

Health and Social Security Scrutiny Panel

Organ Donation

Wednesday, 1st 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

Senator S.C. Ferguson

Witnesses:

Person A

Person B

[14:30]

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

We have got with us Tom from the States Greffe, who you have spoken to on the phone. Behind me is Leah who is also from the States Greffe who is looking after the recording for us. I will just explain to you something on why we are recording, we will talk at the end about how you might want us to use that. But first of all I think you know ... you have been introduced to all of us now. We are very grateful for you coming in to speak to us about this process of organ donation. We know it is tough and we do not want to put any burdens on you. So at the outset I would like to say if you are at all feeling uncomfortable you can stop. If you want to leave the room and not come back that is fine. If you want 5 minutes we can do it that way. You tell us what you want. Largely, I think what we would like to do is to let you tell your stories but we, for ourselves, have prepared some questions that we would like to know your views on. So if while you are talking sometimes we might ask you to think about a particular question, we do that, otherwise we would like you just to tell us what you

have experienced and perhaps how you think things could be improved, if that is your view. Is there anything else you would like me to say, Panel? Right, okay. Good. Would one of you like to start with telling us what your experience of organ donation?

Person A:

You get pretty emotional. It is just he was my grandson.

Person B:

I will cry too. You just get used to it.

The Deputy of St. Ouen:

I should say ...

Deputy T.A. McDonald:

You are in good company, Person A.

Person A:

Obviously how it happened and the speed it happened. What we were prepared for was he was quite willing for his organs to be donated. He had made this note previously and one of the things that came to light when he filled in his driving licence he had put in where there is an area there to ask you. This had been sent in but it appears that where it is administered from the Town Hall that it had not been sent to the central register. That, as I found, very strange. He had already volunteered this. What had happened when we knew he was not going to make it was, I found very disturbing, that they had already made arrangements for the N.H.S. (National Health Service) nurse to come over to interview us without first consulting the family, did not tell us it was going to be an N.H.S. nurse that was going to be interviewing. When we knew on the Wednesday he was not going to make it the nurse was flown in for the Thursday morning, and when we were confronted really with her just coming in and my daughter said to her: "Why are you wearing an N.H.S. uniform?" She says: "This is what I do, I have to go round the country" and she came out with: "I had to leave home at 3.00 a.m. this morning, you know." I could not believe that she had come out with such a comment.

The Deputy of St. Ouen:

You have probably had no sleep either. You have been around all night.

Person A:

Then with this intense questioning. My daughter had to leave the room and her ex-husband had to take over.

The Deputy of St. Ouen:

So, Person A, were you in the room at the time?

Person A:

I left a couple of times because I could not put up with it. Her ex-husband stayed and it was intense questioning and, as you know, since the inquiry it appears that this is ... you are not told this prior. It appears that this is the same questioning you get as if you were going to give a blood transfusion. It is a bit of different circumstances though. His girlfriend that was with him, they had been in [REDACTED] a few weeks before, when she left the room and then this N.H.S. nurse said: "Oh, I want to talk to you after. I want to talk to you personally." This kid, [REDACTED] years old, apparently her first stable relationship, was put through the mill and up to Christmas time her mother was still having to speak with her because she was put through the mill about anything, the activities when they were away, and that. She was not asked if she wanted to have a chaperone or her mother to come in or anything like that. Boy, this disturbed this kid something chronic. Quite honestly, nothing against the process about organ donation, but you have to have a liaison officer to go through the family prior to it happening. "So this is what is going to happen. You are going to have intense questioning" and only I found out in England, I think there are 90-odd cases where the families are basically rejected, the fact is ... and I would think it is because of that process of whether the intense questioning, because it is a gruelling questioning and you are thinking ... well, you know, this is the questioning you are going to be turning off his life support soon. Then the fact is this N.H.S. nurse, once it had been done, said: "It has been arranged for the team to fly in at 9.00 a.m. tomorrow morning." They did not fly in at 9.00 a.m. in the morning but did not tell us and it was only his other grandmother who found out through somebody else and said: "You know, [REDACTED] is still on the life support and the team have not flown in" and she went and sat with him the morning because she could not bear the thought of him being on his own.

The Deputy of St. Ouen:

So the family did not know, they were not informed?

Person A:

No. We were not informed. Maybe it is a lack of experience of it in the Island where they are not coping with it but you cannot go doing this to families.

The Deputy of St. Ouen:

But you knew that [REDACTED] had wanted his organs to be donated?

Person A:

Yes. As it is, I filled it out because he was a member of the [REDACTED] and I was under the impression, and I still am, that under what they call the [REDACTED] that they have to do that because my other grandson is a [REDACTED], and right away they have to sign in whether they like it or not. They go in and I was under impression, so obviously I believe the hospital were getting hold of the [REDACTED] to see if this is right in case there is no proper co-ordination that these are not getting sent into the central register, because we could maybe have thousands of people in Jersey that have not been sent to the central register because the Parish scenario ...

The Deputy of St. Ouen:

We will try and find this out too.

Person A:

I find it very strange that ... I mean I know I was there once when he was filling in his licence and, you know, I said: "[REDACTED]" and he said: "Oh yeah, no problem."

The Deputy of St. Ouen:

So, Person A, there must have come a stage where the family was informed that [REDACTED] was not going to make it.

Person A:

On the Wednesday. Well, it appears now from the report that they had told ... they now confirm he was dead on the Tuesday but they did not confirm it until the Wednesday. So under the ... we was, maybe under false impression, that there was still hope on the Wednesday when they said: "We will be carrying out a test" but it appears that the consultation they had done with Southampton it had been verified that he was not. Then the other thing I want to bring up is the fact is these organs were removed as agreed and then when they got there they found there was a hitch on the test so the organs were disposed of, not used, without even consulting the family, and disposed of in the U.K. (United Kingdom). That my upset my daughter something chronic. They had been used and the fact is somebody had had the benefit but just to ... and you know you are sat there, when I said: "Well, what has happened to the organs?" "Oh, we disposed of them." It was as blatant as that. It was so flippant the way they dealt with it. Then when I had to get ... because I could not get no response and I went to the media and when there was a comment made, you see there, you know: "It is not really an occurrence that we have much of. We have only lost 12 in 15 years teenagers." I could not believe people would make the comment like that. There is no sort of publicity about the impact of [REDACTED], as such. I mean, you go to the doctor's surgery, and there is everything there to tell you what injection you like in every language, apart from Jersey French, and you go in there but you get in ... nothing about [REDACTED] to say this is 18 to 24: "Oh are you 18 to 24?" I mean the

universal age we travel, I mean he is [REDACTED] all over the place. They are all intermingling, he was into all sorts of sports.

The Deputy of St. Ouen:

Yes, it was very tragic.

Person A:

Why is it not brought out to light to these youngsters a lot more?

The Deputy of St. Ouen:

But, Person A, obviously there were a few members of the family around. Were you given a chance to say that one member of the family would be the contact with the organ donation scheme?

Person A:

No, because what happened was his father ... you know, the partner of my daughter and her first husband, really he took over. He was like elected to do it because obviously my daughter could not cope with it and so he done it, but there was no co-ordination with anybody. Like it was who do we get hold of. Then like his godmother ... and everybody was in such a state that the information was not getting through. Then, as you know, when the ... because his brain was taken away for observation and testing and then that was, you know ... the information was so bad from the Viscount's office that my daughter and me were getting the information by the funeral director. If we were to have a liaison officer who would keep the family even after the event, like. You know: "This is exactly what has happened." I mean up to the inquiry we did not know what had happened to the organs.

The Deputy of St. Ouen:

I understand.

Person A:

Only when the U.K. nurse came over and said: "Oh no, we did not use them." "What did you do?" "Oh, we disposed of them."

Deputy J.A. Hilton:

You found that out at the inquiry?

Person A:

At the inquiry.

The Deputy of St. Ouen:

I should explain that Person A and I attended together; as Parish Deputy I went with Person A. This is not panel work but just Parish Deputy. We had a discussion some weeks afterwards.

Person A:

We could not get no answers.

The Deputy of St. Ouen:

But, Person A, do you know whether the N.H.S. informed ██████████ father, whether or not the organs were used?

Person A:

No, I do not know.

The Deputy of St. Ouen:

You do not know?

Person A:

No, I do not know at all.

The Deputy of St. Ouen:

I am just wondering is ... there are various family members and ...

Person A:

Yes, but you see in Jersey because his godmother had taken, you know, because ██████ could not cope with it and she was sort of ... the thing is, it is still a touchy subject. I mean I told my daughter this morning I am here. She said: "What do you think they will ask?" and I was trying to tell her because at the moment we are getting more good days than bad days, but it has been some time. Three weeks before Christmas when you get Income Tax sending you "Where is your I.T.I.S. (Income Tax Instalment Scheme), if you do not mind?" I thought there was a thing now that when there was a cut-off point from Social Security that this never happened. We have had an apology from Income Tax to say it should not have happened. But, you know, you cannot believe it, the inefficiency of civil servants.

The Deputy of St. Ouen:

Shall we give you a break, Person A?

Person A:

Please.

The Deputy of St. Ouen:

Person B, would you like to tell us what your involvement has been?

Person B:

The reason I am really here is because I read Person A's thing and I ...

The Deputy of St. Ouen:

Okay, take your time and have some water, both of you, if you want to.

Person B:

My issue was ... I absolutely support organ donation but I think the thing that people need to know is you can have your next of kinship revoked. I did not know this was possible so I asked my partner, and a month before [REDACTED] we were in hospital and [REDACTED] we changed our medical records, so he was my next of kin and I was his. That is what I thought it was. We planned on [REDACTED] and all that. So unfortunately, [REDACTED] and I was in the hospital. [REDACTED] Anyway, we were in the hospital and I was in A. and E. (Accident and Emergency) and then [REDACTED] got moved to intensive care. The doctor who, luckily, I knew, came out to me and he said ... everyone calls me [REDACTED]. He said: "[REDACTED], the parents are next of kin but they have said you can go in. [REDACTED]" At the time I did not really understand what that meant because I was so stressed.

[14:45]

I would not ever have stopped them being next of kin because they were his parents and I believe that is the right thing for families to do. However, [REDACTED] I do not think anybody else in the world knows that you can have your next of kinship revoked. So when I spoke to the Viscount about it, he said: "Yes, that is a fact. It can happen and it happens quite a lot." I have heard of 2 other people that have had this situation. One was a couple and they had been together for 15 years. The chap, I am not sure what happened to him, but the person who was dying, his family had always disagreed with the relationship so when it came down to it they took over the next of kinship and turned the partner away. That partner was not allowed in the hospital. Can you imagine being with somebody for 15 years and then having that revoked, not allowed to see them? That is appalling. So I think that really needs looking into because I think maybe if everyone does the scheme, when they get their paperwork sorted it needs to be absolutely clarified about the law, about the next of kinship. Say if it was me, I would tell my father and the people

around me and that needs to be stuck to and everybody needs to know because I think it is a really big deal.

The Deputy of St. Ouen:

Thank you for that. Yes, that is something we will ask about.

Deputy J.A. Hilton:

Does it basically mean if you are not married that the parents can come along in that situation and say: "We are next of kin." Is that what happened?

Person B:

We were not married and I do not know if it is about being married or not. But apparently in a court of law, when it comes down to it, in the hospital you can have it overruled by the family. So I do not know what the technical implications are. But it happens. I do not know, that might be something that needs to be looked into.

The Deputy of St. Ouen:

I think it is probably to do with marriage, but we can ask.

Person B:

I think that really does need looking at.

Deputy J.A. Hilton:

Sorry, I may have missed it. So you were there and you were told that the parents were taking the next of kinship. Were you told by them or the staff?

Person B:

No, I was told by the doctor. I think at the time he was trying to kind of say to me: "This is what is happening" but I just did not understand. I would not have argued it anyway because I do not believe that is the right thing to do. But to know that they could have said that I was not allowed in is just awful. I cannot even imagine how bad that would have been. Because of that then, the decision was taken away from me ... well, not from me, I mean it always would have been [REDACTED] whether he wanted to donate his organs or not, but it turns out it was the brother that made the decision about [REDACTED] organs being donated, which is fine. [REDACTED]

[REDACTED]

[REDACTED]

The Deputy of St. Ouen:

Did you know what your partner's wishes were about organ donation?

Person B:

No. I think about it and I think we must have talked about it. I honestly cannot remember, my memory is not so good, but also he was [REDACTED] so I think possibly I might have thought if you have some kind of ... [REDACTED], that might affect it. I do not know enough about it. But we had not made our Wills because we were waiting [REDACTED] ...

Deputy T.A. McDonald:

Could I ask how long you have been together?

Person B:

[REDACTED]
[REDACTED] So it was about 2 years.

The Deputy of St. Ouen:

So you were not involved in the decision about whether or not to donate organs?

Person B:

No, not at all. How it happened is [REDACTED], one of [REDACTED] really good friends, came up with me and we were sitting with him at his bed. I will never forget it because there was this [REDACTED] doctor who came and just sat down and said: "Okay, so the organ donation nurse has just arrived" and I said: "The what?" All the colour drained out of his face and he went grey. I will never forget it because, poor man, he could see obviously by the state of me. That is fine, that was absolutely fine, and I believe that is the right thing to do but it was just such a shock. [REDACTED]

[REDACTED] When it all happened they were doing a thing called the brain stem death test where 2 doctors have to go and test to see if a person has passed away or not. [REDACTED]

It is the worst possible situation in the world. They did that very late at night, it kept getting delayed, and then they did it and then the organ donation nurse went in to speak to them, which was right.

Then eventually [REDACTED]

[REDACTED] she then came in and spoke to me. Another thing, they call it "harvesting organs" and that I found very difficult to cope with because ...

Senator S.C. Ferguson:

It is an awful term.

Person B:

It is. Thank you. [REDACTED] [REDACTED] [REDACTED] I really felt it was a horrible thing. Also when it comes down to it, the machines are on, so there is a rhythmic thing and I held on to him all the time. He was not cold and he kind of ... I know he was dead but he was moving so I was just listening to the doctor, I said: "How am I supposed to walk away and leave him knowing that you are just going to go and cut him up and harvest his organs?" It is a very difficult thing to do. So to do it, having all these other things in place, and it all happened so quickly, is really, really tough. I am absolutely for organ donation but these are things that people just do not know about. So we need to educate people and do some kind of publicity or something to try to make people aware of how tough it can be.

The Deputy of St. Ouen:

Were you asked questions by the organ donation nurse about your relationship?

Person B:

No, and I think I should have been [REDACTED] [REDACTED]. He was practically living with me because I had bought a new house and we were between doing everything like that. I would have known everything, all the up-to-date stuff [REDACTED] [REDACTED].

The Deputy of St. Ouen:

That is strange.

Person B:

So I do not even know what information they gave the nurse. So I have a very different experience to Person A but they are both still valid. If we can make something better from it that is the point of today.

Deputy T.A. McDonald:

Helping other people.

Person A:

You can have a liaison officer to guide you all the way through the process, educating: "This is what is going to happen. Are you in accordance with this happening?" because you are obviously thrown a line and then that is it. Then to be told by an N.H.S. nurse, which is: "This is my job and I had to leave home at 3.00 a.m. this morning, you know", well I just. You know, you just do not believe that these comments come out. Maybe it is very matter of fact because that is what she has to do. But I think it should be all the way through maybe - coming in to repeat myself - a liaison officer: "This is

what is happening. This is how the process goes.” All the way through and even after the organs have been ... because it is an unbelievable experience that you go through.

The Deputy of St. Ouen:

So far as you had involvement did you find the N.H.S. nurse or the team treated you ...

Person B:

Well, I did not have a lot of time with her but when I did it is like 12.35 a.m. or something, very late, and she came in and so she said: “He has been certified as dead and we are going to go ahead and try to harvest the organs.” So the next day all the surgeons, or whoever it is, were supposed to fly in. It was a foggy day, typical, so I was sitting there waiting, and that is really stressful as well because there was like a 3.00 p.m. cut-off in the afternoon. So you are sitting at the bedside all the time clock watching. They were supposed to fly in, I think, at 10.45, or something and did not get in. Then it was all touch and go. Then I thought: “God, if we get to 3.05 and they have not got in because of the fog.”

Deputy T.A. McDonald:

It is another day.

Person B:

Yes, of sitting there. It is so terrible. But they did get in and they did do it.

The Deputy of St. Ouen:

Do you know whether your partner’s organs were used?

Person B:

Yes, one thing the organ donation nurse did say to me, she said: “Is there anything I can do for you?” Very rudely I said: “What can you possibly do?” [REDACTED]
[REDACTED]. Then I apologised, because I was rude and I did not mean to be. She said: “I can give you his handprints and some of his hair.” I have that. She said: “Oh, I can give you a letter to tell you where his organs have gone” so I have that. I have it with me in case you wanted to see it. So it would have been nice if Person A had been informed because when I was trying to leave the hospital I was saying to the doctor: “How on earth am I supposed to walk away and leave him?” and he said: “Other people find comfort in the fact that their organs have helped other people.” I am still not there. I have to tell you it is [REDACTED] years and a week on and I am still not there. At least I have something in the future when I get to that place but Person A does not have that. It is very difficult.

The Deputy of St. Ouen:

That is interesting to hear. Obviously the next of kin must have been told what had happened to the organs but you also specifically received a letter?

Person B:

She asked me if I would like that. [REDACTED]

[REDACTED]

[REDACTED]

Person A:

The critical care unit was so caring. I must say that.

Person B:

They are very good.

Person A:

They were so accommodating ...

The Deputy of St. Ouen:

I understand, Person A, I know it is very tough for you. So all of this is ... we are speaking to you today because of what the Minister is planning to do to introduce an opt-out system that if somebody felt strongly that they did not wish their organs to be available they would have to take steps to opt out of the system. Has your experience of the system given you any views on that?

Person B:

I think it is a great system but under the proviso that lots of education is given and something about next of kinship. I do not know whether that has to be a legal thing or what. But I put it out to my friends: "I am going to do this, does anybody have any views on it?" Different people have been concerned about the age range that this scheme would cover. Because apparently the English Bill is named after a young boy called Max who was 7 or 9 or something. Are you following the English Bill that has been passed on this?

The Deputy of St. Ouen:

Tom has something.

Person B:

So that has come up a lot about age range. One of my friends said: "Oh yeah, of course next of kinship can be overruled. It has to be written in the law." I thought: "Okay, she knows; I do not." So

I think it is a great scheme but I think it has ... the intricacies of it have to be looked at. For example, workers who are coming over to the Island, things like that. I mean I do not know how you plan on rolling it out, if it is through the census or ... I do not know. I am sure you have looked at all of that sort of stuff. But it is a great scheme but there has to be a lot of information widely given about how it will be done and about that next of kinship, I think, is really imperative. It has to be done not all on the internet because my grandparents are not here any more but had they been they would not have known how to do it. So the elderly people or people who do not have computers or people who are dyslexic. All that sort of thing, we need to make sure that everybody can have it in an accessible format.

The Deputy of St. Ouen:

Person A, have you or your family got any thoughts about what the Minister is proposing?

Person A:

No, as I said, we are all in agreement with it. There is nothing against the scheme to go ahead but I hope the States are not going to go and rush this one through without ... like I say, obviously go through Scrutiny. Yes, there is a chance there is going to be good discussion but it is coming in to ... the family have got to be well thought through this as you are going through the whole process and not having the experiences that we both had where, you know, it is just implanted on you willy-nilly when you are also at the most distressing vulnerable time in your life, where you need guidance all the way through. I was listening to the radio this morning and you were being interviewed. I do not know, doing it was sort of being in the system but like it should be going through, what is the problem with this. But, yes, it is not a problem until you have encountered it.

Deputy T.A. McDonald:

Touches you personally.

Person A:

Then you can see where the problem is because I would have been well and truly, prior to this happening, saying: "Yes, go ahead with this" not realising the intensity of what you are having to go through. I thought it was a sort of vehicle, you have done it, then it was up to them and you just started with it. But not to go through those distressing hours that you had to go through.

The Deputy of St. Ouen:

Person A, you knew that ██████ had said he would want to give his organs.

Person A:

Yes.

The Deputy of St. Ouen:

But knowing all the stress you went through would you wish you had not started with the process of getting the team over?

[15:00]

Person A:

My daughter said if this would ever happen again she said: "I would have refused it. I would have refused to do." She said: "If I knew what we were having to go through I would not have allowed it to happen."

The Deputy of St. Ouen:

Okay.

Person A:

Because she was having the same operation as me, he had agreed, and this has come back to I think something needs to be found out if this is right, if the Town Hall have not sent the things on to a central register. Because, if that is the case, there could be loads of people that have signed "yes" on their licence but it has not gone through. So that percentage could be a lot different. You need to find out because, in that case, they said, and I think when we were at that inquiry, they said this had not gone through from the Town Hall, so I find that very strange, why are you filling it in to say "yes" and it could also apply to a lot of sporting organisations where you become a member, and they might have that and it is not going through to the central registration.

Deputy T.A. McDonald:

All that is part of the follow-on where you think the worst is over but then all of a sudden you find these distressing things out and it just opens the wounds all over again.

Person A:

This is it, like I say, Deputy, my daughter said to me: "If I knew this, I would not have allowed it, I would not have allowed it." It was strange that the minute that we were not even told it was an N.H.S. nurse, it was only when she said: "Why are you wearing an N.H.S. uniform?" and it was all very matter of fact and I think you should be told this is how the process works.

Deputy T.A. McDonald:

Fait accompli.

Person A:

Yes, very *fait accompli*.

Deputy T.A. McDonald:

What is her attitude now? I know she wants to talk to you and find out how you have got on and what the thoughts are?

Person A:

Well she will ask me tonight what happened because she just got to face up to a lot of things anyway because, funny this morning, because strangely enough I had to take her to the doctor because she is doing this [REDACTED] walk, and she has gone in training and [REDACTED], so now we have to go and do [REDACTED] instead, so she has asked me: "What do you think they will ask us about?" And I said this is what I think and I said: "I will talk to you tonight." How do I feel? Well, one day you have a [REDACTED] year-old grandson and son [REDACTED] on a Sunday barbecue, not well on Monday, dead on Tuesday. I mean, no disrespect, I mean not saying he was the perfect guy, but I mean sports, he was into everything going, from [REDACTED], [REDACTED], everything going, he was never at home. Ironically enough he stayed at my place because when I lost my wife a couple of years ago he said: "I will look after you, granddad", you know, so ...

The Deputy of St. Ouen:

So, Person A, you have spoken about a liaison officer, a member of staff, stepping in. Presumably you would not want that to be part of the team that have been treating [REDACTED] because they are treating [REDACTED] with a view to trying to bring him back to you, so ...

Person A:

No, no, no, that is right, no, no, I would have thought there must be an independent liaison officer that can come in and go through, from the minute that they have been informed this is what is going to happen and it is not good news: "Will you liaise with the family?" from the very start and they go through the whole process.

Deputy T.A. McDonald:

When you say "come in" would you want that person to be an N.H.S. person to come in or do you think there should be somebody resident ...

Person A:

I would like to see a local contact because local contact knows family circumstances, it is a bit like a parochial system, is it not, I mean I think ...

Person B:

I absolutely agree with that. I think, if this is going to be a Jersey policy, we need some Jersey people based in the hospital, or wherever, who are there whatever time on a shift basis, because there are going to be people dying all the time and to have a friendly face, it does not have to be a local person, a person based in Jersey here who could just even gently introduce the subject because when you are hit with that amount of stress that your loved one is dead or potentially about to pass away you do not even think about it. So for somebody to plant the seed and gently to say: "Is this something you have thought about or is it something I can look into to see if they were registered?" or something, it would be far easier for them to keep coming back to you. Because obviously if you know them and they are here, when you come to meet the people from England, the team that come in, it would be a little bit easier all around.

Deputy T.A. McDonald:

You would need somebody very special. As you say local, so that they understand the way of Jersey and so on.

The Deputy of St. Ouen:

I guess that much of what you said, Person B, is within the job description of the N.H.S. nurse that does come over, but you are saying that does not really work and that did not work in your case.

Person B:

I think if somebody had been there from the word go who could do it very gently and help out, I think it would be a much better system, because the nurse that Person A had saying: "Well I had to get up at 3.00 a.m. in the morning", that is not okay. That is the absolute worst possible thing that could have been said as if he was putting her out. That is not okay.

Person A:

As it happened, there is no reason for me to go and change the system and that is when my daughter walked out and she said to her that: "I cannot cope with it."

The Deputy of St. Ouen:

So in your case it continued with [REDACTED] father, is that ...

Person A:

Yes, he took over then because he had flown in and obviously he took over. I did stay partly and what I found, because [REDACTED], was in there and obviously she was in quite a state, and then when this N.H.S. nurse says to [REDACTED]: "I will want to talk to you alone after", and I mean, okay, this young lady may be [REDACTED] years of age, but she was thinking he was

still going to come around, this was basically her first experience with anything happening in death like this, and then I know that she was taken aside and questioning again about their relationship and, okay, maybe at ■ you say you are an adult, but surely she could say: "Do you want a chaperone, do you want your mother to be coming?"

The Deputy of St. Ouen:

Do you know if ■■■■■ was asked if she wanted ...

Person A:

No, she was not asked, she was not asked. And then of course the family we stayed with, because they were supposed to be going on the Monday, they were both going off to ■■■■■ and she cannot because he has gone, you know, and then in liaison with her parents and her mother said ... and of course what happens, everything is recorded on the phones when they were in ■■■■■, she said the middle of the night she phoned them and she went for counselling and she said she could not get on with it. She said: "I am still having to spend some nights with her."

Deputy J.A. Hilton:

Can I just ask you, Person A, why did the N.H.S. nurse need to speak to ■■■■■?

Person A:

They had been in obviously a relationship; they had been together for ■ months, and to be quite honest I think they probably said about their sexual activity, I do not know.

Deputy J.A. Hilton:

Right, because I am just sort of slightly puzzled by that.

Person A:

I do not know, I mean to say, because that is what I get. I mean I have not really tried to cross-examine ■■■■■ to that extreme, but I know from what her mother has told me that she was put through the mill. Two weeks before they had been on holiday in ■■■■■ and then, because, funny, my nephew phoned me up and says to me: "Has he been ■■■■■ in ■■■■■?" because he was ■■■■■ all over the place, he said: "No, only a young ■■■■■ died of ■■■■■ there a couple of weeks ago." But it's quite a fraternity friendship because they all mixed with one another so consequently he could have just got it like that, you see, or maybe from one of the ■■■■■, I do not know.

Deputy J.A. Hilton:

Because I know, Person B, you said that you were not aware of ██████ thoughts on organ donation before this happened. Person A, did that ever come up with ██████, organ donation, had you discussed it before that?

Person A:

Yes, it did, because he was in my office filling out his licence, you know, that is why he was telling me. But I was always under the impression that his thoughts was, and I think it is being looked at, but I thought it was what they call an ██████, a ██████, and I thought it was already in there as part of their thing. I am sure it was, in fact they were supposed to look into it. Because, if that is the case and it is in there they might be sending it to the central organ thing, you see, so it is a bit of a useless exercise if you are putting this in a questionnaire or tick it off and it is not being followed through. Because, like I say, I know that my other grandson, because he is involved in the ██████ world, right away, because he said to me: "Right away we are committed, granddad", because this has come up in discussion and he said right away: "We are committed, we have to write in if we want to opt out", and I thought that was the same, and I am sure it was the same with the ██████ as well. So a lot could be getting missed through these associations not sending it on.

Deputy J.A. Hilton:

Can I just take you back to the time that it was first mentioned to you when you were in hospital by presumably the medical staff there that there was no hope for ██████, how did they make that initial suggestion about organ donation or did you ...

Person A:

No. That was on the Wednesday, the ██████, that they did talk to my daughter but I know that on the Tuesday they had already arranged for the N.H.S. to come over.

Deputy J.A. Hilton:

So they had already arranged it on the Tuesday for them to come over without discussing that with you?

Person A:

Without discussing it with us.

Deputy J.A. Hilton:

But how did they know that you were going to agree to organ donation?

Person A:

They do not; they take it on assumption because the thing was on the Tuesday, when we were there on the Tuesday, because he was taken in on the Tuesday because they thought he had a kidney infection. My daughter texted me from the hospital at 2 o'clock, she said: "██████ got a bad kidney infection", and ironically enough he said to her: "When you come back tonight get me some fish and chips from ██████". She said: "So he is waiting to go on the ward", and an hour later it is the critical care unit: "You better get in." So what is going on, you know, and that is when it was ... and on the Tuesday night the consultant we saw who came in and he said: "It does not look very good for ██████". Then my daughter said: "Could he die?" and he said: "Yes", and he said: "I can tell you there is nothing wrong with his organs there", and he went like that, so they already knew. He went then: "And I can tell you there is no kidney problem, there is nothing wrong with his organs, they are like that."

Deputy J.A. Hilton:

Had you been told at that point that ██████ had ██████?

Person A:

No, because they could not confirm he did because they were in consultation with what they were doing in Southampton and the scans that were going over.

Deputy J.A. Hilton:

So was it a consultant who mentioned it to you on the Tuesday night then?

Person A:

Yes, but it was not the consultant who we had dealt with at the inquiry and he did say I think when we spoke to him at the inquiry that was his colleague who came to us on the Tuesday night and said, when my daughter said: "Could he die?" he said: "Yes", and that is when he said: "I can tell you there is nothing wrong with his organs" and he went like that as if to say they are A1. So there had already been a decision that ...

Deputy J.A. Hilton:

A discussion behind the scenes type of thing. But they must have asked you at some point was ██████ on the ...

Person A:

Yes, they did, I cannot remember when because my daughter said to me: "Do you know, dad, if he was?" and I said: "Yes, he was." So ...

The Deputy of St. Ouen:

So just to get this clear, so then after that discussion when the consultant said he could die, was there a subsequent discussion where they told you there was no longer any hope?

Person A:

No, because they said: "We are going to be carrying out some more scans tomorrow morning", on Wednesday morning. So I went home, my daughter obviously stayed the night at the hospital and she phoned me at 9.30 and it had been confirmed then, she said: "██████████ not going to make it, Dad."

The Deputy of St. Ouen:

So they had a discussion with your daughter?

Person A:

Yes.

The Deputy of St. Ouen:

Then when did the N.H.S. nurse come?

Person A:

Thursday morning, then it was turned off in the afternoon because that was the Thursday morning, like I say, when she had to leave home early, so it was in the Thursday morning.

The Deputy of St. Ouen:

That same morning that your daughter had rung you?

Person A:

No, she had rung me on the Wednesday saying that ...

The Deputy of St. Ouen:

So there was another 24 hours.

Person A:

So it was in the ...

The Deputy of St. Ouen:

So do you know if anyone within the hospital had a discussion with your daughter about organ donation?

Person A:

No one had a discussion with her at that time. She did not know he had signed up on his licence, because it was me who said to her he had signed up.

The Deputy of St. Ouen:

But your daughter had been told there was no longer any hope ...

Person A:

Wednesday morning.

The Deputy of St. Ouen:

Wednesday morning. But are you saying that the next thing she ...

Person A:

Tuesday night that consultant said, you know, when she said to him, I was there when she said: "Could he die?" He said: "Yes." And that's when he came out with: "And I can assure there's nothing wrong with his kidney and the organs." Then if you read the report it said that [REDACTED] had died from the lunch time, he had died within the 12 hours. So from the lunch time it was, I think when he came to see us, he could not confirm it, but he knew fine well he had gone.

[15:15]

The Deputy of St. Ouen:

So the first time anyone from your family knew about the potential for organ donation was when, do you know?

Person A:

On the Wednesday when ... but we were not told that the N.H.S. nurse was going to be flown in and they said: "[REDACTED], can his organs be used?" Yes, he confirmed this, but ...

The Deputy of St. Ouen:

Okay, so who spoke to who?

Person A:

Well there was a nurse there, a very caring nurse, who was very sympathetic and she stayed with [REDACTED] to the end and she sort of dealt with some of that. But then again as a busy nurse she was away and then next thing is, you know, she did not even prepare us that it was going to be the N.H.S.

nurse that was coming over. You see, we were under the assumption that, yes, he had okayed it, and that was going on, you know, that was him.

The Deputy of St. Ouen:

You thought that was going on?

Person A:

No, no, no, that was him, you know, so she had agreed it was on, did not realise that we were going to be subject to intensive questioning, somebody was going to be flown in, we did not know, we were not prepared for any of that.

Deputy J.A. Hilton:

So, do you think, thinking about that, so you knew that it was [REDACTED] wishes for his organs to be used and so you probably had a discussion with him about that as well, so you knew that prior to the Thursday. What I am not quite understanding is why, when the N.H.S. team come over and the parents and the next of kin are in agreement that this should happen, why there is all this questioning?

Person A:

Well it appears it is the same questionnaire that goes through if you give a blood transfusion, if you go and give blood.

Deputy J.A. Hilton:

So they are just trying to find out medical background?

Person A:

It is pretty intense, you know, and when they said it is the same as if you are going to go and give blood, they ask the same questions, but, like I say, the circumstances are totally different, you know, it is not quite the same.

The Deputy of St. Ouen:

Can you remember any of the questions that you heard?

Person A:

No, I could not, I would not be able to. When they were asking them, they were getting intense, I left, I came back, I left, because that is when [REDACTED] said to her ex-husband, [REDACTED]: "You are going to have to deal with this" and his stepbrother stayed there as well and the minute the questionnaire started I felt it was getting intense, I was breaking down, I was going out, and then my other grandson

had flown in and he was in quite a bad spot, and I thought I would go and see him and he did not want to talk to his mother, he just wanted to be on his own. The whole thing gets into ...

Deputy J.A. Hilton:

So it was around that time of the questionnaire that yourself and [REDACTED] removed yourself from that and your former son-in-law finished.

Person A:

Yes and then we went in and out, in and out, and I suppose the whole process could have been 40 minutes, I do not know, I do not know. Do you think, Person B ...

Person B:

I would say that would be a suggestion of getting the list of questions, so then when people look at what is involved, if you have glanced your eye over them once, I mean you will never remember anything in that much of a stressful situation, but if you have seen something once there is a change that it might prepare you a little.

Deputy J.A. Hilton:

Before the N.H.S. team come over you mean?

Person B:

When this goes through and all of the publicity that goes with it and everything, you know, as I said, my thing is about the next of kin, who does what, but I think that might be a time for you to say: "Here is an example of the questions you may face in this situation." I would definitely like to see them; that would make me feel more informed.

Deputy T.A. McDonald:

Could I just ask, had he ever been involved in a serious accident or ever been in the hospital for any period of time? In other words, looking at it from their point of view, could they have gone to a filing cabinet, for want of better words, to find his antecedent history, or was he ...

Person B:

Well you would have thought because that is what I was thinking, what questions would they ask, has he been taking drugs, what kind of things would have affected his overall health? But that is why I was wondering about [REDACTED] being a [REDACTED], I did not know if they would need to do tests on the organs to see if they were suitable to give to someone else.

Deputy T.A. McDonald:

Now would they have known about that or would that be his G.P. (general practitioner) or did he ever go to a hospital clinic or ...

Person B:

I do not know. He was always in hospital because he had changed his [REDACTED] quite recently so we were monitoring it very closely and, to be honest with you, [REDACTED] [REDACTED] so I should have been the one giving those things. Then the G.P. thing you have hit the nail on the head about something, somebody said to me today the G.P. notes and the hospital notes do not match at the moment, so all the G.P.s are online now, are they not, or they should be, with the hospital, so if you have: "I want Person B to be my next of kin" at my G.P. but not at the hospital, it was the other way around, but those 2 things need to be looked at as well so that is another thing that needs to be done. There are lots of intricate things that need to be fixed in order for this to work smoothly.

Deputy T.A. McDonald:

That is it, because obviously the more information they have about you, the less stress, exactly, I was just going to say intrusive questions at the worst ... as Person A said, the worst possible time in your lives and then you are hit with this barrage of questions, you do not know, awful.

The Deputy of St. Ouen:

Is there anything else you want to tell us, Person B or Person A?

Person A:

No, I do not know if Person B has. I think I have just covered everything in the history, you know, what has happened to us and if there is anything you want to ask, if I can answer it I will do.

Deputy T.A. McDonald:

Would you mind if we had to come back to you at a later stage if anything came up?

Person A:

I have no problems.

Person B:

Please do.

Person A:

Yes, I have no problems. The fact is I would not like to see any other families having to go through what we have gone through. If we can help somebody else, so to focus on something else at the

moment, which, like I said, doing this thing, you know, quite honestly even I have been to talk to schools to make awareness of this because, unless it happens, you just sort of think: "Well, it will not happen to me", and she has sort of put it into this fundraising and I thought, well, this would just back it up. And a sad thing over here, the [REDACTED] on the phone book do not take your calls and tell you not to leave a message. My woman who has been helping me, [REDACTED] from the Parish Hall, she has been helping me with this fundraising to put it in, she has phoned up the [REDACTED] head office in the U.K. and said to them: "You know you have a line in Jersey you are paying for and they will not even take a call and if you try the [REDACTED] line it said: 'Do not leave a message, just keep trying to call us'. You try it." If we are paying for that in Jersey, I mean because we were hoping to get their support for the fundraising and to help us, they could help us a bit, but to be there, maybe because we have been doing this bag-packing at supermarkets to give out the leaflets and that, and you go through the phone book, have a look, you try phoning them, and you cannot even leave a message with them.

The Deputy of St. Ouen:

Well then I hope they get that right. That is daft.

Deputy T.A. McDonald:

That is quite hurtful.

Person A:

Well I know, because this is it, and I would have thought they would be very supportive and say: "Righto, we are going to ..." And then: "Do not leave a message, just keep trying us."

Deputy J.A. Hilton:

It has been really helpful you both coming in today. You have raised some really important points and things that need to be addressed if this goes ahead. So we are really grateful.

The Deputy of St. Ouen:

So we are going to meet with the Minister for Health and Social Services, maybe tomorrow, weather permitting, or some other date. We will definitely raise the next of kin issue with him, I am sure the panel would wish to, and we will talk about how these issues can be approached sensitively because we ...

Senator S.C. Ferguson:

It is proper training for the staff. They do not have a sort of an approach like that, it is appalling.

Deputy T.A. McDonald:

The other thing is, for something that is so sensitive and so delicate, this cannot be a position, because, as you know, recruiting staff is not easy, retaining staff is not easy, but this special position dealing with people who either have been bereaved or are at some stage going to be bereaved, that has to be a very special person. It takes years to gain those skills, how to deal with people, because there are people from all walks of life and now all nationalities, all these sort of things, and you would like to think that we in this Island could recruit somebody or have somebody who could be trained to stay and continue on. Because you know as well as I do, if you are dealing with ... in the old days you could go into hospital, you would know the sister and you would know the ... and that is, at times like this, so I am sure ...

Person A:

I was wondering, like a retired G.P. or something like that, whether they would sort of take that on as their post, you know, if you say: "Well, okay, you have a ..."

Deputy T.A. McDonald:

Somebody who knows how to deal with people and have the knowledge ...

Senator S.C. Ferguson:

When I was young we used to have almoners in the hospital and they were brilliant.

Deputy T.A. McDonald:

There is an expression we have not heard for a long time.

Senator S.C. Ferguson:

They have become social workers, which is a pity because they had particular skills. I cannot remember her name, Miss something or other, who had an office on the ground floor at Peter Crill House and what she did not know about what was going on with the patients in the hospital was not worth knowing.

Person A:

It was very often when they spoke to you they knew somebody from the family was married to somebody. Right away you were on a ... you felt at ease because they would say: "You are related to so and so because I know my daughter was ..." and it was amazing that was the way breaking the ice and it was a lovely way to do things.

Deputy T.A. McDonald:

Would that not have been so much nicer than just to see somebody in an N.H.S. uniform, because you have mentioned that a couple of times and I can just imagine the offence and the shock that created for you?

Person A:

Yes, this is it, you know, it is ...

Deputy T.A. McDonald:

But to see a sort of friendlier face that you trust, well at least he knows or she knows ...

Person B:

Who you can communicate with who is there in the hospital so you can go and leave a message if they are not at their desk or something.

The Deputy of St. Ouen:

Tom, do you think there is anything else that we should raise with Person A and Person B?

Scrutiny Officer:

No, I think there is just the issue about transcripts and how you might want to ...

The Deputy of St. Ouen:

Thank you. So Leah's been tapping away in the back there, so there will be a transcript of what you have said to us, which we can use in different ways and you are in charge really. So Scrutiny is usually a public process, we are doing this for the public good, and so we would normally try to publish everything we can and put that in the public realm. So the transcript will get typed up and Tom will send it to you and then we would ask you to consider whether you are happy with that going on the Scrutiny website, which means it can be accessed by anybody and can be referred to in States debates or in any sort of context. Because what you have said is very personal and private in one way, but you also want people to be aware of the difficulties you have gone through.

Person A:

Well what was said here today is no different to what I have gone through with [REDACTED].

The Deputy of St. Ouen:

But Tom will be willing to check that through with you and we can anonymise it so we do not have to give the names of the families, we can just give initials or person A or person B or something, because there are other members of your families and other members of [REDACTED] family, I do not know how they would ...

