

# Health and Social Security Scrutiny Panel

## Organ Donation

### Mr. N. MacLachlan, Consultant Obstetrician/Gynaecologist and Founder of Jersey Love Hearts Appeal

Tuesday, 13th March 2018

**Panel:**

Deputy R.J. Renouf of St. Ouen (Chairman)

Deputy J.A. Hilton of St. Helier

Deputy T.A. McDonald of St. Saviour

**Witness:**

Mr. N. MacLachlan, Consultant Obstetrician/Gynaecologist and Founder of Jersey Love Hearts Appeal

[14:00]

**Deputy R.J. Renouf of St. Ouen (Chairman):**

Mr. MacLachlan, welcome to the Health and Social Security Scrutiny Panel hearing. This is a public hearing with Mr. Neil MacLachlan, consultant obstetrician/gynaecologist. In the usual way, because these meetings are recorded, we will introduce ourselves. So I am Deputy Richard Renouf, chairman of the panel.

**Deputy J.A. Hilton of St. Helier:**

I am Deputy Jackie Hilton, panel member.

**Deputy T.A. McDonald of St. Saviour:**

I am Deputy Terry McDonald, panel member.

**The Deputy of St. Ouen:**

We are with Tom Leveridge, who is our Scrutiny Officer. We usually ask our people attending to introduce themselves, but I have mentioned your name. But over to you.

**Mr. N. MacLachlan:**

So I am Neil MacLachlan. I have been in Jersey since 1991.

**The Deputy of St. Ouen:**

Thank you for that. We are in the course of reviewing the proposed draft law, which deals with organ donation. We understand that you have had experience and involvement with that in the past. Can you tell us something about that?

**Mr. N. MacLachlan:**

Yes, I suppose I am in a slightly strange position in that I both work within the health service here in Jersey and I am the father of a child, now an adult, who required an organ donation heart transplant. So I have sort of seen it the hard way really. Because of what we saw in London and the fact that children were dying because of the lack of organs and how we were sort of fortunate in some ways that our daughter, Catherine, said she wanted to do something about that. So formed a local Love Hearts Appeal charity group in Jersey associated charities but linked with Great Ormond Street with the idea initially to raise some money for a new intensive care cubicle in the new Great Ormond Street and also very much to raise awareness about the subject. That has really been running since 2012 and is ongoing.

**The Deputy of St. Ouen:**

That is the continuing work of Jersey Love Hearts Appeal, is that right?

**Mr. N. MacLachlan:**

Yes, it is very much awareness but we are in the process ... we met with an immunologist at Guy's Hospital who are linking with the clinical director in the transplant team at Great Ormond Street and we are hoping to fund a research doctor to see how the process of coronary artery disease within a transplanted heart can be reduced by a new therapy involving white cells. So we are hoping to raise money for that now.

**The Deputy of St. Ouen:**

Yes, and I think you sent us some material about that project, and we wish you every success with it.

**Mr. N. MacLachlan:**

Thank you.

**The Deputy of St. Ouen:**

Has organ donation increased in recent years in the U.K. (United Kingdom)?

**Mr. N. MacLachlan:**

There has been an increasing amount of donors consenting and their organs being used. There is a sort of slow increase but, sadly, the available number of organs are clearly much less than those that are needed, those people on the waiting list, so there is a significant discrepancy. I think some of the slides that I have sent you have shown that discrepancy and how the U.K. is quite low down the field compared to some other countries. Really, I think what we are about here is to look to see whether Jersey will move in the same way that the more successful countries have moved, which will probably happen in England. I guess this gives Jersey a chance to have a jump on England because if England moves Jersey will probably have to move. So I mean we can talk about opting out but I mean it is likely that that is the way the whole of the U.K. will move.

**The Deputy of St. Ouen:**

So looking at those other jurisdictions you have mentioned, are their organ donation rates better because they have opt-out systems, would you feel?

**Mr. N. MacLachlan:**

Only partly. The main reason that the number of donations is more than in the U.K. is partly an opt-out system but it is more of a mindset and it is more that their whole health service has been geared up to really thinking about it. So it can be quite ... I mean they will resuscitate someone in Spain to keep them alive enough to go to the next step of organ donation. Some of that medical management would possibly be frowned upon at the moment in England or Jersey because it is quite ... you know, if you pull someone out of a car and they are pretty well dead you might, at the moment, let them go. But if you have a very active policy then that emphasis is changed a little bit. The improvement particularly in Spain, for example, who have this sort of opt out, it was not just the law that did it. It was the setting up of an organisation, the National Transplant Organisation, who concentrated on the intensive care beds, the specialist nurses. There was a whole team that were created that oversaw the process, and there was a massive amount of publicity within the country that was freely accepted. I mean it was not ... I am sure there were some people that felt it a bit challenging. But

it took a few years after the law was brought in for them to reach that. It was not something the law changed and donor numbers doubled overnight. It was really everything that went with it. I think what has happened in the U.K. is there have been some big transplant surgeons who have gone public over them sort of saying: "Well, it is not just the law", and it would be a great mistake if Jersey or England brought in the law and then sat back and waited for the donors to come trickling in. I mean, to be honest, just by having this increases media and people sit down at the tea table and talk about it. You only need to have that ... I mean Spain does not even have a register.

**The Deputy of St. Ouen:**

Does it not?

**Mr. N. MacLachlan:**

No. So you can get a card and say you are on the register. If Jersey brought in an opt-out type situation I think people should still be encouraged to sign in that they are opting into it.

**The Deputy of St. Ouen:**

Yes, it gives clarity.

**Mr. N. MacLachlan:**

Because then there is like, oh yes, well ... I mean I am sure that my son was on the organ donation register. So it would not get rid of that but those who are really against it could then just go online and say: "Look, under no circumstances do I want my organs to be used." There are only one or 2 religions, maybe Jehovah's who would feel like that. That is fine.

**The Deputy of St. Ouen:**

That is the way it is done in Wales, is it, which has adopted the opt-out system? There is a provision to ... does one have to go online in order to opt out or can anyone send in a form?

**Mr. N. MacLachlan:**

If you told your family and said: "You know what, if I did get knocked off my motorbike do not take my organs" then they would know that. So when they are phoned in that ghastly midnight phone call, then they would know that. So the family would say: "Well, no, Steven did not want his organs donated", and that would not happen. But there is a lot more clarity if he has opted out because it is that sort of: "We are not sure, we are too upset to even think about it." You need clarity when it is really difficult. So people should still be encouraged, I believe, to opt in or opt out.

**Deputy J.A. Hilton:**

Can I ask you: when you set up your appeal over here and I can remember sort of yourself and your daughter doing media interviews and things, did that result in a bigger uptake of people opting in, do you know?

**Mr. N. MacLachlan:**

It is very interesting because quite a small ... it is like a town, is it not, a small town in England? Obviously when Catherine was very ill there was an initial sort of: "Gosh, how terrible." We did not know she was ill until it happened. We had no idea she was unwell, typical doctor's family. "Run faster on the hockey pitch." "Actually, Dad, I am in heart failure." No, we did not know that. Then when it happened and then she did become very, very close to not making it and it was a terribly hot summer in 2006, and it is a horrible feeling to be walking around London hoping that someone comes off their motorbike and thinking it needs to rain for there to be a crash. We were not the only parents on that ward with children needing transplants but because she was a big child she could use an adult heart, otherwise the availability of children's organs is terrible. So there was some publicity at the time but it was not really until later that we felt we wanted to give it a nudge. If we look back at the figures, about 9 per cent of the population were on the register. That does not mean that only 9 per cent believed in organ donation because in some ways Jersey, I think, it does provide ... Jersey provides organs, we know that. But only 9 per cent had signed up and now, 5 years later or whatever, it is about 13 per cent. I am not saying that is Love Hearts Appeal, there have been a number of things on the T.V. (television), people have become more aware. But 13 per cent, most places in the U.K. are 36 per cent. Even in the Midlands where there is a very high ethnic minority rate, black African and ethnic minority rate who are traditionally very - I do not know if "poor" is the word - but poor at signing up and, in fact, have the greatest need of organs. Those rates are very poor so we compare, if we are going to compare ourselves, we are way down. We are the worst. Guernsey is a bit worse than us but we are the worst in Britain.

**The Deputy of St. Ouen:**

What would you say is the reason for that?

**Mr. N. MacLachlan:**

The reason is I think it is quite straightforward actually. If you look at where people sign up in the U.K., number one, D.V.L.A. (Driving and Vehicle Licensing Agency), number 2, G.P.s (general practitioners), so if we look at D.V.L.A. and G.P.s in Jersey we try very hard to get the driving licences sorted and sadly, not through Jersey's fault, but through a transfer of data problem, that has not been successful. It is too clunky. It is too costly for the number of donors probably. I do not think it is something that ... they have so many issues in the N.H.S. (National Health Service) transplant area that spending a lot of money transferring data from our driving licences to suck in that data is, I think, quite difficult. I do not know the logistics. We thought it had been done. But I do not think it

has. That is slightly embarrassing. But I think you might be aware of that. So that is one problem. I think this year there are a whole load of driving licences coming up for renewal. I think they have started ...

**The Deputy of St. Ouen:**

Yes, that is due.

**Mr. N. MacLachlan:**

So we were very keen to get that sorted by the next batch because I think there are thousands that are going to need to be ...

**The Deputy of St. Ouen:**

Yes.

**Mr. N. MacLachlan:**

So it will be a shame that we are going to miss that. Then the G.P.s; I have spoken to G.P.s, I have got friends who are G.P.s, and obviously in the U.K. there are a lot of surgeries where you go and wait, and there are things around the waiting room, then you go and talk to your G.P. and they may say: "Have you thought about this at all?" They only need to do that once. But when I have that conversation in Jersey it is like we have got 10 minutes; the patient is paying £30 or something. I do not know what they are paying but quite a lot of money, and the G.P. does not really have the time in this model of primary health care to be spending it talking to the patient about their family and what their thoughts are. So we could say social services will pay the G.P. for one session but how are you going to do that?

[14:15]

Again, it is clumsy. So those are the 2 main areas. Jersey people do not have an issue with organ transplants. They are no different to anywhere else. Jersey, as we found out, use U.K. organs.

**The Deputy of St. Ouen:**

Yes.

**Mr. N. MacLachlan:**

They do not come from Jersey.

**The Deputy of St. Ouen:**

That is right.

**Mr. N. MacLachlan:**

We are not like going down to the fish market. So we rely on the U.K. and Europe for the provision of organs. It is frankly embarrassing to show a rate of 13 per cent.

**The Deputy of St. Ouen:**

There is no logistical reason, is there, why an organ retrieved in Jersey cannot be used in the U.K.?

**Mr. N. MacLachlan:**

No. The hospital does it - not all the time - but most years there are ... we have got the figures, one or 2 where we may get ... you can get 9 organs from someone depending on the quality. So it is really important that the hospital and Jersey really, I think, shows to the U.K. as well that we are grateful for the organs that we have received from our citizens but we are also in the same mindset as the U.K., or even better maybe, of offering up when the situation arises. Now there are logistical things over here that makes it sometimes more difficult; donation after circulatory death, for example, is slightly more difficult to co-ordinate from here but donation after brain death is performed over here. I think the hospital has got slicker at it. There is an organ donation committee that we set up really since following ...

**The Deputy of St. Ouen:**

Yes, the Minister has told us about that.

**Mr. N. MacLachlan:**

That is new; well, a few years. But that followed a bit of pressure from us really.

**The Deputy of St. Ouen:**

Good. We are aware of the issues around the driving licences, which you have mentioned. We are trying to seek more information but, I agree, it is embarrassing and regrettable.

**Mr. N. MacLachlan:**

I do not think it is anyone's ... it is not a fault. It just shows you how transferring data is really quite difficult.

**The Deputy of St. Ouen:**

Yes, such a shame.

**Deputy J.A. Hilton:**

That should be something that the Health Department should be able to run itself, some sort of public ... one of our questions is that the Minister has said if this law is passed he intends to run a public information campaign. You obviously would think that was a good idea.

**Mr. N. MacLachlan:**

If you do not this could seriously backfire. You could end up with fewer organs because if you do not take the public with you they are going to say: "The State is not going to take my organs." You have to explain to people what this is about otherwise you can seriously have an own goal here.

**Deputy T.A. McDonald:**

Can I just point out that every time we, as a panel, undertake one of these reviews wherever possible, as wonderful as it is to have experts on the subject coming in, as wonderful as it is to talk between ourselves and other politicians, I always like to talk to Jersey people. The real, in other words, for something like this everybody could be potentially a donor. Now I have come away with the knowledge that a lot of people lack knowledge and because we have not done all of us - the royal "we" - we have not done a lot in the way of publicity. A lot of people do not realise that because we are an Island and because we are X number of flying hours away from wherever quite a few people are still of the opinion: "Oh, is it possible? Can we actually sign up?" I think this is all about education. So that is certainly one area that needs to be addressed, without a shadow of a doubt. I am sure you would agree with that.

**Mr. N. MacLachlan:**

Absolutely. I mean Catherine and I went round I think about 7 schools a couple of years ago at assembly, giving a sort of 5-minute set of slides. You could hear a pin drop in the room but it was also interesting that the lack of knowledge from the teachers who say: "Well, we cannot do it in Jersey. You cannot donate organs in Jersey."

**Deputy T.A. McDonald:**

The other thing is not just that, and I will plead guilty to this, because I am way past 60, but when we discussed it I said: "Well, it is all right for the youngsters but somebody like me at 68 or whatever, with glasses, my eyes are not going to be of much use to anybody." This was my firm belief because nobody had ever said: "Look, there is not an age limit. There is not this, there is not that." So again there is this great lack of real hard knowledge that the royal "we" should be putting out there to make people realise.

**Mr. N. MacLachlan:**

Some parts of the body are reasonably good at 65.



**Deputy T.A. McDonald:**

We will soon find which are not.

**Mr. N. MacLachlan:**

Interestingly, in Spain, if you look at the age groupings in Spain, there are quite a few deceased donors in that slightly older age group. So there are bits of the body that can be used.

**Deputy T.A. McDonald:**

That is right but unless somebody tells everybody, it is publicity again, those people are told, there could be a lot of people who would quite happily say: "Yes, I will put my name on the list" but there is a perception out there, as I say, this is me talking to you as a result of talking to lots of other people. That is something which we need to overcome, I am sure.

**Deputy J.A. Hilton:**

I just wanted to ask you about - because you very helpfully supplied some data to us - about family refusal rates. On here it gives a figure of 43 per cent, I believe, in the U.K. Is that 43 per cent of families where people have given permission, that the families do not give permission for their organs to be removed?

**Mr. N. MacLachlan:**

There is another slide, if I can refer to that, where it talks about the times at which donation is lost.

**The Deputy of St. Ouen:**

It is a graph immediately before the family refusal rates, our page 13. We have numbered all our pages.

**Mr. N. MacLachlan:**

If you look at that. The blue line is for donors after brain death. So if you follow it along where it says 28 per cent, so we can see that 28 per cent of possible donors are not brain stem tested. Too busy, intensive care, slipped my mind, so you lose 28 per cent of potential donors just by not doing brain stem testing. If you then go along, you lose another 4 per cent because of contraindications, H.I.V. (human immunodeficiency virus), something that they just cannot do it. Then 7 per cent of those are lost because there is no approach to the family, so that is where you need your specialist nurses. But then the big bit is 35 per cent are then lost because of failure of consent. So that is not 35 per cent of the original chunk but 35 per cent at that stage of the remaining donors. So lack of consent is a really big issue and what is really important about this point is that if you know someone is on the register or you have had the conversation around the breakfast table, and you know that in their mind that is what they want, then consent rates go right up. You are 70, 80 per cent

consenting, but if you do not know because they are not on the register and you have not ever had that slightly miserable conversation, then you do not know and family consent rates then are very high.

**The Deputy of St. Ouen:**

They will refuse their consent.

**Mr. N. MacLachlan:**

They are refusing. So Britain is very poor at consenting but it is not just because of that, it is because we do not have the same number of specialist nurses available. So if we have a patient in I.T.U. (intensive treatment unit) now and they have had a major brain haemorrhage and everyone can see what is going to happen because there is a totally unconscious patient, and then either the staff, the doctor or nurses will say: "This is a potential organ donation, is it not?" Really at that point you do not necessarily want the staff involved in the care doing this but you need to then refer this to the specialist nurses in organ donation who are very skilled at speaking to families who are in extreme distress, and it is better that someone who is slightly detached speaks to them than those involved in their care because they may be perceived as: "You just want his organs, don't you?" So you really need a slightly separate group. Now of course we are on an Island, we have got one nurse with that experience but if, I hope, this proceeds and we improve our service there is no reason why some of the nurses could not be trained. So you bring in a nurse who is not on call at that moment. She might be working on a different ward. This is a skill that could become available because at the moment we have to fly over someone from Brighton or somewhere.

**The Deputy of St. Ouen:**

Yes, I understand.

**Mr. N. MacLachlan:**

That can be again logistically difficult because timing is very important.

**Deputy J.A. Hilton:**

So you believe having an on-Island specialist nurse who might be engaged in doing other things in the General Hospital but has those skills to make the initial contact is the current way to go?

**Mr. N. MacLachlan:**

Yes, I mean dare I say it, it should be a Channel Islands. We should go with Guernsey and, say, have 3 or 4 trained people. They just do not do that. There is not enough work so these would probably be intensive care nurses who have been away to learn the way to speak to someone.

**The Deputy of St. Ouen:**

Would they build up sufficient experience of how to deal with families because I imagine the situations where this might arise would be relatively few each year in Jersey?

**Mr. N. MacLachlan:**

Yes, I think that is a good point. But nowadays there are ways ... we go over to the U.K. for the regional transplant meetings and within that the S.N.O.D.s, as they are called, specialist nurse organ donation, they have their own group meetings and things. So there is a way of maintaining skills. I accept if it is not done frequently but I think it would be a start ... I mean to begin with you can still keep the regional people probably coming over and you would probably keep doing that for a while until you felt that the local people had built up their expertise. But it would be better than, I think, what there is at the moment where we have to get someone over from England. But that is detail really. I think it is important but I do not think they are ...

**The Deputy of St. Ouen:**

I suppose the reason why it would be of interest to us is because we have heard from 2 persons who were involved as family members in an organ donation and one, in particular, had great difficulty with a stranger coming along and suddenly being presented with this option at a time of great distress. They were suggesting that there should be a liaison officer or some sort of liaison person to prepare the family through these difficult questions. Can you tell us something of your experience of how it works at the moment?

**Mr. N. MacLachlan:**

Of course our experience was ...

**The Deputy of St. Ouen:**

Perhaps not your personal experience.

**Mr. N. MacLachlan:**

... is from the other aspect. But the problem we have at the moment is because it is such a rare occurrence and because it is not out there it is a shock to people. They do not even know it happens in Jersey. So if someone turns up with N.H.S. Brighton written on their collar, what is going on? If you have an N.T.O. (National Transplant Organisation) like they do in Spain, that has done their work, you go to Madrid there is a coach in the square with the transplant organisation on it and people go and sit in the seats on the coach and talk about donation; if they want to sign they can sign. But it is much more in ...

[14:30]

**Deputy J.A. Hilton:**

It is out there.

**Mr. N. MacLachlan:**

So people who then sadly do go into I.T.U. they should not be shocked by seeing N.H.S. Brighton because they have heard about this on the news and they have heard about it through the Government and the papers, and we are going to have a bus in the square here once a month for the first year. It becomes part of the norm, and most people would not have a problem with that. So when these ghastly things do happen it should not be such a shock. I think at the moment that shock was because this has not happened before and of course to the family to see someone else coming in it obviously upset them. Also the questions that are asked, I know that can be a problem. There have to be personal questions asked because you have to protect the recipient as well. But most people, we all have histories, all been to university and, you know, but it should not be threatening. It is how it is done really and what you should expect and if you do not want anyone to ask about your sexual orientation or something then opt out.

**Deputy T.A. McDonald:**

The trouble is a lot of these questions, you know yourself, are put at the worst possible time in the family's life, their loved one is in the I.C.U. (Intensive Care Unit), this expression like "brain dead" or whatever, a lot of people do not understand and they perceive it through Casualty and programmes on television, but it is an awful time to be asking these questions, so really we are back to preparing people, educating people, much earlier in the day.

**Mr. N. MacLachlan:**

I mean if they are properly prepared you would not really need to ask the questions. They would expect ...

**Deputy T.A. McDonald:**

Yes. But I think it is such a rare occurrence over here obviously with a couple of people who have had an unfortunate experience that has not helped so far, but I am sure it is like everything, we have to improve.

**Deputy J.A. Hilton:**

Can I just take you back to the family refusal and I just wanted to understand the figure given for the U.K., which is 43 per cent, is that 43 per cent of all potential ...

**Mr. N. MacLachlan:**

People approached.

**Deputy J.A. Hilton:**

Approached, so it is 43 per cent whether they were signed up or not?

**Mr. N. MacLachlan:**

At the time.

**Deputy J.A. Hilton:**

So it's 43 per cent of all people approached, the family refused to give consent?

**Mr. N. MacLachlan:**

Yes, so if ...

**Deputy J.A. Hilton:**

In the U.K.?

**Mr. N. MacLachlan:**

Yes, I think these figures do vary a little bit but it is in that order. But if you are on the register then that is very different, so the family refusal rates are usually based on: "Well I did not know what they want so we are not going to go with it."

**Deputy J.A. Hilton:**

I have just noticed that the rate for Spain, because we have been talking about Spain this afternoon, is a lot lower, is it not? So basically do you believe that this is because the whole subject of organ donation is out there in the public domain in a place like Spain and really we need to look at countries like that and really follow their lead?

**Mr. N. MacLachlan:**

Yes, I mean Spain have invented the wheel, have they not? Countries, Wales have done it, if you look there is a picture here somewhere of the countries that have opt out and those with opt in and really most of the countries who are leading with the number of donations per million population have an opt-out system. But the general feeling is that it is not just the opt-out system, it is what goes with it, it is all the I.T.U. beds, it is the specialist nurses, it is the society thinking: "Do you know what, I am not going to throw my organs in a dustbin, I am going to give them to someone, let us do something good."

**The Deputy of St. Ouen:**

Yes, this is why it is valuable to have you in front of us to emphasise that because it is a message that needs to be driven home. Now you mentioned Wales. Have you followed what has been happening in Wales?

**Mr. N. MacLachlan:**

Yes.

**The Deputy of St. Ouen:**

Can you tell us what you have learned?

**Mr. N. MacLachlan:**

So the Welsh system has been in, I think it will be 3 years this year, and what has been interesting is initially there was no significant increase in donation rates, there were more people dying who were prepared to give their organs, but there was not much of a change to begin with. Recently I think they are beginning to start to see an increase in the number of organs that are being used, so they are now using more organs. Of course it is very difficult to know whether that is the law or the publicity and it would be a fascinating study to go through this process, do all the media hype, get your specialist nurses in, do everything else, but not change the law. That is academically interesting but what Wales have done is they have just said: "Well, Spain did it, all these other countries with good rates do it, so let us try to copy that." That is what they have done. In Spain it took about 10 years before they started to see really significant rises, so it would be wrong to criticise the Welsh for massive success because you would not expect that. This is going to take a while to bed in. What they have seen, and I have spoken to our local regional co-ordinator, is that within the young group there has been a real increase in the number of people who are like: "Yes, I am really up for this." Of course that is fantastic because those are the very people we want. They have the good organs. So I think it is too early; I think there is a lot of interest. It is beginning to climb now and I would imagine, over the next 10 years, you will see. Wales now is up to around about 24 per million of population, it is much higher than the U.K. generally, so already it has shown some improvement.

**The Deputy of St. Ouen:**

Do you mean 24 ...?

**Mr. N. MacLachlan:**

The donations per million of population. I mean obviously there are not millions and millions of people that live in Wales, but if you look at the figures, the transplant rates, it is that one that shows the consent by country with Spain, Austria, Portugal, Belgium, France, Italy, Finland, Norway. We tried to go into the schools and the N.H.S.B.T. (National Health Service Blood and Transplant) have these very good online 2 lessons, it is either a one-hour lesson or there is a sort of 3-hour thing,

which you can plug in to the school curriculum. I have met with many of the teachers who do the P.S.E. (Personal Social Education) and they are really keen, they looked at the things, but the curriculum is so jammed full it is a question of where you shoehorn it in and obviously that is a problem. But the work has been done and if Jersey goes down this route it would be good to try. We suggest it during transplant week, which at the moment it is the beginning of September, so even though the curriculum is pretty tight it seems to me that there are slots, particularly towards the end of term, when students are not doing quite so much. We are not looking at more than 3 hours over 3 years.

**The Deputy of St. Ouen:**

Has it got on to curriculums in Wales or in the U.K. anywhere, do you know?

**Mr. N. MacLachlan:**

It is very patchy for the same reasons. I do not know in Wales; it would be interesting whether they pushed for it there.

**The Deputy of St. Ouen:**

Yes, that is something we can consider in our report. Terry, do you want to ask your questions?

**Deputy T.A. McDonald:**

Will the current practice around obtaining consent from family members need to change as a result of the opt-out system and, if so, how?

**Mr. N. MacLachlan:**

What was the start of the ...?

**Deputy T.A. McDonald:**

Will the current practice, because I am not *au fait* and I do not think any of us are totally *au fait* with what the current practice is, but I will repeat the question for you: will the current practice around obtaining consent from family members need to change as a result of the opt-out system and, if so, why?

**Mr. N. MacLachlan:**

You have to get consent and without that consent no donation will take place. That consent can only come from the family for obvious reasons. So that process will have to continue. We have touched upon specialist nurses and whether they are from the U.K. or from Jersey and because of the numbers at the moment it is so important to do that properly that we do not want to change the current system if it is going to be inferior because, again, you may then upset the families because

it has not been done correctly. So I do not see any initial change. I do not think the law will cause a change in the process. I think what the law will do will make everyone talk about it and the media and the Government will put out: "These are the questions you may be asked."

**Deputy T.A. McDonald:**

Prepare people.

**Mr. N. MacLachlan:**

Prepare people, and so it is not such a shock. I mean you are much more likely to need an organ than to be in a position where you are going to donate one, so we need to also be talking about when you might need an organ and how you deal with people and how you talk to them when you tell them there is not one, because that happens more often.

**Deputy T.A. McDonald:**

That would be an awful, awful thing.

**Mr. N. MacLachlan:**

It is.

**Deputy T.A. McDonald:**

Well I cannot even start to imagine what that is like. You see somebody young, somebody fit ...

**Mr. N. MacLachlan:**

And you get situations where you have 2 children on one ward or 2 adults on one ward and there is only one organ and you have been talking to the parents in the coffee room for the last 2 weeks, pretty tough. So you need to care for these people, the recipients and the donors. We need to have a memorial in Jersey for those people and families who have donated, we do not have one.

**Deputy T.A. McDonald:**

No, we do not, but that is ...

**The Deputy of St. Ouen:**

That is very interesting, yes.

**Mr. N. MacLachlan:**

Yes, it could be a few trees on the North Coast, but it needs to be somewhere where people can be, not named, but a sculpture or something.



**Deputy T.A. McDonald:**

Acknowledged, yes, respected for what they have done.

**The Deputy of St. Ouen:**

Again that would create further discussion and a recognition in society that this is something worth doing.

**Mr. N. MacLachlan:**

Yes, it is a most incredible gift. That is why it is so important, if you go for an opt out, that you take the people with you because, if it is put upon them, you could be looking at an initial ... I can just see the blogs.

**The Deputy of St. Ouen:**

Yes. Do you want to ask any of your questions?

**Deputy J.A. Hilton:**

Yes. During our review we have been looking at the current arrangements for supporting family members of potential organ donors. Do you think the current system provides the appropriate support to family members and/or next of kin?

**Mr. N. MacLachlan:**

I am probably not the best person to ask because I do not get involved. I mean I literally sit on the committee as a parent of someone who had an organ donation. The nursing and I.T.U. staff and the chaplain, there is support but I could not honestly say. Usually things could be done better but I do not know, is the honest answer.

[14:45]

I am sure, if you bring in a working group to look at how you are going to educate and prepare people, that will be very much part of that, to look at the sort of psychological aspects of it because that is the ...

**The Deputy of St. Ouen:**

Okay, thank you, yes, we understand your difficulty. Now we have seen in the draft law that there will be protection in that certain groups of people will not be presumed to have given their consent, and they will include children and people lacking capacity and people who are not Jersey residents but happen to be over here temporarily. Do you think that covers vulnerable groups or do you think there are any other groups that may need to be exempted from the presumed consent?

**Mr. N. MacLachlan:**

As with any consent, you know, a foreign language, we have to make sure that they understand what is being said. So good interpretation may be for certain languages, so Polish, Portuguese, but they are much higher up and probably should be teaching us. But I do not think so. I mean obviously children, they are too young, so it has to be through the family, but there is a picture of a young girl there who died on her mother's 35th birthday, Jemima Layzell, and they had obviously had the conversation, so she did not consent but her parents knew, they had the family chat and so the parents were able to consent for her. I know that a lot of families who lose certainly children, but also young adults or any member of the family, they take a lot of, I am not sure what the word is here, but ...

**The Deputy of St. Ouen:**

Solace.

**Mr. N. MacLachlan:**

Yes, in knowing that their daughter lives on, is helping ... we did not have to, but we wrote to the donor and it is a wonderful thing, if you lose your daughter, to know that she has helped 8 people survive. I mean it is tough that you have lost her, but you knew that she was a generous person and she wanted to help those people and you managed to do it. So again this is really all about communication. So children obviously cannot and those who lack capacity through mental illness obviously that is difficult. So we would have to protect those groups but I cannot really think of anyone else off hand.

**The Deputy of St. Ouen:**

Thank you. I just want to ask my fellow members if they have any other questions.

**Deputy J.A. Hilton:**

Just this last one, yes, we touched on this briefly a little bit before about the questioning of families before the organ donation process starts, about intrusive questions. Do you think it would be worth highlighting this fact so that families are more prepared if and when the situation arises, because both the witnesses that we had did find that particularly difficult? I do not suppose there is any easy way around asking intrusive questions when you are in this highly emotional state but have you any thoughts on that at all?

**Mr. N. MacLachlan:**

Well again I think it is in the preparation for the whole population to know that, if you donate blood, for example, you are a blood donor, you have to say what you have been up to in so many words,

so you have a responsibility, the donor has a responsibility to not put at risk anyone who may be a recipient. So if you are opting out and you know what the questions will be and if you think you may be at risk because you had a bit of a difficult time in Thailand one summer then you have an opportunity to say: "I am going to opt out of this because I do not want my parents to know I had a party in Thailand." So, as long as people are prepared, I do not see that it should be a problem. I mean what questions are that ... whether their sexual preferences are ...

**Deputy J.A. Hilton:**

I think it was questions around sexual activity that ... I just think it was an enormously emotional time and families being asked these ...

**Mr. N. MacLachlan:**

Absolutely, and for some families that would be very difficult, for other families they probably know what their relative's sexual activity has been, so I understand that and it has to be respected and I think in the preparatory work that needs to be stressed that, for these reasons, these questions are asked. It is not because they are trying to be sort of nosy, the reason for this is because they may have sexually-transmitted diseases.

**Deputy J.A. Hilton:**

Yes. It was really your daughter wrote this, it was lovely to read.

**Mr. N. MacLachlan:**

It was published in the *Times* in 2012.

**Deputy J.A. Hilton:**

It was really touching; it must have been an extremely difficult time for you as parents with her in such a critical state.

**Mr. N. MacLachlan:**

Yes, in my career I have seen some pretty awful things but I think when your child is so profoundly ill it is paralysing, but the whole of the Great Ormond Street Hospital was like that and you suddenly realise that you are just one of many. It is very upsetting, which is why I think we are trying to do something positive. But I mean there is not a day that goes past where you do not think about it.

**Deputy J.A. Hilton:**

Some of the data that you gave us, 176 children, 3 die every day waiting.

**Mr. N. MacLachlan:**

Yes, I do not think that is 3 children, that is not presented very well. But there are children on the ward, on Flamingo Ward, who are on an external pump, so they are on what is called a left ventricular assist, which is a mechanical pump, so the blood comes out, goes through a pump and goes back in. They are bridged on that until a heart becomes available.

**Deputy J.A. Hilton:**

So that is keeping them alive, an external pump?

**Mr. N. MacLachlan:**

Yes, and because of the problems with batteries most of them have to stay in hospital because you wheel your battery around and some of those children have been on bridging for over a year waiting for an organ. We thought we were going to have to do that and the risks, while you are on that, of having a major stroke are scary. It really is awful and it is so tragic that young organs are being thrown away that could be used.

**Deputy J.A. Hilton:**

It is difficult for children, is it not, because of the size?

**Mr. N. MacLachlan:**

If you are only 20 kilograms you have to have a small heart or pair of lungs. I mean you can chop livers up into bits but big organs, you have to use small ones, otherwise the blood pressure would just ... So I think a lot of children's organs come from Europe, in England. You have 3 to 4 hours of transfer time, or there is a new device that again the charity was looking at helping with, where you can now take a heart or lungs and perfuse it in a box, the heart in a box, and by doing that you can keep the heart or lungs in better condition, because they are being perfused, during the transfer. Because if we had a donation in Jersey, once that heart is out you have to have it plugged in to the recipient within 3 to 4 hours. So you really do need to be slick. Whereas if you have a box with a perfusion thing you can extend that and also, you know, when Catherine was waiting, we were told there may be a heart, but it is not until they have checked the heart at the time when they open the box as to see what condition it is in and if the coronary arteries look dodgy ...

**Deputy J.A. Hilton:**

Do all children's heart transplants take place at Great Ormond Street or are there other centres around the U.K.?

**Mr. N. MacLachlan:**

At Newcastle and Great Ormond Street. Yes, I think there have been one or 2 other places, maybe Glasgow, but the main centres are Newcastle, the Freeman, and Great Ormond Street.

**Deputy J.A. Hilton:**

As far as adult transplants go, again, do they have dedicated centres in the U.K., do they tend to concentrate in ...

**Mr. N. MacLachlan:**

So there is Harefield and Papworth are the main 2 centres; I mean Catherine has now transitioned into Papworth.

**Deputy J.A. Hilton:**

It is lovely to read how successful it has been for her and everything that she has gone on to do, going to university and travelling.

**Mr. N. MacLachlan:**

The future is the future but she never complained once but she remains so grateful to all those who helped her.

**Deputy J.A. Hilton:**

She is living in Jersey now?

**Mr. N. MacLachlan:**

No, she was at school at Girls College and it was during her G.C.S.E.s (General Certificate of Secondary Education). Great Ormond Street have a school within the hospital anyhow, so she did her G.C.S.E.s and then had her heart transplant Easter and then went and did her A Levels at Girls College and then went to Durham, where she met Bill Bryson who was very interested in trying to get all the students in the U.K. to be on the register, but for confidentiality and data protection could not do that, they were not allowed to do it. So Bill Bryson was very supportive and then became patron of Love Hearts and remains a very good supporter. Then after that she went back to Spain because she was doing languages and worked in a school, thinking she might do teaching, and then she did not, and then she came back and did a masters at U.C.L. (University College London), which is next to Great Ormond Street, where she did speech and language. She used the languages, and she is now working, she has just started in Lewisham at Guys looking after people who have had strokes and cannot speak.

**The Deputy of St. Ouen:**

So it was really moving reading her story and very grateful that she wanted to share that.

**Mr. N. MacLachlan:**

She is inspirational and I think she worries about us more than herself.

**The Deputy of St. Ouen:**

Thank you very much, Mr. MacLachlan, is there anything else that you would like to tell us?

**Mr. N. MacLachlan:**

No, other than to say I was trying to think why Jersey should do it, to make this jump, and I think because we are so low on the registration rate that the potential to do good would be greater than if you were in England where you already have 36 per cent registered. So because we have such a difficult primary healthcare system and driving licences and everything else, I think the gain could be greater because 13 per cent, and if we are going to continue to use organs from Britain then I think it beholds us really to do a little bit more. I mean it just does not look very good and I think there has to be a big, big drive on education and do not make this look threatening, you know: "We want you to understand why this law is coming in." So hopefully that will happen and I think if we could get in front of England that is a little feather in Jersey's cap.

**Deputy T.A. McDonald:**

There is one question I would certainly like to ask you, it should hopefully sum everything up, the Minister for Health and Social Services has said, once the law has been passed, he will delay the introduction of the new opt-out system by a year in order to run a public information campaign. What do you feel should be some of the key messages that would need to be conveyed during that campaign? So, in other words, everything we have talked about today, all very important things, but if you could pick 3 or maybe 4 points, which you think that has to be ...

[15:00]

**Mr. N. MacLachlan:**

Well I think the needless loss of life has to be number one. I mean we now have transplant centres that are doing this every day. It is not such a difficult procedure as it used to be. So that is there and we saw what possible loss could be and since we have had 12 years of fantastic life, so that message needs to go out that it is because of that loss of life that we are doing this. If you ask the public whether they would accept an organ if it meant dying by not having one, over 90 per cent would say: "Yes, of course, I would accept an organ." So you need to flip this so that the message is: "Well, you are more likely to need an organ than to give one", so that message is very important. But also we do need to look at intensive care beds; the hospital is full today, full, absolutely full. So to try to keep someone alive for an extra 12 hours while you co-ordinate retrieval has quite an impact and most retrievals are done at night when there is no list on. So you need to have the infrastructure, so that needs to be looked at, and then you need the staffing, the specialist nurses, the support, the

care for people who are going through a very difficult time. I think if it was laid out in a very sort of compassionate way, I think the public would go with it. When I spoke to N.H.S. Transplant about 2 years ago about trying to get the education, and I met with Rod Bryans about this, about trying to get it into the curriculum, they were interested in looking at Jersey as a model for other towns to see how we could, as an Island, do things that could then be used as a model in England, in Winchester or Salisbury or somewhere like that. So they were very interested in that idea and I think this could be a chance for us to do something quite well really.

**Deputy T.A. McDonald:**

Yes, and gain some recognition and, more importantly, do a lot of people, some recipients ...

**Mr. N. MacLachlan:**

We are never going to have a lot of organs, we are only 100,000 people, but we must capture each opportunity.

**The Deputy of St. Ouen:**

Indeed. Thank you. It has been a very enlightening afternoon.

**Mr. N. MacLachlan:**

Thank you for asking me along.

**The Deputy of St. Ouen:**

We are most grateful. You have both had that personal experience and you have a lot of knowledge through your work subsequently. Thank you very much indeed. That brings our meeting to an end.

[15:03]