



Northern Ireland  
Assembly

Committee for Health, Social Services and  
Public Safety

# OFFICIAL REPORT (Hansard)

Human Transplantation Bill:  
Opt for Life and  
Royal College of Physicians of Edinburgh

6 January 2016

# NORTHERN IRELAND ASSEMBLY

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**Members present for all or part of the proceedings:**

Ms Maeve McLaughlin (Chairperson)  
Mr Kieran McCarthy  
Ms Rosaleen McCorley  
Mr Michael McGimpsey  
Mr Daithí McKay  
Mr Fearghal McKinney  
Mr Gary Middleton

**Witnesses:**

Mr Joe Brolly	Opt for Life
Dr Mike Jones	Royal College of Physicians of Edinburgh

**The Chairperson (Ms Maeve McLaughlin):** You are very welcome. We are pleased that you had the time to attend today.

We have with us Mr Joe Brolly, the co-chair of Opt for Life, and Dr Mike Jones, the director of standards at the Royal College of Physicians of Edinburgh. Mike, do you want to go first, or does Joe want to? Is there any battle that needs to take place?

**Dr Mike Jones (Royal College of Physicians of Edinburgh):** I think that the original order had Joe down to go first, so I am happy with that.

**The Chairperson (Ms Maeve McLaughlin):** OK. We will take both presentations, and then we will open the meeting up to comments or questions from Committee members. I hand over to Mr Brolly.

**Mr Joe Brolly (Opt for Life):** There are three important things about any organ donation system. The first is that there is good infrastructure. We have excellent infrastructure in Northern Ireland, and I will give you an illustration of that. When we began the campaign three years ago — I am a living donor, obviously — it achieved a lot of celebrity at the time, and we have worked closely with the unit. I will give you an idea of how good the infrastructure is and how well the unit is run. Three years ago, we were languishing towards the bottom of the European tables for living donations of kidneys. As of two weeks ago, we are number one in the world. We have the number one living donor unit in the world in the Northern Ireland, run by Aisling Courtney, Tim Brown and so on. There is very good will here. There is a generous community and a good communitarian spirit.

The three important things about any organ donation system are good infrastructure, very good public awareness and, least important, an organ donation Act. It is important that any organ donation Act be

simple, unthreatening and non-divisive. If you have an organ donation Act that is simple, it is easy to publicise. What we have always supported is a very simple organ donation Act that reflects reality. When we brought the issue to the First Ministers three years ago, neither of them understood the current system. They both thought that, if you are on the organ donor register, your organs will be donated, so they were stunned to learn that it depends entirely on family consent or that of people in a qualifying relationship; that is, a civil partner, a gay partner, a long-standing friend if you have no immediate family, a brother, a sister and so on. They must be there to consent in writing; otherwise, the organs will never be retrieved.

There are a couple of bottom lines that the Committee has to understand. We have met the entire intensive care community. The 15 lead intensive care consultants met us at the offices of Shane Finnegan from Opt for Life. They all said exactly the same thing: "In no circumstances, regardless of any donation law, will we ever retrieve organs unless there is a qualifying person there to consent to that". In no circumstances. You can easily see why. We have always pushed for a simple, family consent or qualifying relationship consent Act, with an opt-out so that people who have a strong conviction that they do not want to donate have that facility.

Let me start on a positive note: the Bill can be saved with amendment. The problem with the Bill as it stands is that it is very confusing. I do not think that Stephen Hawking could understand the Bill. I am a lawyer. It is what I do; it is my daily bread. The Bill is impossible to understand. Confusing is bad, not good. The Bill also creates division. It has clearly been heavily cut and pasted from the Welsh Act. When the draftsman came to draft what I think I can say was Jo-Anne Dobson's vision and our vision — what we had always supported — he virtually recreated the Welsh Act, save for the one provision in the Welsh Act that actually has presumed consent. That is where the person is not on an organ donor register, where there is no appointee and where organs will be taken unless a family member objects. That is how it is described in the Welsh legislation. That is the only part that has been taken out of our legislation.

I imagine that all members have a copy of the Bill in front of them. It would be easy to amend it to make it something simple, easy to understand and easily publicised. Let me say what I mean by that. If you have an Act that, first, accords with the reality — no doubt, the good doctor will tell you this — that organs will never be retrieved without express consent at the time that they are about to be retrieved. If you have an Act that accords with that and states, "In all circumstances, this protects the rights of children and the vulnerable", you do not have to worry about endless sections on all of that.

The current system is that, in all circumstances, people in the qualifying relationship make the decision, unless the person has opted out. At all times and in all circumstances, the family makes the decision. I use "family" in the loosest, most modern sense. When you have an Act like that, you have something that is easy to publicise. All that you say is, "Have you had the conversation? Have the conversation". The intensive care unit (ICU) consultants have told us that the most important thing is that, if a family has come in and has had the conversation at any time before death, it is likely to say yes. The family will say, "Yes. We have talked about it, and we think that it is a good thing". That is what countries such as Croatia and Spain have achieved. They have achieved simple, easy-to-understand messages and created public awareness and a totally unthreatening system. Part and parcel of an unthreatening system is the removal of any suggestion of deeming consent or presuming consent.

Table 1 is at clause 3. I assume that all members know what a qualifying relationship is and have looked at the definition of "qualifying relationships" at the back of the Bill. It is basically family consent or wider family consent. Table 1 states that, if the person is alive, the person's consent is sufficient. That is how it is at the moment. You get the very rare case — maybe one in 500 or one in 600 — where the person is alive but knows that they are going to die and are able to fill out the consent forms with the specialist nurses and doctors. That happens on very rare occasions. Would it be one in 1,000 cases or one in 500?

**Dr Jones:** It is very rare. Possibly even less than that.

**Mr Brolly:** Possibly even less than that. That is fine as it is, because it accords with morality and current practice. Case 1 is fine.

Case 2 refers to people being on the organ donor register and states that the person's consent is sufficient. All that has to be done there is for it to be amended to state:

*"those in a qualifying relationship to consent".*

ICU doctors will never remove organs because someone is on the organ donor register. Let me give you an easy explanation for that. Some of you will have children. Say that your 18-year-old daughter, God forbid, is in an accident and is on the organ donor register. You arrive at the hospital, but the operation has already taken place and her organs have been retrieved. You are devastated, and you go to the press and say, "We did not want this". Then 'The Stephen Nolan Show' picks it up, and that is the end of organ donation for a decade. Organ donation is a family gift, a sacred thing and something very special. There was a mistake made in England at Alder Hey where organs were retrieved from a deceased and used for scientific experimentation. When that was discovered, according to the Organ Donation Taskforce in the UK, it set back the cause of organ donation by a decade. For those reasons, in no circumstances can an Act allow organs to be taken without family consent in the wider sense. What if, for example, your child is on the organ donor register and you, going in as a grieving mother, simply cannot face the prospect of the organs being retrieved and say no, and the response is, "Sorry, the law allows us to do this, and we are going to do it"? That is never going to happen. The ICU consultants have made it absolutely clear to us that it will not happen in any circumstances. Case 2 does not accord with the reality — it is meaningless — so the table can be amended to include qualifying relationships.

Case 3 is fine. It will be a very rare occurrence. The Welsh already have experience of the system. Say that you do not want to be an organ donor or are not sure, you can appoint someone to make the decision for you. You may say, "I do not want to think about this during my lifetime, but I will appoint someone to make the decision for me". That will happen in very rare and unusual circumstances, but it is fine. There is nothing particularly objectionable about it. If someone wants to do that in a one-in-a-million case, it is fine. That case could be left in.

The next case in the table is fine as well. Where you cannot find an appointee or get in contact with the appointee, a person in a qualifying relationship makes the decision.

The only thing that is required is to add a fifth case, and that would be to say that, if none of the above applies, the consent of a person in a qualifying relationship with the person is required. If the person is alive and able to sign the consent form, that is fine. If the person has died and is on the organ donation register or not on it, the family or the qualifying person decides. Case 3 is fine as it is. Case 4 is fine as it is, but it could do with an additional case 5 to state that, if none of the above applies and there are no appointees, the consent of a person in a qualifying relationship with the person is the express consent.

Clause 4 on deemed consent and deceased adults is where the problem arises. This is what you might call a Frankenstein Bill, in that it makes no sense because it has been cut and pasted from the Welsh Act. Clause 4(1) states:

*"Where this section applies, consent is deemed for a transplantation activity".*

The phrase "deemed consent" is completely meaningless; it is a total misnomer. It will scare people, because there is no deemed consent in the Bill, for these reasons. Clause 4(2) states:

*"But deemed consent is only effective if—*

*(a) such efforts as are reasonable ... have been made to contact persons who stood in a qualifying relationship with the person immediately before death".*

Paragraph (a) is not disjunctive. Paragraphs (a), (b) and (c) are conjunctive as a matter of statutory interpretation. Paragraph (a) is immediately rendered meaningless by (b), which states:

*"a person ... who stood in a qualifying relationship with the person immediately before death affirms that the person would not have objected to that transplantation activity".*

I do not really know what "affirms" means, but anyway. Paragraph (c) states:

*"has reasonable grounds for believing that the person would not have objected to that transplantation activity."*

Clause 4 has to go altogether if table 1 is amended as I have suggested to include a case 5 that states that, if none of the above applies, the family must consent. That deals with all of that. You will see that clause 4 is just a confusing way of saying that, if cases 1 to 4 in table 1 do not apply, the family makes the decision. It is entirely confusing. It is totally convoluted. I mean this sincerely: I had to read this 10 times and look really carefully at it to make head or tail of it. Clause 4 could come out altogether.

Clause 5 on excepted adults is probably not required at all. It is very difficult to understand. Let me give you an example of what the draftsman has done. This is total gobbledygook. Maybe the doctor can understand this better than I can. Clause 5(3)(b) states that an "excepted adult" means:

*"an adult who has died and who for a significant period before dying lacked capacity to understand the notion that consent to transplantation activities can be deemed to be given."*

Can you understand what that means? Honestly, I mean this sincerely: I do not understand what it means. I do not think that anyone could understand what it means. Therefore, we would all qualify as excepted adults — as vulnerable adults. In any event, the definition of a "significant period" in subsection (4):

*"means such a significantly long period as to lead a reasonable person to conclude that it would be inappropriate for consent to be deemed to be given."*

Again, that comes from the Welsh legislation, but it is meaningless: there is no presumed consent in the Bill. However, because the heading "deemed consent" appears and the word "deemed" has been used and so on and language borrowed, it creates an entirely confusing picture. Clause 5 is not required.

Clause 3 would deal with everything if amended. You would have the live person who consents in person before dying, which is very unusual, and a person on the organ donor register or not on the register for whom the family makes the decision. If the person has an appointee, the appointee makes the decision. If the appointee cannot be found, the family makes the decision. That would be simple, easy to understand and unthreatening.

A real anomaly occurs in clause 5 — the excepted adults clause — which, again, recreates the Welsh section. Go to table 2 in clause 5. I say sincerely and, no doubt, she would say as well that this was not Mrs Dobson's intention. It certainly was not our intention when we lobbied all the parties and received almost unanimous support for the idea of a simple family consent Act with an opt-out facility for people who, for conscience reasons, did not want to be considered for organ donation after death. Table 2 states that in a case in which:

*"A decision of the excepted adult to consent, or not to consent, was in force",*

what applies is the excepted adult's consent. A vulnerable adult who cannot understand the meaning of the legislation can consent in person by signing the documentation. That, of course, is never going to happen. That consent would never be taken in the ICU. Again, we say that that is meaningless. We would revert to what it should be, which is that the people in the qualifying relationship make the decision. That would take care of the rights of the vulnerable, children and so on.

The same situation exists — again, it has just been transcribed from Welsh case law — for children's express consent in clause 6. Table 3 states that when:

*"The child is alive and case 2 does not apply",*

the child's consent is sufficient. According to subsection (2), if a child is on the organ donor register, that consent is sufficient. Again, that is nonsensical. It does not accord with reality and is never going to happen.

We say that the Bill can readily be saved by making the simple amendments that I have suggested at clause 3 to add a case 5. It would then be described as a family consent Act, where the qualifying relationships are set out, and the only exception to that would be where people have gone on a register and said that they do not wish to be considered for organ donation after death.

I spent last night going through the Bill with the team from Belfast City Hospital. The clinicians will not support or operate the Bill in its current format in any circumstances — that is unanimous — for the reasons that I have outlined.

I should give you the up-to-date figures so that you are aware of where we are. I want to say this to you: organ donation is, as I have learnt, a very fragile ecosystem. There has to be great sensitivity around it. There has to be great harmony around it. There has to be great public awareness. One of the three things that I have talked to you about is good infrastructure. We have a brilliant infrastructure. It is arguably the best in the world after some of the highly resourced American hospitals. You know that, as of two weeks ago, we are the number one living donor country in the world. The second thing is good public awareness, while the third — the least important — is an organ donation Act. The most important thing about having an organ donation Act is that it facilitates debate and discussion. We get on the radio and in the newspapers. We can talk about it. The public representatives become aware of it, and you are all conversant with it. The crucial factor in all of that, however, is that the Act has to be simple, easy to understand and easy to publicise. In Spanish schools, they say, "Have you had the conversation? Have the conversation".

It is easy to amend the Bill to make it work. Where we are at the moment with organ donation is here: we have come up to 25 donors per million of the population from a low base of about 16 in 2008 and 14 in 2007. That is because of the excellent infrastructure, including the specialist nurses. We have had a good boost in the past three years because there has been a lot of discussion about the issue. There have been a lot of newspaper stories. Newspapers are alert to someone who has just donated a kidney or a child who has survived because of a liver transplant. That is all good. Parliament is talking about it, and that is all good. However, for us to get from 24 donors per million of the population to the Spanish situation of 36 per million of the population, we need good awareness, and that means an Act that is easy to publicise and is not confusing.

I have spoken to the party leaders, and they are all in favour of legislation so long as it is that harmonious, simple and easy-to-understand Act. It would be easy to do that with the amendments that we have proposed today, and then the Bill will work. Tim Brown, to my mind, has the leading mind of any clinician whom I have ever met, and I have met them all over the world in the past three years. He says that we can get to 35 or 36 donors per million of the population but not with the Bill in its current format. He says that we can get there with the family consent Bill as proposed. In essence, I am just a messenger. Obviously, I believe passionately in organ donation. I do not want to do anything that will upset the cause of organ donation, and I think that the last thing that is required is a Bill such as this that is confusing and will cause division and debate. It is very difficult to understand, and there will be huge arguments over the idea of deemed consent, which is meaningless but can easily be removed. I will open it up if anyone has questions.

**The Chairperson (Ms Maeve McLaughlin):** Thank you for that, Joe. We will take both presentations before we open up the meeting.

**Mr Brolly:** Sorry.

**Dr Jones:** Thank you very much for the invitation to present to this august body. The college, although it has a somewhat parochial name, in that it identifies itself as belonging to Edinburgh, is an international college and, indeed, has almost 500 fellows and members in Northern Ireland. Therefore, it views the legislation as extremely important and has contributed to the Welsh and the Scottish consideration of changes to organ donation, because we welcome the attempts to increase organ donation, recognising that that is being done internationally. We should learn from the international evidence. My colleague has considered the legal aspects, and I will consider the clinical aspects, and, on that basis, we support the soft opt-out.

We have to remember, of course, that presumed consent, as defined in the Bill, is not everything. Although, as I think the Committee has heard, studies from a number of countries have shown that association with presumed consent has increased rates of donation, it is fair to say that there is also evidence to suggest that the increase in donation is due not to the legislation itself but to other changes. We can also look at that fact that, where changes in the law have occurred, they have caused detriment to transplantation. The Committee needs to be concerned about that. In 1997, Brazil introduced a hard opt-out, and, within a year, the provision had to be repealed, on the basis that the population thought that this was association with bodysnatching. In 1992 in France, although they had a soft opt-out, because a cornea was taken from a donor who had given limited consent and the

family then decided that that was more than it had consented to, the publicity associated with that had detrimental effects on organ donation.

Whatever is done has to be done carefully. I share the concerns that the media have an enormous potential both for harm and, hopefully, good in promoting better organ donation. The media influence significantly the three things that I believe are more important than legislation. Societal attitudes are very important, as is education on the benefit of organ donation. Certainly important is the benefit to those who are dying from their conditions or are being kept alive by other methods of treatment that are extremely substandard compared with transplantation.

The Spanish experience has already been mentioned, but an improved clinical infrastructure with enthusiasm for transplantation is vital. Rafael Matesanz was the lead for the Spanish human transplant organisation change. He says that the law change had virtually no effect. The law change in Spain came in 1979. The transplant coordination, however, came in 1989, and it was at that point that Spain saw the massive increase in donation that they now experience. The 36 per million of population has already been mentioned, and it has been better than that. It is part of society in Spain. We have also heard that the Spanish have it discussed in schools. It is an accepted part of being in Spain. It is popularised. It is ensured that everybody knows about it.

There are examples in the UK of enthusiastic individuals promoting transplantation and donation rates. Before a certain surgeon retired, Aberdeen, as a centre, had the highest donation rates, simply because that surgeon had made sure that every time a donation occurred it was publicised by the local press to ensure that the local population knew of the benefits. It is very much about using the media to ensure that people know the benefits of transplantation.

We need to be clear about what we mean by a soft opt-out. The fellows and members who have responded to the consultation that I bring to you have concerns that, if the family's wishes are not taken into consideration, the loss of the solace that can be associated with the altruistic gift of organ donation will be tremendous. Again, the adverse publicity associated with that could lead to a significant detriment, when the aim is to improve organ donation.

We had concerns about certain clauses. Some of those concerns have already been heard by the Committee, but I will reiterate them. Clause 8, which brings in living donation for the first time, complicates the Bill considerably. Although the college initially said that there were no human rights issues associated with the Bill, as soon as we start looking at living donation, we see that there are particular human rights issues involved, especially for those who lack capacity. That causes complication in the Bill. It is fair to say that the Human Tissue Act covers much of this, and including it in the Bill complicates it unnecessarily when you already have legislation that works quite well.

On clause 6, the 18-year-old is undoubtedly legally responsible, but so are 16-year-olds in other aspects of life. We feel that a 16-year-old has the ability to express a wish or otherwise. For those who are younger, there are immediate possibilities that they could have an opt-in. If we are truly getting out to the schools and making sure that children are aware of the benefit of transplantation, in the horrific event that such individuals die early, if they have heard about transplantation and have expressed a wish, as some children do, there should be no reason why, with parental guidance, someone who is 12 or older could not be given the right to opt in as a potential organ donor. Clause 9 is about other individuals who can be appointed representatives. This was part of the consultation. Where appointed representatives are being considered, if there is also family involved and there is disagreement between what the appointed representative says and what the family may wish for the potential donor, there are potential issues with the Human Rights Act 1998. People's ability to have concerns expressed through the courts because of differences of opinion between the appointed representative and, potentially, a family member should be considered in advance of it occurring.

In summary, from the college's point of view, we feel that there is a need to continue to improve organ donation. The improved infrastructure that we have seen, with better nursing staff who are dedicated to transplant coordination, has led to improved rates of donation in the UK as a whole. There remain concerns about the ability for patients who have had a catastrophic brain event and have been ventilated but may not be kept in intensive care because of the pressures on intensive care beds. The infrastructure associated with the need to support potential donors while a donation is being clinically sorted, which takes a matter of hours to days, is also part of the requirement for improving organ donation. It is within the remit of the Northern Ireland Assembly to ensure that there are adequate resources available for the whole of organ donation to ensure that maximum organ donation can occur.

Thank you for your time.

**The Chairperson (Ms Maeve McLaughlin):** Thank you both. I have a question for both of you. In the course of our evidence we have heard that, as it is drafted, the legislation is unhelpful and is potentially damaging. Do you share that view?

**Dr Jones:** Without the clarity that has been expressed by both of us in slightly different ways, that is potentially true. We need to make this as simple as possible while ensuring that there is no possibility of organ donation getting a bad press. We have lots of examples where the press has got hold of something that has caused a deterioration in organ donation rather than promoting it.

**Mr Brolly:** There is no doubt that that is right. You have to remember that the bottom line is that consultants and the ICU teams will never take organs without consent. There is no point in an Act unless it reflects reality. The problem with the current Bill is that it does not do what it says it does. It is labelled and marketed as an individual choice system, but I agree that it would be better to do nothing than to introduce the Bill in its current form. Having said that, it could be easily amended.

May I make a further point? I agree entirely with the doctor. It was not something that I had thought through in its entirety, but, of course, it must be right that, before appointees have any opportunity to make a decision on consent, the family would have to be higher in the hierarchy. If you are going to retain appointees, that would be in circumstances where no qualifying family member would be available to give consent. It is the only way that it can work, is it not? It is just not workable otherwise.

**The Chairperson (Ms Maeve McLaughlin):** Dr Jones, I am thinking specifically about you, because part of the evidence that we heard today, particularly from clinicians, was in and around the notion of mandated choice as opposed to deemed or presumed consent. Apparently, mandated choice grew some traction during the Welsh debate, but there seemed to be challenges around human rights aspects. I am interested in that.

**Dr Jones:** There are issues associated with mandated choice, including human rights issues, on the basis that, if you have an issue where the patient expresses a wish other than the legislation would suggest, we have a problem. More to the point, if you have the family saying that there are significant concerns, you will also run into the difficulty of the family saying, "We don't want this to occur", and I would entirely agree. No clinician in that situation will ensure that the organs are donated, for the reasons that I have outlined. International experience shows us that that is a very bad thing to do, because, if the press gets hold of it — at the very least, that is the problem — it leads to a decrease in organ donation, and that is not what we are trying to do. It causes extreme upset to the clinicians and to the family, and I can see no reason why that would be a good thing to do.

**Mr Brolly:** We have an increasingly young population. The older generation has all sorts of myths about what happens after death and the sanctity of the body, but all of that is starting to disappear, slowly but surely. There is no reason why our organ donation rates should not continue to rise. The panacea for legislators is a simple family consent Act that says that, in all circumstances, the decision will be made by qualifying persons, save for the circumstance where the person is still alive and can himself sign the consent forms at the relevant moment, with the only proviso being a simple opt-out. That deals with every concern that you can think of.

Autonomy is never going to work. I have discussed and debated autonomy with doctors, friends and philosophers. A decision made by you will never work, for the reasons that we have both outlined. It is widely accepted by people in that sphere that the fact that you are on the organ donor register is never going to be sufficient. What we suggest would accord with reality. It would be harmonious and easy to publicise. I genuinely mean that. When we started this crusade, that is what we envisaged.

We thought to ourselves, in tandem with the doctors, "We will get to 35 or 36", because the numbers are there. We know that the numbers are there. We know that, for example, there is still roughly a 50% refusal rate, but we can shift that. About five years ago, Belgium had a 2% refusal rate for the entire year. You know what our society is like: it is small, so it is easy to publicise things. If someone goes on 'Talkback', everybody hears it, and you are in 'The Irish News' and the 'Belfast Telegraph'. Good messages are easy to publicise. I make this point to you again: we are the world's number one living donor society now. You think about that.

Aisling Courtney told me that, three weeks ago, a family came in with a son who was about to have full kidney failure. He had not reached dialysis yet, so he was in the perfect situation. There were seven



volunteers from the same family. We can translate that goodwill into an enormous life-saving project so long as the Bill is harmonious, as the doctor described. I do not think that there is anything between us on that, is there?

**The Chairperson (Ms Maeve McLaughlin):** Neither of you is saying that legislation is a bad idea.

**Mr Brolly:** Oh no. It is a very good idea.

**Dr Jones:** Absolutely not. We would support legislation. It is just not the complete answer, as I think we are both saying.

**The Chairperson (Ms Maeve McLaughlin):** The Spanish example is heralded as a model of good practice almost. However, the levels stayed the same for 10 years from the introduction of the legislation, is that right?

**Mr Brolly:** They rose very slightly. The problem was that they had terrible infrastructure. You can have great goodwill and great cultural approval of the idea. Let me give you a classic example. In the South of Ireland, there is great goodwill. There are 300 GAA clubs wearing Opt for Life shirts; I give talks to them. The Dáil is unanimous in its support for the family consent Act that it will bring forward. There is massive awareness, but their rates are among the lowest in Europe because they have only four kidney surgeons and they are simply besieged. They have closed their living donor programme. Their infrastructure is so poor that it does not matter how strong awareness is. We are in a brilliant position here; we can close the gap. In my experience, there can be no doubt that we can close that gap. We can go up to 36 per million of the population, but we can do it only if there is a good, simple, easy-to-understand and easy-to-publicise organ donation Act. That is the last part of the jigsaw puzzle. You people can definitely do it. This can be easily amended, as I have suggested.

**The Chairperson (Ms Maeve McLaughlin):** The model that you referred to that is working its way through Leinster House is for a soft opt-out.

**Mr Brolly:** Aye, but there is no deemed consent; it is family consent in all circumstances. Those who do not wish to consent can opt out.

**The Chairperson (Ms Maeve McLaughlin):** And are there other safeguards built in?

**Mr Brolly:** Family consent. There must be express family consent.

**The Chairperson (Ms Maeve McLaughlin):** Effectively, you are saying that it is confusing; it is a lift from the Welsh model, bar an important part; it needs to be simple and "unthreatening", as you said; practically, clause 4 has to go; clause 3, as amended, would deal with everything; and clause 5 is probably not needed.

**Mr Brolly:** Clause 4 is entirely meaningless; it is meaningless mumbo jumbo in the context of the Bill. It has to go entirely, because it is threatening and will cause a lot of division. Think about this: as far as I understand it, we want to be the first country in Europe to have a simple, easy-to-understand organ donation Act. We will have all the MLAs standing at the front of Stormont, give it a massive boost, then go to the publicity — the important side of things — and say, "Have the conversation. Have you had the conversation?". It is a beautiful thing. It will work, because there is nil resistance to that anywhere and it makes perfect sense.

**Dr Jones:** Sweden has an opt-out and has one of the lowest rates of organ donation in Europe. The clinical infrastructure has to include adequacy of transplantation facilities and adequacy of transplant coordinators. They are the people who go into the difficult and horrendous situation and are good at getting consent. If you have a transplant coordinator network that works well, you get about a 10% rejection, compared with the 50% that has been alluded to. You have to have adequacy of intensive care facilities so that intensive care is not always full of people who are being looked after incredibly well but which automatically means that those who are essentially brain-dead cannot get into an intensive care environment. You will automatically lose a series of organs because of a lack of that facility.

**Mr Brolly:** To copper-fasten the point that the doctor makes, I will give the exact statistic in a nutshell. I will deal first with circulatory donors, where life support has to be withdrawn. It is a painful process for the family, as the doctor will tell you. It is a difficult situation, a horrible situation. Over the past 12 months, there has been 30% consent here when the doctor has gone by himself. When the specialist nurses have gone with the doctor to speak to the family of the soon-to-be deceased, there has been 74% consent. That underlines his point. Here, we have specialist nurses covering that in almost every circumstance. We have 16 for the North, which is an enormous number, given how small we are. The South, for example, has five specialist nurses, and they have only just come on board. We have 16 in a country that is less than a third of its size.

**Mr McKinney:** Thank you both for your comprehensive contributions, which have addressed a lot of the issues. Mike, what is your view of the Welsh Act?

**Dr Jones:** We need to see how the Welsh Act progresses, because there are concerns about it and how it has been implemented. Whether it will have the overall benefit that everybody hopes for is still very much open to question. We need to see how it is in practice, because I am not sure that it will give the benefits that they hope for.

**Mr McKinney:** I am glad that you said that the Edinburgh college is bigger than Edinburgh, as that allows me to ask about Wales. I get the sense that there was not the passion in the debate in Wales, possibly because it was led by the Government, who were pushing it through.

**Dr Jones:** Yes.

**Mr McKinney:** Is that a failing in the system?

**Dr Jones:** It was not given the same consultation as you, by this process, have been giving to get the breadth of professional opinion, which is absolutely necessary for what is, after all, an extremely sensitive and complex ethical issue.

**Mr McKinney:** Thank you very much. Joe, I will be brief. You have been before the Committee before but not with me. I pay tribute to your courage and efforts in raising the profile. Raising the profile of this is hugely important, as is getting the balance right. Personally, I do not see any difficulty with having the big debate. It has been good. To sum up, Joe, if this is right, the balance of these things is important: correct legislative balance, with the correct publicity and the correct capacity.

**Mr Brolly:** I think so, yes. It would work really well then because Northern Ireland's society has shown that we are very much up for it. People do not like to be told what to do. Deemed consent and presumed consent have to go. It will transform the Bill and make it shorter and simpler. Do the things that I have suggested, which I suggest with great respect and after a huge amount of research and working through it with all the people who will have to operate the system. We hope that that commends itself. I will speak to Jo-Anne, as I have not had an opportunity to do that since the draft came out. It would be a great thing if you were able to enact this. It will make a huge difference to people's lives.

**Mr McKinney:** What about the fact that, in some respects, this has been controversial for a range of reasons, including politically? Do you think that will strengthen its ultimate aim?

**Mr Brolly:** I think so. The publicity has been overwhelmingly positive. Seven members of one family have volunteered. When I gave a kidney, it was a very uncommon thing to do. Very few people were doing it. We had about 17 or 18 donors in the whole year and all were intra-family; this year, we have already done 67 or 68. It is enormous. The situation is arising that, at a very early stage, people get a kidney when they need one. There is no fear because there has been good publicity and good awareness. It is a positive, feel-good story. That is what to think of when you think about the Bill: is it feel-good, positive, simple and something that accords with reality? Basically, call the process what it is already and then get on with publicising it. At the moment, it is too confusing. People go in and say, "Your loved one is on the organ donor register — *[Inaudible.]*", and the mother says, "I cannot face this. No". So we have a 50% refusal rate, which is entirely needless.

**Ms McCorley:** Go raibh maith agat, a Chathaoirligh. Joe, how are you? How are you doing?

**Mr Brolly:** Really?

**Ms McCorley:** Yes.

**Mr Brolly:** Is this going into Hansard? *[Laughter.]* Very good.

**Ms McCorley:** Do you feel that your health has been depleted or affected?

**Mr Brolly:** My health is good. It is a big thing; it was bigger than I thought. Everyone will react differently. It is a big intrusion into your body, and your body does not like it. A kidney is a big thing to come out. The clinicians can talk you through the safety of the process and the risks etc, but nothing can prepare you for the reality of what happens when you stand over a toilet stitched like Frankenstein and, for the third day in a row you cannot pee and you are thinking, "Jesus, I did not mind giving him the kidney but, Christ — please, God".

**The Chairperson (Ms Maeve McLaughlin):** That is going into Hansard as well.

**Mr Brolly:** It is a long process and a long recovery, but it is well worth it. Everyone should do it at least once in their lifetime. *[Laughter.]*

**Ms McCorley:** It was a very courageous thing to do. Your case is very well publicised. You are a high-profile person, and that has been part of the increase in general.

**Mr Brolly:** It is easy to chart these things. At the City Hospital, which I visit regularly, they will tell you things all the time anecdotally. People ring me and come to my house all the time and say, "I am going to give a kidney. Can you talk me through it? Can I meet you?". Publicity is easily spread in the North; it is a very small and homogenous community. We do not have the problems that the UK has. We do not have disparate populations with different religious beliefs. We do not have a multicultural society in the sense that they have. It is very homogenous and very easy to spread these messages here.

When we got Ulster Rugby involved with Opt for Life and got photos with Tommy Bowe etc, the City Hospital immediately reported that living donations from the Protestant community soared. It needs simple, easy-to-understand, good messages; that is what you guys can do with the deceased donors. That is where we have the real sticking point, because living donors only work for someone who needs a kidney. We have kids who need livers, hearts, lungs and all that. That is where the real problem lies now.

**Ms McCorley:** You mentioned that, in the South of Ireland, the infrastructure is poor. What is the upshot of that?

**Mr Brolly:** The upshot is a very low organ donation rate. For example, a country that is almost four times the size of ours had 23 living donors last year and has now closed the programme altogether. We are continually being contacted by people in the South who are saying, "Is there any way that we can get an address in the North?". We have brilliant capacity in the North. They run a brilliant unit.

We have been involved in talks with the Irish Government that look as though they might bear fruit to take 20 donor pairs who have been sitting on the waiting list for 18 months. You imagine sitting on the waiting list here, which has the very top figure in the world. From the moment you go now from the living donor unit to be assessed, you will be transplanted within eight weeks. If you have a match, within eight weeks you will be transplanted. That is astonishing, is it not?

**Ms McCorley:** It is amazing, yes.

**Mr Brolly:** It gives you an idea of what we are capable of here and what our resources are here. We just need to get the Act right.

**Ms McCorley:** I agree with you about the publicity because, a while back, I was struck when a surgeon announced that he had just done five transplants in that day. I would not have known, and it really had an impact because people generally do not know that this is going on. Publicity is very important. You said that there is a big difference in the outcome between whether the doctor or the specialist nurse has the conversation.

**Mr Brolly:** There is a massive difference, but we have 16 specially trained nurses. It is called a long-contact model, and they meet the family at a very early stage. They have already checked out on the computer whether the person is on the organ donation register. They have the details of the family, and they are waiting for them when the ambulance arrives. With that long-contact model, they spend time with them, and it is very sensitively done. They follow a protocol that has been shown to be very successful. They are not in any sense salespeople; they do not approach it in that way. The doctor said to me that the crucial point that you must remember — I overlooked it, having been immersed in this, but it is so obvious — is, apart from the fact that we have dead men and women walking as a result of organ donation, the solace that the family gets.

I was at the opening of the remembrance garden in Galway, which I played a very part in, and I took the opportunity to speak to as many of the families as I could over the course of the day. They all said the same thing: the fact that people were alive as a result of the bereavement that they had had was the one redemption for them. They said that they thought of them every day and prayed for them etc. It is a beautiful thing in society, and that is why the doctor has made the point that it is a fragile system and you have to be very careful to get it right. We think that it is easy to get it right.

**Ms McCorley:** Yes, the key thing is how it is managed.

**Dr Jones:** Sorry, I will just come in on that. The other thing about the nurses is that they are often perceived as not being an integral part of the care. They are not the intensivist, they are not the transplant surgeon and they are not the nephrologist or cardiologist or the specialist to do with whatever organ is being thought about. They are independent of it, and, therefore, they can come in a very different way to those who have been involved in the care or those who will care for the patients who receive the organs. Therefore, it is seen very much as an impartial role, and they are appropriately trained for it. If we were to say that the retrieval rate of Rafael Matesanz, who is an intensivist doctor, was poor, he would object strongly to that, so it is not universal, but nurses tend to do better than doctors.

**Ms McCorley:** That is very useful. Joe, finally, can you give me again the addition to table 1, number 5 that you suggested?

**Mr Brolly:** It is an addition to table 1. If the person is alive and, in those circumstances, they can sign the consent forms. That happens at the moment. Case 2 is a non-runner. In the second table, you would have the qualifying person's consent. Case 3 is the qualifying person's consent or appointees in the absence of qualifying persons. In 4, the appointees cannot be found and 5 would be the qualifying person. So, 5 would be where none of the above applies — where there are no appointees — and it would then be the consent of a person in a qualifying relationship with the person.

In truth, all of this could be reduced to two sections: one, where the person is alive, they can consent; and, two, in all other circumstances. That would either be people in a qualifying relationship, and, if there is no one in a qualifying relationship, it would be someone who has been appointed during that person's lifetime to make the decision. It would just be a three-grade thing. You would say, "The person is alive. The person has given consent", and otherwise in all circumstances a qualifying person would consent. Alternatively, if there is no qualifying person, there would be an appointee. Failing an appointee, there is no donation because it is not going to happen because the ICU people are not going to take it. Those three lines would be sufficient. That would do the whole system, and, for those who do not wish to be considered for organ donation, you would say that they can opt out in an online register, and that decision would be final.

**Mr McCarthy:** Thank you very much for your presentation; it has been fascinating. We sat through evidence from the consultants this morning, and they told us a different story from the one that we heard from you. Joe, you mentioned that you had not had time to talk to Jo-Anne, the sponsor of the Bill.

**Mr Brolly:** Yes.

**Mr McCarthy:** We are under awful pressure to get this through. What you say seems to be so simple and straightforward.

**Mr Brolly:** It is totally simple.

**Mr McCarthy:** Yes, there you go again. The guys who were here this morning are not on the same wavelength.

**Mr Brolly:** Bureaucrats are afraid of simplicity. That is what has happened. This has gone to the draftsman's office, and he has said, "Jesus, you can't have that". If I drafted it in three lines, he would say, "Jesus, what's that? People will actually understand that". Did you ever see 'Yes, Minister'? [Laughter.] "We can't have this, Minister; people will actually understand it".

**Mr McCarthy:** Jo-Anne is not here, which is unfortunate. I mentioned this to the consultants, and they were prepared to talk to Jo-Anne to bring the situation forward. Is it doable? We are all trying to get more organs for those who need them.

**Mr Brolly:** You just need a bit more self-confidence. It is absolutely doable. The Belgian Act is two short lines.

**Mr McCarthy:** The Committee is certainly up for it. Unless something is done quickly, we will lose the opportunity, which would be very unfortunate.

**Mr Brolly:** It pains me to say this, because we have been on the road for a few years talking about this, but it would be better not to rush this through and to get the amendments right. You people have got the point, and I am in no doubt that you have not heard anything contradictory. It would be easy enough to get it done.

**Mr McCarthy:** Within the time that we have.

**Mr Brolly:** With the right will, yes. It is not threatening to anybody with those amendments.

**Mr McKay:** You are right, Joe. With any Bill that goes through the House, the more detail there is, the more hamstrung you are when it comes out the other side. We need to remember to focus on the outcome as opposed to the detail of the Bill. It is interesting, from listening and reading some of the evidence, that there is so much hope and fear in this. We need to address some of that fear.

With regard to flexibility and making this a success in the longer term, how much responsibility do you give the Department? Do you put in regulations in case there are adverse impacts that we have not foreseen?

**Mr Brolly:** There will be wholesale confusion if this Bill is enacted. If you simply have an Act that says that organ donation can proceed only, if the person is alive, with the express consent of that person or, in all other circumstances, with the express consent of the family, as defined below. You then define the family widely, including gay partner, civil partner, partner, half-brother, stepmother and all the other gradations. Then you say that those who do not wish to be considered for organ donation for any reason after death can opt out in an online register. That deals with it; it is as simple as that. It is not threatening, everybody understands it, it is easy to publicise, and you guys will make an enormous difference. It is really as simple as that, Daithí. There is no trap. It is simple language that is easy to understand.

**Mr McKay:** If there are disputes in families, for example, how do you deal with that? The BMA representative said that the BMA supported clause 4 and the outcome that I am looking for. You are coming at it from a completely different angle.

**Mr Brolly:** There is no point in supporting clause 4; the ICU consultants will not retrieve the organs. It is a complete waste of time, Daithí. They will not retrieve organs unless there is express consent from family members.

**Mr McKay:** What is your view on the BMA's position? It says, "We represent over 70% of those" —

**Mr Brolly:** In theory, it works OK if you read the academic works et cetera, but in practice it will not work. What is the point of it?

**Dr Jones:** Sorry for coming in again, but, if you presented the BMA with what Joe is suggesting and said, "OK, which option do you want?", you may well find that they go with that rather than what they

have on paper, because it is simple. I think that most doctors, being very much of concrete thought, will go for what is simple rather than what is complex. The more complex you make it, the more difficult doctors and the general population find it and the greater the potential for adverse publicity. We have already acknowledged that positive publicity for transplantation is enormously helpful; adverse publicity has a really significant detrimental effect that can take months or years to get over.

**Mr McKay:** Are you satisfied as well that the Bill, as amended, will deal with issues of dispute within families? Somebody's wife, husband or partner may have no problem with their partner's organs being donated, but their parents may have a religious view.

**Mr Brolly:** That is a matter for the family. You cannot legislate for that. If you try to legislate for family disputes —

**Mr McKay:** That is what I am saying. Would there be a need for scope for regulations if that leads to a dispute?

**Mr Brolly:** No. This works really well at the moment. Families make the decisions, and it works really well. You know what families are like; they will make a decision together. There may be disputes, but they will communicate the decision. You cannot deal with every vagary of human behaviour, and you certainly cannot legislate for family disputes. If you can do that, you will get a Nobel Prize or something. You could dispense with family law.

**The Chairperson (Ms Maeve McLaughlin):** Finally, I will pick up on the clause 8 issue that you referred to, Mike. In a previous evidence session, the BMA expressed genuine concerns about the notion of living donors who may lack capacity and the huge human rights implications to all of that. You are simply saying that the Human Tissue Act —

**Mr Brolly:** Yes, it deals with that already.

**Dr Jones:** It will deal with that. You run the risk of duplicating legislation, and the potential for further confusion would be enormous.

**Mr Brolly:** The clause came straight out of the Welsh Act. It is not even relevant. Nobody has even thought about it. It has just been a case of "We will stick that in".

**The Chairperson (Ms Maeve McLaughlin):** Folks, thank you very much. That was extremely useful, very succinct and very clear. We will reflect on everything that we have heard from you. Thank you for your time.