

<b>VIDEO TRANSCRIPTS</b>	
<b>Project name</b>	Organ Donation New Zealand
<b>Project code</b> (to be added by LML)	LML78/2797-01
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<b>Title</b>	Chris and Wendy
<b>File name</b>	Chris & Wendy_F9 512x288 (16x9)MASTER_576k.mp4
<b>Transcript</b> (to be added by CWA)	
<p>Chris Southerwood Registered Nurse, Intensive Care Unit</p> <p>1:00:00 In my experience, every family responds very differently and uniquely. It's very hard to predict, and we don't predict anymore. In our experience, we've found that you can't judge families by the way they look or their ethnicity or their age. We often get quite surprised with families when we think "Oh, we're going to ask if their loved one can be an organ donor", and you go into the room expecting them to say no and they say yes. And vice versa, so no, you can't judge.</p> <p>Wendy Gray Registered Nurse, Intensive Care Unit</p> <p>1:00:37 The concept of brain death is something that's very difficult for a lot of people to understand, and I'm not just talking about families but even for medical and nursing staff, particularly if they don't have a lot of experience with it. But brain death is actual physical death of the brain. There's absolutely no circulation to the brain, and there are very specific tests that the patient will undergo to determine that their brain has died, and the test is performed by two different doctors. And it's under very rigorous testing circumstances and done very professionally. The family can be present during testing so that they can see for themselves the responses or lack thereof, that indicate whether the patient is brain-dead or not. So the other thing is too, that for families that have had, and most of our families have had no experience of brain death before, finding themselves with their precious loved one in our Intensive Care Unit. It's very difficult to grasp the concept of brain death when in some situations, we've had the patient in our unit for maybe several days. They may have initially been sedated after their initial injury or the medical event that rendered them, you know, in our Intensive Care Unit. And so they still look like they're sleeping – they've still got all the tubes and wires and things connected. They've still got a ventilator attached and their chest is rising and falling giving the impression that they might be breathing even though the machine is actually doing the mechanical work of breathing for them. The patient will feel warm, they look pink because the ventilator is pushing air and oxygen into the lungs, the circulation is taking that up and feeding that oxygen to the heart. You remove the ventilator and the patient will not breathe; you know, in the case of brain death, there will be absolutely no effort to breathe because it is not possible because the brain has died. So, you know, I realise that it is a very difficult thing to get your head around, and it's very hard to comprehend "How can, how can my loved one be dead when they still feel warm, they don't look dead and I can still see, you know, heart beat squiggles coming across the screen, how can they be dead?"</p> <p>Chris Southerwood Registered Nurse, Intensive Care Unit</p> <p>1:02:54 I think it's really important that everyone talks about death because it's part of everyday life. And in the context of organ donation, if you've had that conversation at home within your family, when it becomes time to make that decision, it's much easier if you know what your loved one's views were on organ donation.</p> <p>Wendy Gray Registered Nurse, Intensive Care Unit</p>	

1:03:23

I know that Chris and I very much view our role as supporting the families and also our medical and nursing staff through this whole process. If I just focus on the family, it's providing them with factual information and answering questions. And sort of putting to rest any issues they might have around organ donation. There's a lot of urban myths out there around organ donation, and you know a lot of those things need clarifying before people can make a decision. By no means is it anyone's job in our hospital, and I believe in this country, to go in and try and twist someone's arm and say you must donate your loved one's organ, there's no choice. It's not necessarily the right thing for every family, and people will have their own individual reasons and we won't question people about their decision to say no. We accept and support and treat everyone the same regardless of their decision. And whilst we know the huge impact that it has when someone is able to say yes to donation, we are also dealing with a family at a time of huge loss and immense grief and, as I say, it's not for us to make that decision on their behalf. The families have to live with that decision afterwards, and really we want to support them through their decision-making process so that they can live with that decision afterwards. I do know from things like attending the thanksgiving services and various study days that Chris and I have attended or spoken on, there have often been donor families that have spoken and also recipients that have spoken. And I've been really impacted by both sides. When I hear the donor families speak, there's that overwhelming sense of grief that comes through, but there's an also of huge overwhelming sense of gratitude for being able to have an opportunity to make something positive come out of such a negative experience as losing their precious loved one. And of course, we, you know, hear from recipients who are just so incredibly grateful to have literally a new lease on life, to have, you know, what was a death sentence hanging over them, you know, is now giving them life and it's amazing to see that and just to, I know that Chris and I feel very privileged to be part of, or a very small part of, that process where that can happen.

<b>Interviewee:</b>	Wendy Gray Chris Southerwood	<b>Organisation:</b>	Registered Nurse, Intensive Care Unit
<b>Duration</b> (to be added by CWA)		<b>06.49</b>	

<b>Title</b>	Mr Adam Bartlett
<b>File name</b>	Adam Bartlett_F9 512x288 (16x9)MASTER_576k.mp4
<b>Transcript</b> (to be added by CWA)	
Mr Adam Bartlett Transplant Surgeon	
1:00:00	
<p>Liver transplantation is a relatively new operation. The first attempt at a liver transplant in a human was in 1963. A gentleman by the name of Thomas Starzl attempted it, and unfortunately that first recipient, Bennie Solis was his name, he died on the operating table. He then attempted on a number of other children and, again, same outcome. And as a result of that he was dismissed from his university. And he went away and thought he could try and solve this problem. And tried to develop the technique using dogs at home in his garage. And fortunately he developed the technique, which is very similar to what we're doing even today. And he was successful in doing the first human transplant in 1967 in Pittsburgh. And since that time, transplantation has taken off. But we've moved from a survival back then of about 10 percent five-year survival to almost 90 percent five-year survival we're achieving today. Most of that has only been achieved in the last 30-odd years. So it's come from a treatment that wasn't even available not that long ago, to something which is used quite commonly for patients which have no liver function.</p>	
1:01:12	
<p>The problem in liver transplantation is there is no dialysis; there is no machine I can put the patient on and hold them for a period of time. So if your liver doesn't work, you need another liver, that's the only way out. In contrast to that is renal transplantation (or kidney transplantation) where you can put them on a dialysis machine for a period of time and hold them. We don't have that benefit with liver transplants. So if somebody goes into liver failure, they need a liver. The two places we can get it from is either somebody</p>	

who is dead, a deceased donor, or somebody who is alive. Preferentially we'd prefer to use a deceased donor because it doesn't place an alive person at risk to give their organ. If one was to step forward and donate to their family or friend, then they do have a risk associated with undergoing what is a major operation. Whereas if we use the deceased organ, which has equivalent outcome for that recipient, we enable a benefit from a tragedy. Something which is, for which nothing of any further benefit is going to come, we can actually pass that on to a potential recipient, who if they aren't transplanted have no other option to them.

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Most people, especially in New Zealand, are only confronted with the question about death when it actually happens. You know it's – maybe it's our British heritage, I don't know – but you don't talk about the ugly things, you don't talk about the war. You know just "hey, I'm alive and kicking so carry on doing that", and for a lot of people the issue of donation, the issue of "after I die, what will happen with me?" is only brought up once they have actually reached that point in their life. And for many of the donors, they die suddenly. They don't die after being told a diagnosis and they've got a week or a month to sort their things out at home. It's a sudden death, and they can't communicate or contribute to the conversation about what would they want. And so people around them become very protected, you would become protected, you think, "Oh, they can't speak, I'm not sure really what they want." And so the natural response is – if you don't know is – "I'm sorry, no, I'd rather not put them through this because I'm not sure whether they would want to be a donor or not." And I guess if the conversation has been had in the past, then you'd probably find more often than not that people would say, "Yeah, sure, I'd be open to being a donor, I'd be open to my organs being consented to be transplanted into other people." But I think it's human nature, the natural instinct is to protect that person who is in a very vulnerable position at that point.

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There is a belief out there that Māori are less likely to donate 'cause of cultural reasons. But actually if you look at our rates of donation in New Zealand, they ... ah, proportionally donate at the same rate as the European population. And interestingly, if you look at live donation, which is somebody wanting to step forward and be the donor, so they are actually speaking for themselves at that stage – whereas in a deceased situation, they can't speak for themselves – they are more forthcoming than the other European counterparts. They're more often they'll step forward and more of them will step forward to try and be the donor and put themselves through assessment, which tells you that, hey maybe if they could speak for themselves at the time when they're deceased, they may actually donate more commonly than we are led to believe.

<b>Interviewee:</b>	Mr Adam Bartlett	<b>Organisation:</b>	Transplant Surgeon
<b>Duration</b> (to be added by CWA)		<b>05.13</b>	

<b>Title</b>	Janice Langlands
<b>File name</b>	Janice Langlands_F9 512x288 (16x9)MASTER_576k.mp4
<b>Transcript</b> (to be added by CWA)	
Janice Langlands Donor Co-ordinator, ODNZ  1:00:00 One of the hardest parts of our role is that we are meeting the family at, you know, probably their worst possible time, and they're very aware that that time that they've got with their family member is now very short before ... very shortly their loved one will go to the operating theatres for their organ removal. So if the family does want to meet us, we meet with them, obviously introduce ourselves, tell them a little about our role and tell them also a little about the support that we can provide for them after the donation. What information they can receive about the outcome of the donation. And I guess probably for me, I think it's always what I need to do is reassure the families that we will care for their family member during the organ retrieval operation. Because I think you know the Intensive Care staff have done a lot of work in supporting	

and caring for the, you know, their family member and for them, and then we're taking over that role.

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In the thanksgiving service, we probably started ... oh ... ah, probably nearly 15 years ago. And I guess it was a respectful way of thanking families for what they've done for others. Because we're very aware that the recipients get lots of follow-up, support from medical teams, and so the donor families we thought were the forgotten people in this process. And so we had started in Auckland, and we had a service at the Auckland cathedral and it's been there yearly since, or annually since then. Donor families, recipients and health professionals are invited, and there's a little bit of a ritual now. We have the recipients light candles to acknowledge the life that they've been given, and donor families are invited to come forward to get a camellia plant called, or the variety's called 'Donation'. And we usually have a donor family speaking and a recipient speaking and a health professional. So it's, it doesn't suit everyone, it's held in a cathedral and obviously that's not appropriate for some families. But some families attend year after year, others come and it's not for them and they don't come again, and there'll be many families who never want to attend such a service. So we have one in Auckland annually and we alternate between Wellington and Christchurch.

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The reality is that most of us won't be able to donate organs for transplantation even if we want to, but potentially we're more likely to be able to donate tissue, such as eye donation, skin or heart valves. And in fact there's no upper age limit for skin donation, eyes can be donated up to 85 years of age and heart valves younger – but up to 60 years of age.

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The families that we talk to after donation, not necessarily at the time but further down the track, usually say that if they know what their family member wanted, that it has been easier for them. That they're not actually making the decision at the time – that was made years before, or months before.

<b>Interviewee:</b>	Janice Langlands	<b>Organisation:</b>	Donor Co-ordinator, ODNZ
<b>Duration</b> (to be added by CWA)		<b>03.21</b>	

<b>Title</b>	Melanie Stevenson
<b>File name</b>	Melanie_Stevenson_FIX_F9 512x288 (16x9)MASTER_576k.mp4
<b>Transcript</b> (to be added by CWA)	
Melanie Stevenson Communications Advisor, ODNZ	
1:00:00 It's very different for Mum, Dad and I, we all feel very differently about organ donation. For all of us, it was a positive thing. For Mum, it's been particularly helpful in her grieving process, and she wanted to know straight away who'd received Jarrod's organs in that you know it's kept confidential but you find out that a man in his 50s received his heart and that sort of information. And Mum after about 6 months wrote letters to all the recipients through Organ Donation New Zealand and just told them a little about Jarrod. And heard back from some of the recipients and that meant a lot to her. I didn't really think about it all until I started working here five years after Jarrod died. And then that's when I started meeting recipients and thinking "wow that's a pretty amazing thing that Jarrod's done". And Dad on the other hand is sort of like, Jarrod's dead, it's great that we donated his organs, the end. So, for me personally, it's been, it's been really helpful and especially in my role here.	
1:01:04 You can't say how you're going to feel in that situation. My aunty always says she doesn't know that she would be able to follow through with her children's wishes if she was in that, ever in that situation. And she was in the hospital when Jarrod was in hospital. So you know even, that's why it's difficult, it's not such a cut	

and dry thing. You never how you're going to feel when you're thrown into that awful situation. So I think that that's definitely worth considering and more people need to be aware of it. It's all very well and good to say "oh, I don't want the family overruling my wishes", but you don't know how you're going to act when you're actually in that situation.

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Jarrold donated his heart, liver, kidneys and his eyes. And so that was six people whose lives were saved, were dramatically improved, from us saying yes to donation. And I, you know one donor can save or greatly improve the lives of up to 10 people. So that in itself is fairly powerful and a bit overwhelming actually. Just we received a letter from Jarrold's heart recipient, not, about 6 months after Jarrold died, and he was just saying that he was a man in his 50s and he was saying just how his life had been saved, well literally but now he was able to spend time with his children and play with his grandchildren. And he was able to exercise again and, you know, do all these things that he hadn't been able to do for years. And receiving information like that really just, you know, makes you go "oh goodness, that's really powerful and we certainly did the right thing" and if we've helped, you know, just one person that much it's what Jarrold would've wanted.

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I can 100 percent understand how families say no when you're in that situation and, you know, Jarrold was 22, fit, healthy, had everything going for him, and they're telling you that he's dead but he doesn't look dead. So that that, is the hardest hardest thing to grasp when you're faced in that, when you're in that situation and faced with that decision to make.

<b>Interviewee:</b>	Melanie Stevenson	<b>Organisation:</b>	Communications Advisor, ODNZ
<b>Duration</b> (to be added by CWA)		<b>03.45</b>	

<b>Title</b>	Dr Stephen Streat
<b>File name</b>	Stephen Streat_F9 512x288 (16x9)MASTER_576k.mp4
<b>Transcript</b> (to be added by CWA)	
<p>Dr Stephen Streat          Clinical Director, ODNZ          Intensive Care Specialist</p> <p>1:00:00          Again I think it's a commonly held misconception, a myth that this decision making is fraught, difficult, complicated, stressful; usually it's none of those things. Why? Because families come together usually, when somebody is dying. They come together as a family. So that the people that you're meeting there are there for a reason. They are there to support the person and to support each other. And they bring that kind of an attitude to this discussion. They tend to be very open to discussion. Remember this discussion is by no means the first time there's been a family discussion about some pretty dreadful things. You don't come to Intensive Care for a haircut; you've come there because your life is in danger. And the family will have had a meeting about that, and then when it's clearer that the person is probably dying, there will likely have been another meeting about that. So the family are all known to each other, they're known to the staff and vice versa. There's already a relationship and there's already an atmosphere where we're all working together co-operatively to address the needs of the person, the patient, now the dying patient, or the dead patient, and the family. And the family have that kind of collaborative co-operative relationship with the staff and with each other. And although people have individual views, it's not the individual that's making a decision here, it's the family as a family. And sometimes that means that some people in the family want to participate strongly in this discussion and others don't. They say, you know, I'm here to support so and so and whatever decision so and so makes, that's fine. The atmosphere is usually one of calm and of compassionate, rational sort of interaction between the staff and the family and between each other. And people don't tend to agonise over the decision, they discuss it and what decision they make arises fairly naturally and usually fairly quickly. They've already had to deal with something, I think, much more momentous, that is the death of their family member. Compared to organ donation, that's a much bigger deal. They often will have had to</p>	

confront the issue of should treatment be limited or withdrawn, or should we continue to treat the person in the hope that they might recover.

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People think if I've put donor on my licence then I'm going to be a donor – that's it, don't have to do anything else. Well very few people actually die in circumstances where donation is possible. It's less than half of 1 percent of all deaths take place in a circumstance where organ donation is possible. Lot more people could donate tissues such as eyes and skin and heart valves, but organs, very few people can donate. So lots of people confront the driver's licence question but less than half of 1 percent of them are ever going to be in a circumstance where they could truly donate. And then, regardless of what they've put on their licence, if they are dying in a circumstance where donation might be possible, somebody will talk about that with their family. Now when that occurs, it's very rare in fact, for the family to request that information. Commonly they don't know what that information is, they know the person and they may think they know what's on the licence and maybe they do. But it's not often even that it's been discussed by the person. And sometimes when they say we'd actually like you to find out and we can find out what is on the licence, they don't get the response that they expect or the response that they would want.

<b>Interviewee:</b>	Dr Stephen Streat	<b>Organisation:</b>	Clinical Director, ODNZ Intensive Care Specialist
<b>Duration</b> (to be added by CWA)		<b>05.25</b>	