intimately tied up together. So in short the courts should not have the final say because they must recognise the importance of parental discretion. Third, I will argue, that although the courts are well placed to be involved in disputes over the upbringing of children, and they can make very helpful contributions, their role should not be to have the final say. That is an unhelpful way to understand what judges do and should do when working with parents and medical professionals to fulfil their commitments.

So, looking at my first point in more detail: the limitations on the powers of the court. When a court hears a case about children it can only respond to the application before it. So in a medical case if the doctors propose treatment X the court only has the power to declare it lawful to provide treatment X or to decline to make any such declaration. The court has no power to force the doctors to provide treatment Y if that is not being offered. That is an extremely well established principle. To quote from the speech of Baroness Hale in the Aintree case, 'a patient

cannot order a doctor to give a particular form of treatment… the court's position is no different'. And there are very good reasons for that approach. It must be remembered the judge will normally have no particular expertise in medical matters and if there is no doctor who is willing to provide a particular treatment then the judge should be very wary of thinking that they know better than the medical profession. Perhaps even more significantly the court will not be familiar with the competing demands on NHS resources. The medical professionals will be aware of the strained resources facing the commissioning group and the hospital and the policies they have to operate under. They will know how providing expensive treatment to one patient may impact on what treatments can be offered to other patients. The court cannot know these competing factors. To compel a hospital to give a treatment which it has not proposed may have significant impacts on many other patients who are not represented in court and about which the judge will know nothing. Similarly the law protects the conscience of doctors. For a court to compel a medical professional to provide treatment that they do not think is in a patient's best interest would require a strong justification.

So quite properly the role of the courts in the context of medical cases is not as decision-maker as such but rather offering confirmation or authorisation for a decision that's been made by the medical team, it cannot be claimed then that the court has a final say in disputes over medical treatment; it's input is to saying yes or no to the options presented. Even if the court does approve the proposals from the doctors that is not the last say, the court can declare the treatment is lawful, but it cannot demand that it is done. In the Charlie Gard case the orders of Mr Justice Francis were declarations about whether the proposed conduct would be lawful and would be in Charlie's best interests. They did not require anyone to do anything. Lady Hale in dismissing the leave to appeal in the Gard case was absolutely correct to describe the case as one where, 'Hospitals were asking for guidance as to what treatment is or is not in the best interests of their patient'. So the court offers guidance and statements about what would be in a patient's interests but that is not the court having the final say.

I move onto my second point about parental discretion. Generally family law is structured to give parents a broad leeway in deciding how to raise their children. You may find that the number of sweets your next door neighbour gives their children outrageous, you may believe their policy on screen time absurd, you might think their willingness to allow their children to use foul language most shocking, but you would get nowhere if you sought to use court procedures to improve your neighbour's parenting skills. And it would be no different if you were a local authority social worke. Because unless the court is persuaded that the parents are causing their children significant harm the court will not interfere in the way that parents raise their children on the application of a third party. In short, parents are permitted to raise their children in a harmful way as long as that does not reach the level of significant harm. Mr Justice Baker in the Ashya King correctly summarised the law's approach, "It's a fundamental principle of family law in this jurisdiction that responsibility for making decisions about children rest with his parents. In most cases the parents are the best people to make decisions about a child, and the state whether it be court or other public authority has no business interfering with the exercise of parental responsibility unless the child is suffering or likely to suffer significant harm." And there are very good reasons for this approach. Society benefits from having a wide range of different kinds of people, diversity and religious belief, political belief, food preferences, support for sports teams, hobbies, ways of celebrating holidays are all part of what make life fun. The fact that we're different creates a diverse and flourishing society, a society in which there is a rulebook on how all children had to be raised would be an authoritarian society; it would also be a very boring one.

There is a further reason for showing deference to parents and that is as a society we do not have clearly decided views on a wide range of issues relating to children. Should children be raised as vegan or meat loving, should they be asleep by 8pm or learn the joys of going to bed early by trial and error, should they be raised to admire the works of Aristotle or Pewdiepie? Very often we must accept there is no wide-spread agreement on these issues. There's no expert a

judge can turn to to inform us on such matters. So, not surprisingly, the law takes the approach that the views of parents are as valid as anyone else's. Indeed, given that parents know their children better than anyone else and are going to have to implement and live with the decision that's made there are very good reasons for respecting their decision.

Now, it might be thought that those arguments apply less strongly in the context of medical cases, because in relation to health matters we do have an expert, the doctor, whose views on medical matters are not open to challenge. Further, there are no particular benefits to society in children receiving diverse standards of medical treatment; we want all children to receive the best medical treatment. So, it might be argued that although we should broadly respect the views of parents that is less true in medical cases. But I would disagree. Particularly in cases such as Charlie Gard and the complex medical cases, and that is because the welfare of a child is not simply a medical matter. Children's welfare must be broadly understood, the courts have told us, and not just in medical terms. There are emotional, religious, cultural, family factors all connected to medical treatment and the quality of life. How important is functional ability or cognitive capacity, how important is social interaction? The touch of a hand, the smile of a child, the slightest giggle, how are we to value such things in deciding whether a life is worth living. Those are not matters of medical expertise and it seems to me that quite rightly. A] matter of parental discretion can be brought into the equation in giving weight to those. Of course, like in other cases, there comes a point where a child is suffering significant harm and parental discretion wains. So, in summary, the law quite rightly acknowledges that parents have a broad discretion in making decisions about children. So courts cannot have the final say. They must respect and protect the important principle that, save where children are suffering significant harm, the parents are best placed, not the courts, to determine the welfare of the child.

My third and final point rests on the role of the court. The welfare of children in medical cases, whether there is a dispute or not, depends on partnership between the parents who have their unique insight, knowledge and expertise of the child, and the medical professionals who will have their training and understanding of medical matters. I suggest, in line with an argument developed by Jo Bridgeman, that legal intervention should be designed to support parents and carers in fulfilling their responsibilities. That means there should be duties on health care professionals and public authorities to work with parents, to join together their skills to promote the best result for the child. Of course in the vast majority of cases parents and medical professionals do cooperate together for the welfare of the child in partnership. Parents provide an invaluable source of information about the child. In medical cases especially children must be treated with an understanding of the relationships they live in, their quirkiness and their particular unique needs. The best results for the child will be produced where the parents, the family, the medical team, perhaps other professionals, join together in a common endeavour. Not only that, the relationship between the child and parent is central to the child's identity, it's a primary point of reference to the world. The wellbeing of children and parents are bound up together, for sick children the support and love of their parents is fundamental. For a child to receive medical treatment and not have their parents by their side offering support will greatly reduce the likelihood of that treatment working. Forcing parents to accept treatment they strongly oppose is likely to significantly impact on children's emotional wellbeing. Whether it is the parents preparing a child who's terrified before an operation, whether it's the parents encouraging the child through months of recuperation and therapy, or holding the child as they die, the child's welfare is tied up with the care of their parents and carers. So it's wrong to see these cases as some kind of tension between parental autonomy on the one hand and child welfare on the other. The lives and loves of parents and children are deeply entwined in complex ways.

In family law generally nowadays we seek to avoid bringing matters to court and the same approach should be used here. We should be doing what we can to facilitate a cooperative approach to respond to issues facing the children. The courts have an important role to play, they should be enabling discussion to take place, assisting the parties to reach agreement,

ensuring there is open communication, but this requires a sensitive intervention by the judiciary, something I think we often do see the courts doing in family cases and it's the everyday business of many family judges. Because the job they're engaged in is not a "court gets the final say" approach. The primary role of the court is facilitating communication, opening up options, helping the parties use mediation, alternative disputes. Ultimately it involves the court doing everything it can to ensure the courts don't have the final say.

So, I conclude with a summary of my three points. The first is the courts do not have the final say because they can only approve the options presented by the doctors. The second is that the courts quite rightly should recognise the broad discretion that we give families, parents know their children better than anyone else and are best placed to make decisions. And third, the role of the courts should not be to impose a solution on the parties but to facilitate and encourage and enable the parties to work together to find a solution that promotes the welfare of the child. In short, no, in cases of disputes over children courts should not have the final say. We need a much more nuanced approach that involves bringing the skills that the parents have, the skills of the doctors and the skills of the court together to encourage dialogue, interchange and cooperation. A solution that will promote the welfare of the child requires teamwork between all three of those groups, not one party having a final say. Thank you.

VICTORIA BUTLER COLE: So I'm speaking in support of the proposition that the courts should have the final say and I'm going to speak based on my experience of cases that I've been involved in, primarily. I just want to say at the outset that of course it's true that a court can't order a doctor to provide treatment and so on, but I do think it's really important that we think about these issues in terms of real life, because if you are a parent in one of these cases or a doctor, that's certainly how it feels. It feels as though the court's decision is going to determine what happens next and, much as someone could explain to you that in legal terms a declaration is simply asserting that something is lawful but not requiring it to happen, that isn't how it feels in real life.

When I was thinking about what I was going to say this evening I thought I would ask my own children for their perspectives on this proposition (I like to comply with the UN Convention on the Rights of the Child even at home) and I said to my children, what do you think, who should have the final say, should it be judges or should it be parents? My elder child who's nearly ten said "it should be the judges, mummy", I think probably because she thought I wouldn't have a job otherwise. My younger child who's eight said it should be the parents, and I said, "okay, what if you needed some treatment because you were sick and I didn't want you to have it because I didn't think it was very good treatment, but the doctor said if you didn't have it you were going to die?" And he said, "I still think the parents should decide, but not about me." In an odd sort of way I think that response of an eight-year-old child sort of does capture quite a lot of this, and I think for a lot of us our starting point would be, of course parents are the most important people in a child's life and of course they should be the ones to make these decisions. But there are cases where it seems to me it's almost impossible to argue that a parent's decision should stand, and those include cases that people are familiar with - a family who refuse a blood transfusion for religious reasons, a mother who is refusing her new-born baby to be given antiretroviral medicine even though she's HIV positive and if it's not given within the first three hours of life there's a much higher chance that her baby will have the virus, or a family who simply don't believe that their child has a brain tumour and so will not allow any scans or treatment to be provided and won't even open the door to the social workers or attend the court hearings, and so the idea that we can all work together to reach a consensual solution is just not possible.

There was a particularly difficult case in 2016 about an 11-year-old boy who was dying of cancer and his parents just did not believe that that was the case and the refusal of treatment extended to refusing him pain relief. Now, I defy anyone to come up with an argument in real life rather than on an academic basis that suggests that we should sanction a situation where parents can

refuse pain relief to a dying child. They might generally speaking be the best decision-makers, but there are clearly cases where I would say someone has got to be able to step in and make sure that the child's interests are properly protected. Now, you might say, well it's all very well to identify those cases, we can all agree about those, but what about the ones at the other end of the spectrum? In The Court of Appeal back in 1997 in a medical treatment case involving a child, Lord Justice Waite said this - it's an incredibly long sentence but I'm going to read it all anyway, because it seems to me that it just really conveys quite a lot of truth about these cases. So he said this, "It can only be said safely that there is a scale at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with the principles of child health and welfare widely accepted by the generality of mankind, and at the other end lie highly problematic cases where there's genuine scope for a difference of view between parent and judge. In both situations it's the duty of the judge to allow the court's own opinion to prevail in the perceived paramount interests of the child concerned, but in cases at the latter end of the scale there must be a likelihood, though never of course a certainty, that the greater the scope for genuine debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature." That description of the scale of cases and the fact that at one end it might be very obvious what the right answer seems to be, but at the other it will be much more difficult, seems to me clearly right.

That then leads to the next question -can you draw a line somewhere along that spectrum and invent a criterion or some way of separating out the easy cases where clearly the child's interests require some intervention, from the cases where parents' decisions should be allowed to stand. The difficulty with that, I think, is if you try and come up with a criterion like "significant harm" or "the decision that a reasonable parent would make" you're not really answering the question, you're just replacing one vague term, "best interests" or "welfare" or "paramount best interests of the child", with another slightly vague term, and the problem is just going to reappear somewhere else. An example of that is a case from 2007 in which Mr Justice Holman had to decide whether or not a bone marrow transplant should be authorised in respect of a young child whose parents did not want to consent to it, and the medical evidence was that the prospect of success for this child were 50/50, but without the bone marrow transplant the child would inevitably die. Now, the parents said, no, we don't consent to the bone marrow transplant. I'm not going to do it, but I imagine if I took a straw poll of people in this room as to whether that's a reasonable parental decision or not we probably wouldn't all agree with each other. What if the prospects were 30 percent or ten percent? You can't do this by identifying a percentage, clearly, and then if you read the judgement you discover that one of the reasons for the parents refusing was that they'd spent weeks in intensive care with their child while it received horribly painful treatment and suffered appalling side-effects as a result of all the interventions that it needed to keep it alive, and so having had that experience suddenly one looks at the refusal, I think, in a different light.

So, just to sort of come up with some easy point on this scale and say reasonable/unreasonable decisions, if the prospects of success are over 50 percent parents should agree to it, isn't going to help you. There's a criticism obviously made that if you don't do something like this, if you don't try and put some guidance in place about how courts or whether courts should intervene at various points along this spectrum is that you just get ad hoc decision making by judges who might or might not give the right weight to the various competing factors. I went back to my old medical law text book from 20 years ago which had a quote in it to this effect, saying that "the court is just determining the particular case, this atomises the legal approach and prevents the emergence of any general outlines of the boundaries of the proxy's power. If it's accepted that a court's role should offer such an outline the court's been slow to undertake this, and even when the court begins to try and set out this sort of guideline it's going to take a long time." I sort of looked back at that and thought, yes I imagine I wrote an essay at that point about how best

interest was a meaningless term, about how the courts had failed to give any guidance, and about how the whole system needed completely shaking up and starting again. 20 years later and having experience in some of the cases it's still right to say that general criteria haven't exactly been set out, attempts to identify thresholds for intervention or criteria which should be applied have been largely resisted because the courts know that trying to come up with these categories and trying to invent ways of making the many, many different issues that could crop up fit into those categories isn't going to work.

On the other hand, you can derive from the case law certain guidance about what is and isn't likely to happen. So, for example, it's incredibly unlikely that the court would sanction attempts at CPR on a child who was dying. It's an incredibly invasive and violent intervention on a child, usually doctors would refuse to offer it in any event, but it's fairly predictable that the court would say it didn't approve of that sort of intervention. In 2015 the Royal College of Paediatrics and Child Health tried to do this exercise, tried to go through the case law and tried to identify the sorts of cases where a court might say that continuing life sustaining treatment wasn't in a child's best interest, and they identify various categories where the child's life is limited in quantity or quality, and they go through different scenarios where it might well be the case that life sustaining treatment wouldn't be appropriate. And that guidance has been cited with approval by the courts including the Court of Appeal and it illustrates, I would say, one of the reasons why even a test like significant harm doesn't really help. If you imagine a child who is in intensive care, receiving what would otherwise be a painful intervention, such as ventilation, but who is sedated to an extent they can't feel the pain and so are barely conscious, is that child suffering significant harm? It's not feeling pain because it's been sedated to prevent the experience of pain, it's receiving a treatment which is keeping it alive, but if the child is dying anyway is that significant harm to be kept alive in that state for another few weeks? Futile treatment in a medical context seems to me doesn't really fall naturally within the meaning of the phrase significant harm.

The best interest tests, although widely stated and not subject to specific guidance or criteria, is perfectly capable of dealing with cases like the case of Charlie Gard. Charlie's case was not the first case where the courts have had to consider experimental treatment in relation to children, but it was unusual in that for Charlie conventional medicine had really nothing more that it could do, there was no other intervention being offered. It wasn't a case like the earlier case of Neon Roberts who was able to be given conventional treatment - surgery, radiotherapy, chemotherapy - which had an 80 percent prospect of success, but whose mother said, well actually I'd rather something else happened. So it's a different and very difficult and appalling set of circumstances for the family to be told, I'm afraid there is nothing else we can do. I went back to a case from 2002 in which the court looked at experimental treatment for two young people who had variant Creutzfeldt-Jakob disease, and at that time no-one really had any idea how to treat the condition or whether it was treatable at all, but there was experimental treatment being developed in Japan which had never been tested on humans, there was no peer reviewed literature, It was at an incredibly early stage, but there was nothing else on the horizon. And the relatives of the young people wanted this drug to be tried and the court agreed with them that that would be appropriate and the judge, Lady Justice Butler-Slows, said, that if you had to wait until there was enough scientific evidence and peer reviewed studies then no innovative work would ever be attempted, and "Where there is no alternative treatment available and the disease is progressive and fatal, it seems to me to be reasonable to consider experimental treatment with unknown benefits and risks, but without significant risks of increased suffering to the patient, in cases where there is some chance of benefit to the patient." So, I would say that that case is an example which shows that while the courts might have the final say that isn't to say that they're likely going to override the views of parents or that they can't cope with cases that raise these incredibly difficult judgements. Nor is there any reason to think that the courts are inherently unlikely to support innovative experimental or unusual treatments particularly in such desperate cases where there's nothing else that can be offered.

Why didn't the court then reach that conclusion in the case of Charlie Gard? Well, there were two very fundamental reasons which perhaps didn't come across in the press coverage of the case as much as they might have done. The first was that Charlie's condition by the time of the hearing was already so poor that his parents themselves agreed that it wouldn't be right to keep him alive in that state. They weren't saying, this quality of life is good enough and we would like to try this experimental treatment which had been the case in the Simms case. They were saying this quality of life is not good enough, but we are desperate because there is nothing else and we would like the opportunity to try this treatment. The other reason was that even the doctor offering the treatment was very unconvinced that it was going to have the slightest bit of benefit. In the original judgement from Mr Justice Francis there are two quotes from that doctor, who on the first day of the hearing had been given some updating information about Charlie's condition and had discussed it with his treating doctors, and the quotes were these from the doctor. "Seeing the documents this morning has been very helpful. I can understand the opinion that he's so severely affected by encephalopathy that any attempt at therapy would be futile. I agree that it's very unlikely that he will improve with that therapy, it's unlikely. Perhaps if I were there I would support the application [by the hospital to withdraw ventilation]. Not seeing the child, not seeing the progression, it's difficult for me to make an assessment." Now, it's easy to say parents in these cases can't separate their own interests from the child, they're too emotional, but imagine being those parents on the first day of the hearing and being told this is what the doctor in America has said. What prospect is there of you taking that on board, processing it, dealing with it in circumstances where for months you have been raising funds, fighting for the opportunity to give this treatment which you had been led to believe by the doctor in America, was actually going to lead to some benefit. I think that no-one could begin to criticise the parents for pursuing their views when that is the way in which information is given to them and the way in which the events unfold.

So, drawing all of that together, my argument is this, that a final arbiter is required in cases of dispute because parents can and do make decisions that are so obviously contrary to the interests of their children. While there are clear cases where that is the position, there are clearly also cases where it is much more difficult, but I don't see an easy way of inventing a criterion, a threshold or some other means of drawing a line along that spectrum. Having said that, that's not an excuse for the court and for other bodies not to try and extract guidance or general principles that can help people understand how these decisions are made, nor is it to say that parental choices should be lightly overridden, and particularly in these most desperate cases where there is nothing else that conventional medicine has to offer. But, as I say, the framework that we have, I would say, allows those sorts of difficult decisions to be taken.

The last thing I want to say is that it's very easy to jump to conclusions about a parent's refusal to consent to treatment that is being recommended by a doctor. There are so many reasons why parents might not agree with doctors, dogma might be part of it as Lord Justice Waite says, but so often there are so many other factors to do with the breakdown in communication, to do with careless language, to do with the simple things like the fact that a doctor cannot predict with accuracy exactly what is going to happen, and so when the doctor's predictions don't come true the ability of parents to believe what they say later on is automatically reduced. All of these are such complex and such subtle things that they really have no hope of being dealt with in a court hearing and so the recent exhortations to try mediation and other mechanisms of dispute resolution first have got to be right. While the court, I would say, does have to have the final say, that really should be a last resort because there are going to be other ways that are going to be so much better, like trying to understand how people have got to the positions they have reached and whether or not there is any scope for agreement between them. Thank you.

MATTHEW PARRIS: Well, I feel somewhat nervous because I'm a journalist fallen among lawyers and I'm dealing in an area which lawyers understand and where journalists' knowledge is

imperfect to say the least. I agreed with the nascently distinguished Victoria Butler Cole's pragmatic conclusions, I thought there was some tension between her conclusions and her earlier argument that it couldn't be a matter of percentages. Percentages is how human beings reason, probabilities is how human beings reason, and if one thought there was a one percent chance, let us say a one in a thousand chance that a medical treatment might help a child and 999 in a thousand that it wouldn't, I would give greater weight to the parents' passionate belief that it was going to land them all in hell, and the parents' sorrow and regret for the rest of their lives if the treatment were given and it failed. I think there's a difference between 50/50 and one in a thousand, and I think that's the way human beings reason.

Parental autonomy in a child's best interests, should the courts have the final say, in a sense if I'm to be slightly Jesuitical, of course the courts should have the final say, when a matter comes to court the court does have the final say and that's that. If you ask someone to adjudicate, they adjudicate. The question is, how much if at all should a court take into account, in having the final say, the beliefs or representations of the parents even when the court is not persuaded what the parents want is in the child's best interests. Now, if you're going to say hard cases make bad law, I might agree with you. If you're going to say that best interests of the child is simple, it's straightforward, everybody understands it and in practice it's worked very well, leave it alone, I might agree with you. But hard cases make bad law means that occasionally natural justice will not be served but should be overbalanced by the need for a clear rule to which everybody which is applicable in every case. I do think that natural justice is not always served by saying that the child's interests should be paramount. I don't think it was well served in the Charlie Gard case, the child was going to die anyway and quite quickly, it appears to me that the child was sedated or opiated or whatever the expression is, to the extent that it's quite unlikely that the child was suffering in the way that we would use that word, and it also appeared to me that for the rest of their lives now the parents are going to believe that a great injustice was done and the possibility of life for their child was taken away from them by the courts. In those circumstances I would have been very drawn to the conclusion that the child's best interests were not the only thing that should serve, that what the parents wanted might have been the best thing to do given that the child was doomed anyway.

Diamond will always scratch glass. It doesn't matter how blunt the diamond or how hard the glass, diamond will always scratch glass, glass can never scratch diamond however sharp the glass, however comparatively soft the diamond. I think that rules in Jurisprudence such as the child's best interests must always prevail are not of that kind. There is no interest to any particular party that must always prevail against any imaginable interest to any other party. I think that outside the law 99.999 percent of the cases of all parental decisions, parents do not always make their decisions only on the best interests of the child, a parent may for instance decide not to live in penury in order that a child should have a slightly better education for which they would pay, than the child would get for one that they would not pay. In a family the interests of all different members of the family are weighted against each other including the parents' interests, including the parents' own selfish interests sometimes. It's only when a case comes to court that suddenly this idea seems to arise that there is something as in scissors can't cut rock but can cut paper that this idea seems to arise that the best interests of the child must always prevail.

My solution, I'm not a lawyer, but I'm interested in law because I do see the appeal of the simplicity of the argument that the best interests of the child should prevail, is that we leave that rule in place, but that we accept that a child may have an interest, even an interest of which the child is unaware or unconscious, in the happiness, in the peace of mind of the child's parents. And so, just as we may suppose that a parent has the interests of a child, after the parent dies in very much to heart, I would like to think that little Charlie Gard though he in a sense never knew his parents and in a sense could not be said to have contemplated what was in their best interests, that that child perhaps had an interest in a rather abstract sense, an interest in the lives

of the parents and who knows perhaps the marriage of the parents being wrecked by something that was being proposed.

So, if I can just reprise, parental autonomy and the child's best interests, the court must have the final say, but I think that the court in reaching that final decision should take account of parents' strong beliefs and strong feelings, and if the interests of the child are not enormously damaged, if only very, very slightly or marginally damaged by going with a parental wish that the court may not think is in the best interests of the child, then I think the court should be free to judge that the parents' passionate beliefs might have some weight over what the court thinks are the best interests of the child.

SIR JAMES MUNBY: Well, that, if I may say so, demonstrates the advantage of not being a lawyer. Now, who is going to set the ball rolling in terms of a question or a comment? Yes?

DENISE LESTER: My name's Denise Lester, I'm a solicitor specialising in family law and I'm here as the organisation's Law Society, but I'm going to speak very personally and I'm going to direct my comments to Matthew and the panel, and the judges here. I was a bone marrow donor and there were considerable risks at the time to myself, the procedure was not so advanced as it is now, some 20-odd years ago, and I was an adult and my mother was firmly against me giving bone marrow. The percentage argument did not occur to me at all, it was for a stranger and it was a one chance shot and opportunity for them to have the right to life, and I say that against the context of these cases being the declaration in terms of medical consent or refusal, and the court's inherent jurisdiction, the role of the judges and the courts being the most difficult for the courts to deal with. I mean, they will deal with them on the evidence and adjudicate on the facts, but I took a leap of faith in terms of what I did. Parents come before the courts and hospitals come before the courts and I think it's an absolute credit to our judiciary, particularly when there was the international spotlight in the Charlie Gard case and Mr Justice Francis exercising complete compassion in his judgement, and I've not spoken to him about the case, but the media commentary, and I was behind the scenes being asked for press comment or press steer for various news outlets, that the decision-making process and the judicial management process was conducted so finely as it was. So I say, yes, the court should have the final decision, but be completely alive and acutely alive to the emotionality and the non-percentages arguments that may happen with reference to the bone marrow case, and other cases in particular. Thank you.

MATTHEW PARRIS: That's very persuasive and obviously in your own case it's completely persuasive because that's what persuaded you. I would be different; I would donate bone marrow or a kidney to perhaps a completely anonymous stranger if I was persuaded that that gave them a good chance of recovery. If I were not persuaded that it was a good chance but only an outside chance of recovery I would not donate a kidney or bone marrow.

DENISE LESTER: I entirely respect that.

SIR JAMES MUNBY: I think one of the things, as I understand it, which some research has demonstrated is that layman's views as to what the percentages are and what the percentages mean, particularly if you've got a two-stage analysis with two lots of percentages, it is often very wide of the mark. And the other comment, pretty personally comment I suspect than what we've just heard rather suggests this, that the kind of percentage which will be persuasive is a very personal, very individual matter, which depends on all sorts of factors of which the medical may be completely absent or the least important. Now, that of course doesn't make life any easier for the judges, because the judge in a sense is looking at the abstract reasonable parent, the abstract reasonable this, the best interests in a rather abstract sense.

UNIDENTIFIED SPEAKER: I'm a consultant child and adolescent psychiatrist and I think one of the things that might be worth thinking about is the fact that we have much more scientific

evidence on the nature of care giver relationships that are permanently damaging to the young child and his or her development; there's more to learn. I've worked with adolescents in secure welfare units, in young offender institutes and in secure psychiatric units, many of them have histories of trauma, neglect, abuse, multiple placements and multiple placement breakdowns, and these combine to produce young people who are both distressed, disturbed and many of them have a psychiatric disorder. We actually know that trauma, neglect and abuse, we now have evidence to say that it actually changes the young child's brain, and we also have some evidence that early intervention can actually alter and right those changes if the child has the right circumstances. Many of those parents are not really aware of the harm that they're causing; they've often experienced similar… had similar experiences themselves. Many of the young people say to me, at adolescence, why didn't we act sooner? So, I wonder whether the panel think that actually the court should have the final say earlier in these sorts of circumstances.

SIR JAMES MUNBY: Jonathan, you better go first on this one.

JONATHAN HERRING: I think you're right, often delay and leaving a child in a harmful situation is the very worst thing that can happen. But I think the difference for the law, I suppose, is coming up with one rule that will work for such a huge range of cases. So for every case where you might in retrospect look back and say, "if only we'd intervened earlier on we could have done so much good", there'll be another case where you can say, "oh thank goodness we didn't remove the child at that early point because the parents have got their lives sorted out and now the child is flourishing". Of course the real difficulty is that you know what was the right answer sometimes in retrospect. But the court are trying to make the decision at the particular moment in time, and so I don't think there's a right and ready answer to just say, "yes we should intervene early" or "we should intervene late". I think it's weighing up the information in the particular case very carefully in each particular situation.

VICTORIA BUTLER COLE: Often in a case, for example, where the child is dying of a progressive disease but is being ventilated in an intensive care unit, the case will come to court eventually and the doctors will say, we need to withdraw ventilation, and the parents will say, we don't want you to withdraw ventilation. When you then look back at the timeline the doctors will have reached that view months ago and have been trying to persuade the parents to agree with them to avoid having to go to court, but in the intervening period a child will have been receiving painful treatment that's ultimately futile, but from the best of motivations of trying to agree things without having a court process. There was some research published last year, I think, or possibly earlier this year which suggested that children were routinely receiving painful and futile treatments in intensive care units because it took parents much longer to come to terms with the fact that treatment was futile than it did the doctors who had seen it before in numerous patients, and that one of the things that triggered the parents' acceptance often was a physical change in the child's presentation which gave them some evidence they could see that the doctors were right and that the child was deteriorating. The authors concluded that the upshot of this was that there should be much earlier intervention because children were receiving painful, futile treatment for too long, but while I think I would agree that steps should have been taken sooner to try and facilitate agreement a bit more enthusiastically than just having repeated multidisciplinary team meetings every fortnight - perhaps with specialist mediators involved, some more sort of active steps. Equally the idea that you would go to court at the outset without having given families a chance to come to terms with what must just be the most unimaginably upsetting thought, seems to me that would be a mistake. That's why I think you shouldn't leave these things to just take months and months and then come to court, and then insist that everything's dealt with overnight because that's equally unfair to the families. Some form of intervention earlier that perhaps involves external expertise in resolving these sorts of conflicts would definitely be a good idea.

SIR JAMES MUNBY: It's a question of balance and perspective in an area whether one's talking about the care case situation or medical situation, where the right answer, whatever they mean

by that, is much more obvious in retrospect than it was at the time. There's a tension between… and it's exactly the same in the care case where one tries to shore up for far too long the parent who sadly in the end they can't do it, and the medical case. Partly it's a process issue and these decisions are so important, not least in the fact that they're invading family life that there's got to be a fair process and you can't just rush the judgement. And on the other hand an understandable hope in the one case that if you go on long enough the parents will be able to improve to keep the child and in the other case that a consensus will break up and the parents will agree that it's futile to go on. I think that the problem is that for very human reasons in both those contexts, too often if judged by the benefit of hindsight, professionals allow their compassion, their desire to achieve consensus to override a more hard-edged professional view, and partly, I think, it's a question of education, and if more professionals were more aware of the research which you've just read and the research you've just referred to and bore that in mind, it might just move the professional approach away from the compassionate end of the spectrum, not to a ruthless end of the spectrum but to a more balanced view. Recognising, going back to your example, that there is a trade-off which is almost measurable in terms of graphs and pictures and scans of the brain between the time you're spending in an effort to improve things and the time which is being taken up with the child on a downward trajectory, and these things are terribly, terribly difficult.

In my experience they come across the entire spectrum of family law and in a sense it's not that different between the case you've raised which is in the care context and the case which has been raised here in the medical context. But it's a terrible thing, so often the medical hindsight makes very clear what wasn't clear at the time, and I've always realised this as a judge, by the time the case comes to court partly because you are completely detached, you're looking at the matter objectively, partly because you've got the benefit of adversarial argument, things are very clear indeed and very often you can pinpoint the point in the past when something should have been done and wasn't, but that's the advantage which the judge has and it's an advantage which is denied to the professionals on the ground at the time. In a sense, each side is going to have to be reflective of and accepting of that difference in perspective.

MICHAEL FREEMAN: One very brief observation and that is how important it is to take account of the child's sense of time, the child's sense of time is very different from an adult's sense of time.

MATTHEW PARRIS: I agree with Sir James, particularly the use of the word trade-off, could I offer you a journalist's perspective on the question of should we intervene earlier, either in social work cases or in medical cases? You can't win if you intervene late you'll get the Daily Mail headline, this appalling thing was going on and nobody stepped in to stop it, and if you intervene early you'll get the headline in the Daily Mail that the authorities took my child away, or the doctors killed my child when my child had a chance of survival, so it is a trade-off and it is a matter of balance.

LUCY CLARK: Hello, I'm Lucy Clark. I'm a solicitor at Penningtons Manches. My question was, if the parents are considered to be the best decision-makers, what should the approach be when the views of those parents are not aligned?

JONATHAN HERRING: I think my response to that is why do we want the parents to be the decision-maker? And I think my answer to that is we want the parents to be the decision-maker because they'll make the decision which is in the best interest of the child. So I'd look to see if there's any way we could tell whether one of those parents was better positioned to make the decision in the child's welfare. was there one parent who knew the child better, had spent more time, spent more caring time with the child, in which case I'd prefer their views. Otherwise, I suppose you wouldn't have a way of telling between them, if they were equally involved in the child's life.

SIR JAMES MUNBY: One of the problems is, and in a sense your question has brought it out, we tend to conceptualise these cases into two classes, one a case where the state is intervening, either in the care case context or in the medical context, where one thinks of it, one conceptualises, one truly one thinks it's the state on one side, that state, the doctors and social workers on one side and on the other side the family and the parents. The other family context which is what family law used to call private law is where the family has fallen out between themselves, and where the task of the judge, again applying the same test, against the background of parental discord or dispute between parents and grandparents is to answer the same question. In the one context we treat it as obvious and elementary and axiomatic, that the family is all at loggerheads internally, in the other we tend to fall too easily into the trap of assuming that the family is monolithic. When we have as it were, a potential crossover between the two, as judges, one finds it rather difficult and I suspect a lot of the discussion we're having today is actually affected by the assumptions one make as one's making as to the kind of context in which the parental decision-making is in question.

MATTHEW PARRIS: If the adversarial system works in the criminal courts and the counsel for the defence makes the best case they can, and the counsel for the prosecution the best case they can, perhaps it might even be useful if one parent makes the best case he can and the other parent makes the best case she can, and one adjudicates between the two.

SIR JAMES MUNBY: That, after all, is what we do every day of the week in private law cases where there's no guardian, the child isn't a party, it's the clash of argument in dispute between the mother and the father out of which emerges, somehow by some miraculous process, a judicial decision as to what's in the best interests of the child.

JANE CRAIG: Jane Craig, I'm a partner at Penningtons Manches private law, I do private law. Jonathan, you said, I actually made a note of it because I was so annoyed when you said it, you said, well what should happen is these cases should be resolved by teamwork, parents, doctors, the courts all working together, and I thought that's a wonderful, wonderful idea, but as Lucy said you're going to get a situation, very often in my experience in the private law context, where they don't, and in that context someone has to make a decision. As a solicitor practicing in private law, please, I'd like the court to make a clear decision because by the time it gets to court everyone's done everything they can to get the parents to reach an agreement, usually, they've tried mediation, therapy, you name it, and we need the court to make a decision for the benefit of the child.

JONATHAN HERRING: Yes, but it would be false to see it as just the court making the decision, because prior to that the doctors decided which treatments are going to be appropriate. So you've already had input into the outcome that's going to be produced. A very important part of that has been restricted and decided by what the doctors think are suitable available treatments. So just to see it as the courts saying, "right, this is the answer", is actually a false presentation of what's going on. You've got the doctors have come in and said, well these are the options you've got, you've got the parents who will be bringing in their particular knowledge and understanding of the child and their particular relationships, and then now you've got the judge being involved. So the actual outcome is a product of three different decision-makers combining. It will look like the judge saying, "right this is the answer", but if you look behind it and the contributions that have fed in, it's from all three of the parties that actually lead to the outcome. It might be declared by the court but it's made by the involvement of all three of the parties.

JANE CRAIG: Well, I think all three of the parties are offering different alternatives and I think what the judge is doing is making a final decision about which of those alternatives is in the best interests of the child. But anyway, I've said enough.

JONATHAN HERRING: But the judge can't, the judge—

SIR JAMES MUNBY: Well, as between available options.

JONATHAN HERRING: Yes, between available options, yes.

SIR JAMES MUNBY: But, you see, even in a private law case all the judge can do in a pure private law case where there are no third parties involved, no doctors or anything involved, the judge undoubtedly has the final say, in the sense the judge makes an order, but the judge's final say only runs until the child is 18. I constantly find myself saying in court, you, mum and dad, are going to be with us for another 50 years probably, this child is going to be with us for another 80 years, I can regulate the next six years if you insist I do, but beyond that and the reality in that context is that parental decision-making, parental attitudes, family attitudes are determinative in the long run. So even in that context which might seem to be a very pure situation of the judge having the final word, in one sense yes, but actually the final word in that kind of terrible private law dispute turns on what the mother and the father and the by then 25-year-old child are doing.

SHARON FLEMING: Good evening, my name is Sharon Fleming and I'm from Rotherham Borough Council, so I'm coming here from a local authority perspective and I'm very honoured to be sat before you today. I did have a few minutes with Mr Freeman before the session began and interestingly he'd said he'd written an article back in 1976 about sex abuse and it wasn't published because somebody said it doesn't exist. Clearly it does, and we're now in a position where we're trying to move forward. So, my question is to Ms Butler Cole, in terms of moving forward after the Charlie Gard case, I understand that the local authority was not a party to the proceedings. In a case where there may be something moving forward similar to Charlie Gard where one might argue that threshold is met, would your view be for the local authority to actually step in and make the application, which would obviously, had it have happened in Charlie Gard's case, the parents would have received legal aid?

VICTORIA BUTLER COLE: There are cases where local authorities are party to the proceedings even though it's a medical treatment issue, and they might be cases where, for example, there really is a real issue about the child's wellbeing generally and they may need to be moved into foster care in order to receive the treatment that the parents don't consent to, but which will save their lives. There are cases where local authorities are involved at the moment. I think I would find it very difficult to characterise the parents of Charlie Gard as in any way parents who were neglecting their child or who were subjecting him to significant harm (in the care context). They were parents who had done everything they could to find out if there was something they could do to help their desperately sick child. It turned out that when all of the evidence was available that the thing which they thought was going to help wasn't going to help. I think for completely understandable reasons they weren't able to accept that, but then to characterise that as a sort of local authority/social, services issue - you're not proper people to be parents, it's just a huge leap, I think. I think that where parents disagree with doctors those medical issues should be sorted out by the court if that really has to happen, if it can't be resolved through mediation, but that that shouldn't slip into a view generally about their ability to look after their child unless it really has to, and there will be cases where it really has to because the child is actually not being looked after properly as well as the medical dispute, that's just one facet of parenting that really is of such a degree or nature that there does need to be some further intervention.

I would hope that following Charlie's case that there won't be lots of similar cases ... in that I hope that where those sorts of disagreements arise people will stop and think much sooner, what other expertise could we bring in to try and stop this from developing into a full-scale conflict or stand-off, and we'll try and do more to avoid reaching that point. Now, as always, with the benefit of hindsight it's very easy to look back and say, well, perhaps we could have done this, could have

done that a different time, I don't think that's necessarily a productive thing to do, but I think for future cases there are probably lessons about how to try and stop… divert things from this path at an early stage wherever possible. I might be naively optimistic, but I do think that there is reason to think that can happen, but I do also think that often it will require intervention from someone who isn't the hospital, that you can have as many meetings as you like where you try and persuade parents that your evidence is right, but where those relationships are breaking down, where the trust is going or has gone, I think expertise is needed, specific expertise and external input is probably needed to try and help everyone in those situations to actually talk to each other and understand each other's perspectives.

SIR JAMES MUNBY: It is very difficult this question. As it happens I've had two examples of this myself in recent years, one is a reported case called baby Jake, and that first came to the court as a medical emergency, and there were parallel care proceedings going on. Having resolved the medical case the question then arose as to what should happen to the care proceedings. In a sense, partly because I deliberately tried to manufacture this, we managed to avoid ever coming to a decision on the care proceedings before the child died, which was going to be pretty soon. It actually crystallised in this very difficult question, the hospital was saying the child didn't need to be in hospital. It needed a level of care and commitment, or particular kind of care, which the local authority was questioning the parents would be able to deliver or would wish to deliver, the parents in fact had learning difficulties, and it crystallised eventually in terms of this issue where they found specialist foster carers who could look after the child who lived, I think, 60 or 70 miles away from where the parents were. The parents had been in hospital with the child every day and the crunch was, you can have contact three times a week two hours a day, as it were, and how can you actually, in a way which meets the child's needs and in terms of common humanity to these devoted parents who need to be with the child every day, how can you actually make that work? In fact the resolution in that case was the hospital stretched the point, the child, I think, remained in hospital where the parents were semi-resident, they were there all the time and I never had to come to a decision because the child died. A very difficult case.

Then there was a contingency plan to place the child in a very, very good residential establishment which was in some nice old place in the middle of nowhere, and I said, well, how are the parents going to get from A to B? Oh, well there's a local bus service. So I said, all right, how close to the institution is the bus stop? Oh it's walking distance. So I said, well, how far? Well, it's about a mile and a half down country lanes. And I said, well it's high summer now that sounds quite attractive, but are you really suggesting this mother and father, even if you're paying for it, should be expected to travel on a bus then walk down an unlit country lane for a mile and a half, get real, and are you prepared to pay taxis? All these things eventually disappeared, but those are very, very real questions, and as it happens I'm about to shut up, watch this space because I'm about to give judgement in a similar case where it began off as a medical case, it then went into formal care proceedings, the care judge made a care order, that was appealed successfully, the Court of Appeal set that aside, remitted to me for final hearing, and it all then eventually sorted itself out where the local authority on reflection decided that there were not grounds for seeking a care order. Again, the issue was a concern that the parents couldn't be relied upon for whatever reason actually to support the child in the treatment he needed, and that child is, as a result of the outcome, with the parents where it's always been, and I've heard nothing in the last couple of months since I had the case to suggest anything's gone wrong. So I'm afraid, in a sense, it's a very real issue you raise, and it's one which actually the courts have had to grapple with, but there's no definitive answer to it, and it's not one I envy any local authority having to face. In my book, but perhaps I'm just sentimental, it does very much come down to very practical things. Are you saying, I say to counsel, are you saying that it is in the child's best interest these devoted parents shouldn't be able to see the child every day? I'm not saying that. Well, are you prepared to pay for the taxis every day for the next five years? Oh well, I'll have to take instructions. And that's the reality at the sharp edge and it's not very obvious what the answers are.

In a sense, going back to the teamwork, it may be impermissible for the judicial approach, but in a sense one is mediating, not using the word technically, one is actually trying to manoeuvre people, get people to talk, get people to discuss, and the judge is an important part of that process, and out of that process comes a consensus, even if the consensus is simply, well, we'll adjourn the matter generally, or well, on reflection we won't proceed. So in that sense the judge is facilitating an outcome but the judge is not actually taking the final decision.

SARAH FAIRBAIRN: I make a similar point. My name's Sarah, I'm from Cambridge Family Mediation Service. We believe in alternative disputes and to take Jonathan's example, there are parents who will break down contact arrangements because they cannot agree whether their children can eat three bags of sweets on a weekend or six bags of sweets on a weekend, or whether there's a drop-off at half past six or at quarter to seven. In those circumstances, as hard as we try to bring them round, due to high conflict or the parents' mental health after the distress of the separation, we need to let the judge make the final decision, and the matter sometimes in a few cases will have to go back to court.

SIR JAMES MUNBY: There is another solution. I apologise if I seem to be talking an awful lot, that is for the judge to refuse to make a decision, I mean, there are high conflict cases and Mr Justice Hedley who's now retired, very wise man, he had a high conflict case involving highly articulate middle-class parents and the eventual issue was, they agreed the handover point should be Clapham Junction Station, they couldn't agree which platform it should be, and he said, I refuse to decide this. He said if the consequence is that this poor, frightened little boy of six stands shivering in the wet in the middle of winter on the wrong platform at Clapham Junction that is your fault and your responsibility. By the way, he said, I think I'm right in saying the train to Brighton, which is where dad lived, goes from platform whatever it is, and I have an idea that on platform whatever it is, there's a café, so go away and think about it. I've done it myself, simply refusing to decide and saying, I'm sorry, you are the parents, you have parental responsibility, you have got to decide and the court is not going to decide. It's a high risk strategy. Now, whether that analytically is the court having the final say or whether not, I just don't know.

MICHAEL LEWKOWICZ: Michael Lewkowicz. I'm from the charity Families Need Fathers, so I suppose I'm here representing a stakeholder group, essentially in private law. A few people have already made the kind of points which I would have made as well, but I suppose one of them was about delay, and I know there's a lot of lawyers here and lawyers tend to think about things in rather legal purist terms, but that assumes that everybody's got reasonable access to the law and reasonable representation under the law, and what happens when there are delays which actually in themselves cause significant harm to the child, as happens so often in private family law cases, and what happens when having been through that lengthy and arduous and emotional and stressful process through the courts, and finally a decision is made, that the judge makes that decision and says, this is what should happen, but in family law that's not the end of it, as very frequently or certainly not infrequently orders are not complied with and hardly any are ever enforced. Is it not making a nonsense of the courts, whilst we're sort of here debating the purity of legal argument and Michael Freeman talked about having barristers on either side, but these days in family law hardly ever a barrister on both sides it's becoming a rarity, sometimes it's only on one side. In some cases if there are allegations made, which are not infrequent in family cases, only the accusing side gets qualified for legal aid, the accused does not, what does that do to our confidence in justice and in law itself when the case can't be made equally and when having made it, a decision is made and isn't then enforced in any way?

JONATHAN HERRING: I think in response I'd pick up perhaps the point that Sir James was just making that we've got to realise there are limits to what the law can do. I think there's a sort of image that somehow the law can make everything well. The judge has a magic wand and can say, "bumph, there we are" and that's the answer. 'm not sure in many of these high conflict

cases that enforcing a contact order or other orders will actually produce any long-term solution for the parties. There is sometimes a case where you just have to say, “this has all gone horribly wrong, this is a horrible situation, but actually it can’t be mended, or at least the law has reached the limits of what it can do.”

MICHAEL LEWKOWICZ: Are the parents being mis-sold something having spent tens of thousands of pounds on each side?

JONATHAN HERRING: Well, maybe, I think if the image that going to the family court is going to make everything wonderful and sort everything out, and if anyone thinks that’s what happens in the family courts then perhaps they are being mis-sold something.

MICHAEL LEWKOWICZ: It could be a medical situation—

JONATHAN HERRING: Absolutely.

MICHAEL LEWKOWICZ: —if parents don’t necessarily agree on a course of treatment whether they’re together or apart, so a decision has to be made in the end, and in the case of a medical treatment it will almost certainly happen based on a decision of the court. I think it’s, forgive me, but I think it feels a little bit complacent to say, well, actually we have this system, this is the only system that’s available to you, you then avail yourself of it, you spend your life savings on it and then somebody says, well I’m not going to do anything more because it just feels a bit difficult, when actually there’s many things that could be done both in policy and in legislation, in different options and routes for enforcement, different interventions. An awful lot of money is spent both by the state and by the parties on trying to get some assistance, but perhaps they’re getting the wrong assistance, but that’s the only one that is available to them at the moment.

SIR JAMES MUNBY: If I can conceptualise the point, and you’ll probably not find this helpful or not tackling the real problem. The point you’ve made, one point you’ve made is that when we talk about the judge having the final say, that assumes complacently that what the judge says then turns into reality, and in a medical case it does because once the judge has had the say there’s somebody out there who will implement the judicial decision, namely the doctors. Of course in private law we don’t have that and therefore, again this is all context, if you think about this in terms of medical cases it’s very easy to say, well, the judge ought to have and does have the final say because you’re assuming, probably correctly, that what the judge says then becomes the reality. Of course in a private law context it doesn’t necessarily happen, but Matthew I think you want—

MICHAEL LEWKOWICZ: The judge may well have made a finding of significant harm taking place and in one situation action is taken to avoid the significant harm continuing, and in the other scenario action is not taken to avoid the significant harm continuing.

IMOGEN GOOLD: Imogen Goold, University of Oxford. I wanted to ask a question about futility, so one of the concepts that has quite a lot of traction in the Charlie Gard case is the notion of futility, and you’ve been talking about how it’s difficult to determine what are best interests, what is significant harm. I think the same is true of futility, because in the case Dr Aya is saying, there’s a very small chance, but there is some chance it might work, particularly later on, and in the philosophical issue, Julian Savulescu said, well, look, if there’s any chance that a treatment might work and the life that it precipitates is better than death, then logically you ought to take that chance. So my question is, in a case like this who should really be deciding what we mean by futility, is it purely a medical question, is that a question for the judges, or is that again a question for parents?

VICTORIA BUTLER COLE: I think it's difficult to respond to that question with the specific example of the Charlie Gard case, because the point at which the court decided or accepted the medical evidence that treatment was futile was the point at which the American doctor was saying, it wasn't going to work. And whether he later said something different or not, I think, one has to be a little bit sceptical about the context in which that was said and then the later evidence that was given, having actually read the medical records and seen Charlie. But having said that I think that that is one of the reasons why the case generated so much adverse comment, is that if it were right that this treatment did have a chance of working then why wouldn't you go for it, and it was, I think, difficult for people to understand how a judge could conclude that you wouldn't give something a go if it had a chance of working. If that had been the finding then that would have been a criticism that people could have made, but it wasn't the finding, but all of that was very much lost in translation partly because the way in which the matter had been in the public domain prior to the judge making a decision, and of course, the fact that people don't read long court judgements, understandably. Even when there are 50 journalists in court they can't tweet every single piece of relevant evidence, even if they want to.

But in relation to the question about futility there's guidance in the Supreme Court case of Aintree in relation to adults about what futility means, which was the subject of debate between the court, the doctors in that case and also the Intensive Care Society who intervened. And there clearly is a medical understanding of futility which, I think, the Supreme Court were essentially adopting, largely, that if the treatment can't benefit the person in any way then you can safely call it futile. That's much easier in a case where someone is dying of a progressive deteriorating disease on a ventilator, you know what is happening, you've seen it before, you know that there is no way in which that can help, and I think the futility arguments are often easier to understand in relation to intensive care units where the doctors will say to you, well, intensive care isn't a treatment, intensive care is a mechanism of keeping people alive while you try and treat them. So if you can't treat them, the things you're doing to them in intensive care become futile because they were never themselves medical treatments aimed at benefitting the patient, other than, to keep them alive while we tried to fix the problem. But I agree that when you get into other territory of experimental treatment where, like in the vCJD case where it was very difficult to put a percentage on the prospect of that treatment having any beneficial effect at all, but no-one will say it's zero percent chance because no-one knows, that you do get into that much more difficult territory where you're just trying to form a judgment about whether or not a tiny chance is a chance worth taking.

SIR JAMES MUNBY: Any comment from the academy on the concept of futility?

MICHAEL FREEMAN: All I was going to say was, futility's got a number of different meanings, and I think they often tend to be conflated.

SIR JAMES MUNBY: I've always thought and I was told by the Court of Appeal in the Burke case I was wrong to think this, that there is advantage in the use of the word futility, because it has more content and is more comprehensible to people than this rather vacuous expression best interests which mean everything and mean nothing. Futility does have some kind of connotation, it can't be a benchmark or a test but it gives you the flavour of what it is you're trying to grasp, and in that sense it's a more useful word, perhaps, than best interest, and it seems to have come back into fashion now following Aintree. It wasn't my word, it was first used 25 years ago by Lord Justice Taylor in a case I did at the bar and it has the attraction that it's a word which has some kind of connotation, meaning for people, although as Michael says it may mean many different things, but it's also a word which is used by doctors. So I have some… it has some use as long as one doesn't become enslaved with the idea it is the concept and you then get little satellite jurisprudence and satellite medical issue as to, is something futile or not, but that's a very purely personal reason.

MICHAEL FREEMAN: I think the advantage of looking at best interest as opposed to futility is that best interests concentrates on the person, whereas futility can take into account all sorts of other things as well, it could even be economic.

JONATHAN HERRING: So, you could imagine a case, couldn't you, where giving treatment to someone would not be medically beneficial, so in a medical sense it might be futile, but it might give them emotional benefits to feel that they're trying something, or a broad understanding of best interests, it might be in their best interests to receive this.

SIR JAMES MUNBY: In a sense this goes all the way back to the very first question, if you have a case of bone marrow donation where the donor is a child, how does one say that it's in the child's best interest to subject the child to a process which I understand can still be painful, and so on and so forth?

DENISE LESTER: Well, that would have been the extension, had I been younger there would have been that… there was that conflict and the court would have had to have decided it as a pre-issue, and it's not a hypothetical issue, it could happen, certainly with a child who's competent, you could have that type of litigation and matter before the court.

SIR JAMES MUNBY: Well, it has happened and I was in the case at the bar where the donor was an adult who lacked capacity, and the question was since it was axiomatic, it had to be in the best interests of the donor, how was it in the donor's best interests to have herself subjected to a process which she wouldn't have understood for the benefit of somebody she was dimly aware of but would not have been able to conceptualise as being her sister. By quite a lot of mental gymnastics on the part of both the expert and the lawyers they managed to persuade the judge that it was in the donor's best interest and the process went ahead and very sadly didn't work.

KYAH MUFTI: Hi, my name is Kyah, I'm a pupil barrister, and I was just curious about the situation of a slightly older child who's able to have a view or at least be able to articulate a view, and whether the various members of the panel attributed a different weight perhaps to that relative to parents and relative to doctors, and any examples that you've experienced. Thank you.

VICTORIA BUTLER COLE: So, obviously it's difficult to make general statements but certainly if a child's able to express their own view about something then that, you would think, is going to be of huge significance. Interestingly in the case I mentioned about the child who was dying of advanced cancer whose parents were refusing, his mother was refusing consent to pain relief for him, in fact the judgement that was given said, it's clearly in the child's best interests to be given pain relief, but if the child is really actively refusing it then don't go in heavy handed, this child's in the last weeks or months of his life and his relationship with his parents is so strong that he has inevitably taken on board some of their views and perspectives, and so to just sort of barge in saying, no you've got to have this treatment, even though it's in your best interests, you would take a much more sensitive approach to it. So the court does try and reflect the child's preferences even where the conclusion is that actually something else is in the child's best interests.

SIR JAMES MUNBY: It's the great unresolved conundrum in English law. It's said to be determined by two judgements of Lord Donaldson 25 years ago which were heavily criticised at the time and have been criticised ever since, but if you have a very stark, in a sense pure problem, of a 17-year-old suffering from a life-threatening condition which is treatable, and the 17-year-old whether for [inaudible] reasons is saying, I will not agree to this, what do you do? Do you go through the motions of saying, well, I've listened very carefully to what you say, I give all proper weight to what you're saying, but… or do you actually give effect to what they're saying?

That is not a medical question, it's scarcely even a legal question, it's a question of doing what you ought to do, and what's the answer? Jonathan, what would your answer be?

JONATHAN HERRING: I think I would say we assess the capacity of the person, whatever age they are: do they have sufficient understanding of all of the relevant issues, are they able to weigh those up and reach a decision using their own values free from independent, improper outside influence? If they are, if they've got the maturity to make that decision it doesn't matter if they're 50, 20 or 16 or 12, we should respect their view based on their capacity not on the somewhat arbitrary factor of what age they are.

MICHAEL FREEMAN: It's really a question of the minutes of [inaudible].

VICTORIA BUTLER COLE: And it's so different, isn't it, because I think we could all sign up to that statement, and then I think back to asking my eight year old what he thinks about my talk, and think, well if he's 17 and refusing life sustaining treatment I don't want a judge to say that he can go ahead and do that. I'm pretty sure I'd be saying, no absolutely not, forget the Human Rights Act, forget the United Nations, get on with it, he's only 17, he couldn't possibly make a sensible decision, I think that's what so difficult about it.

MICHAEL FREEMAN: Would you say that if he was 27 as well?

VICTORIA BUTLER COLE: I probably would, yes.

SIR JAMES MUNBY: Can I, and these are both real cases which actually illustrate the problem, in 1997 I appeared in front of Mr Justice Ward as he then was when I was at the bar, and the question which was partly a legal question was, could a wardship judge order a 17-year-old anorexic to be detained and put in plaster for the purpose of saving her life and enabling her to be treated? The point about putting her in plaster was to stop her sticking her fingers down her throat and vomiting. The judge said, yes, it was possible and the judge made an order, it's in the law reports and we all went home. Some years earlier I'd been in front of Mr Justice Ward as he then was in the Jehovah's Witness case of the 15½-year-old boy who was refusing on religious grounds a blood transfusion, and Mr Justice Ward in that case ordered that he should have a blood transfusion and he did, we all went home. Now, the point I'm about to come to is what happened after that. The boy in the Jehovah's Witness case, it was leukaemia, and most unfortunately, unexpectedly the leukaemia came back when he was 19 or 20 and he refused the blood transfusion and he died. What does one draw from that, I'm not quite sure.

The other case which was in 1997 you may remember, I think in about 2002, Mr Justice Johnson had a case where the question was whether, I think, a 15-year-old girl should have a heart transplant, where without the heart transplant she'd die and where the med school evidence was with a heart transplant there was a very high degree of likelihood that she would survive for a long time. The judge ordered her to have the heart transplant and this caused a lot of disquiet, because she was 15, she was articulate and she'd thought about it. The punch line is, I happened to be watching television that night and some young woman in her early 20s appeared on the box talking about the heart transplant case, and I suddenly realised who it was, I'd last seen her five years before weighing about six stone, she was the anorexic, and she had been completely cured and she looked the picture of health. What she said was, she said, I was in the situation some years ago, same kind of age as this girl and mercifully there was a judge who in effect said, I'm not prepared to listen to this nonsense from a young child who doesn't know what they're doing, and her punch line was, thank god there are judges who will actually stop us being silly.

MICHAEL FREEMAN: I think the important point about that case was Johnson's judgement was directed in child-friendly language.

SIR JAMES MUNBY: Yes, indeed. So if you contrast the two cases the moral you draw from one case is you would steam ahead, and do what needs to be done whatever the child says, whatever the child's capacity. The moral you might draw from the other case is rather different, and it just so happens we know the aftermath of those two cases so we can actually contrast what was done with what happened. What the moral is one draws from all that I'm not quite sure, but it does make me queasy about the idea which Jonathan's been proposing, that if you've got the 16-year-old who's completely articulate, completely understands all the issues, has capacity and all the rest of it, and you let them take the decision which leads to their death, of course one never knows on that hypothesis, but the questions arise, well, what would they think five years down the line if they were still alive?

MICHAEL FREEMAN: Will our attitudes be different when 16-year-olds have a vote?

JONATHAN HERRING: My response with the anorexic would be, that's exactly the same problem if they're 22. It's not a problem of age, the problem there is trying to determine whether it really is their genuine wishes. If there's a feeling that the condition has impacted upon their decision-making. So I don't think that's an age issue, that's a, do we have a good test for capacity issue?

SIR JAMES MUNBY: Except the law actually says there is an age policy, it's a bright line—

JONATHAN HERRING: It does, it does.

SARAH: I wondered if I might just share a few thoughts about the use of mediation, I've been working as a mediator in and around the NHS for the last five years and I think one of the really striking things in the Charlie Gard judgement was to say, should we be using mediation more often? One of the questions I would ask is, what do we mean by mediation and should we be using it much more widely? And just to share a couple of observations, we've been running a project in a children's hospital in London for the last four years now, and I think one of the things that I've really noticed is that the window of opportunity before things start to feel like a battle ground is relatively narrow, and I think there is huge value, as we've tried to do, in trying to in-bed the use of mediation skills in their widest possible sense into medical teams so that they become more able to recognise the symptoms, if you like, or the beginnings of a conflict, right at the ground level before the situation begins to escalate. I'm very struck often when conflicts arise and I'm asked to intervene that both sides, all sides, parents and doctors, will say they're just not listening to me, and one of the things I think mediation does and mediation skills do is to help people to listen to each other and to keep an eye on what the big picture is, and so often it's the big picture, the whole story that gets lost.

So I think, I'm encouraged in one way to think that their mediation skills and mediation can achieve a lot, but I think we have to think very carefully about what sort of cases are best fitted to mediation, because equally I'm concerned by the fact that sometimes situations have arisen and in recent cases where actually there seems to be no room for manoeuvre, no mediatable ground between the family on the one hand and the medical teams on the other. Fuelled by social media families are often feeling that they need to gear up for a fight, that they must fight, and I think that's a very precarious position to be in, and curiously I've begun to think thank goodness we do have the courts. But I think we need to think much more carefully about what we do on the ground to help doctors and parents communicate better and I think there's a lot of good and positive work that can be done there.

SIR JAMES MUNBY: Victoria, what's your take on that point?

VICTORIA BUTLER COLE: Yes, I completely agree because I have experience of cases where mediation has happened and has been successful even where I've been told at the outset that one or both sides have got completely fixed positions that they will not shift from, and it turns out they haven't after a day of mediation. So because I have experience of it working repeatedly in medical treatment disputes I'm an enormous fan of it, equally there clearly are cases where it's going to be impossible to reach agreement and the more delay there is the worse it is for everyone. I think it's a reflection of what I was saying earlier, about getting in at an earlier stage, not necessarily with lawyers and mediation in a kind of legal sense, but just in getting those discussions to try and divert things much sooner. I also think that the social media and that side of things is going to make things like mediation much more difficult. If you've raised £600,000 on this crowd funding site in order to do X, how can you go to a mediation process, the outcome of which might be you have to give all the money back and say you're not going to do it. I mean, you've sort of pushed yourself into a corner which it's going to be very difficult to come out of, so I think that's why Sarah's right that if you can start this at a much earlier stage in the process it's going to be more likely to be successful.

SIR JAMES MUNBY: I'm very struck by what you said about, there's a narrow window, because it's exactly what we see in intractable private law disputes, there's a narrow window of opportunity and a lot of the sadness and difficulties of those cases, is it's usually after much easier to identify what the window was than at the time. If one has one of these terrible cases and one crawls through the history you can identify that was the optimum moment and probably the only moment, it's quite a narrow window, and the great difficulty, certainly in that context, and I suspect it may be the same in the medical context, is identifying at the time on the ground that you are in or entering the critical window. Any process, I'm always reluctant to sign up to the word mediation, [it seems to me] any kind of process mediation in the more colloquial general sense must be a good thing, if only to sort of narrow the issues. Wasn't it Churchill who was alleged to have said that jaw-jaw was better than war-war and there's a terrible truth in that, and we need more of this.

MICHAEL FREEMAN: It was Hailsham.

SIR JAMES MUNBY: It was Hailsham, I defer! It's good to hear that this is now becoming part of medical practice and I suspect there's probably an educative process within the NHS that this is the sort of thing which I suspect may be practised more in the great teaching hospitals and one needs to spread the message generally that this kind of approach is valuable.

Now, it is seven o'clock. Have we actually run out of questions? I see nobody with their hand up so I think that brings proceedings to a close. Thank you all very much for coming and listening so attentively. Thank you very much indeed for raising some very searching and interesting questions, and thank you most of all to the members of the panel who've come and exposed themselves, not merely to the rigours of preparation and presentation but to your searching questions. So in different ways, thank you all very much indeed.
