



What if you were told your child needed a new liver or their life would end? Or what if the lung transplant you desperately needed just wasn't there and your family had to watch you slowly die, all the while knowing it was avoidable? These are just two stories of many real people whose lives are in the hands of our organ donation systems, or lack of them.

**MELODY TOWNS**

reports

**T**oday in Australia, a man sits in his home, struggling for each breath he takes. With every wheeze his condition worsens and although he continues to take the hundred or more medications laid out for him on the kitchen bench every morning, he can't hide his ailing condition, from the people that he wants to protect most. As his every breath continues to worsen, his family look on horrified – only too aware of the fact that with the right lung transplant, this husband, father and grandfather would not only live but would share in the life that they have built together for a whole lot longer.

The condition is rare, but Idiopathic Pulmonary Fibrosis, a rare respiratory illness that destroys the lungs within three or four years, is curable, for a time, with the right lung transplant. Now, time is everything when you are fighting for your life, but for Rudie Sypkes, time is running out. Now, the fact that Rudie is a pinnacle of success in the Australian business world means little when it comes to saving his own life, but a large donation by his family to the Australian Royal Hobart Research Foundation in aid of medical research is one way that he hopes to see change come about in the lives of those who outlive him.

"It's too late for me, but if it can help others that's what it's all about".

What this sad story makes us ask, is why are lives like this being lost in a country that supports organ donation? Australia has the organ register that New Zealand doesn't; yet with a lack of publicity, support and a well-run campaign the public are still under the misconception that if they tick the box on their licences then they are organ donors. Yet as we will soon explain that is not the case; the fact that only 200 people in Australia donated organs last year highlights the assumption that the system is not working.

"More donors would change figures dramatically for people who die needing a transplant," says Rudie. "In other countries the problem is virtually obsolete with people readily donating their organs, but here in Australia confusion and ignorance is confounding the problem".

It is however, a far better situation than the one that many New Zealanders in need of organs may find themselves in. With only 25 organs donated last year, our need for any type of change is crucial in meeting the basic right to human life. Andy Tookey knows only too well the fight that is on his hands to save the lives of hundreds, if not thousands of New Zealanders when it comes to organ donation.

Andy's involvement began when his daughter Katie was diagnosed with a rare liver condition at birth and told she would need a liver transplant or she would die. Describing the situation the family found themselves in, Andy describes his daughter's dire need of a new liver on his organ donation campaign website, [givelife.org.nz](http://givelife.org.nz)

"Katie was born on the 12th September 2001. Apart from having jaundice, which can be normal for newborns, she was what appeared to be a normal baby. Her jaundice didn't clear up after about ten days, but we were told, 'not to worry, as some babies can be jaundiced for up to three months.'"

"It wasn't until she went for her six-week checkup at the doctor's that he thought she should have a blood test to see why the jaundice hadn't cleared up. The normal 'bilirubin level' (amount of bile) in a healthy person is anywhere between 1 and 20.

"We had a call the next day to go straight to Starship Hospital, as Katie's bilirubin level was 270 plus!"

"After days of tests, it was confirmed that Katie had Biliary Atresia. We had no idea what Biliary Atresia was, initially it was explained that it was a blocked tube and that she would need an operation to 'bypass' the blockage. Though this is devastating enough to hear we thought it would be a routine operation.

"At 11am one Friday morning we overheard a nurse talking to the doctor on the phone confirming Katie would need this operation on the Monday. As we were to be allowed home for the weekend (we were fed up with sleeping on the hospital floor) we accepted that we would have to bring Katie back on the Monday for surgery. As Katie didn't 'seem' ill we were keen to leave the hospital for a weekend at home.

"The nurses said we had to wait to see the doctor, which we couldn't understand why we would have to wait another three hours for him to tell us to come back on Monday.

"We sat in the waiting room for the three hours before the Consultant Paediatric Surgeon (Mr. Vipul Upadhyay) explained the depth of the problem. When 'liver transplant' was mentioned, we went into shock.

"We went home for the weekend not knowing if Katie could survive this, how successful a transplant is or anything. It was the longest weekend of our lives.

"On the Monday, we returned to Starship. Katie had a four-hour operation, which involves cutting out a piece of intestine and attaching to the liver to drain it directly to the bowel. This is not a cure, it buys a bit of time, without this operation (Kasai) life expectancy is around eight months.

"Researching liver transplants, our hopes went up when we found out that they can be up to 97% successful. Our hopes went down again when we found that New Zealand is the worst in the civilised world for the number of organ donors we have!

"I went back to the research to find out why we had low rates, and found a system badly neglected by the government. This is where GiveLife.org comes in..."

Little Katie is now five, but her father's search to get her on a waiting list has not only been to save the life of his child but has also made him take a long hard look at New Zealand's current organ donation system and propelled him to fight for change in the hope of saving the many, many lives of those that are continuing to be lost.

"Not knowing anything about organ donation or transplants I did some research and discovered a liver transplant had a 97% success rate, of course my hopes went down when I discovered that we were the lowest in the western world for the number of donors we have; at that stage there were 40 donors a year (last year it went down to just 25! Which makes us the worst in the western world – between Iceland and Mexico that is).

"I went to the donor service and said 'what can I do to help raise the donor numbers?' says Andy. "They basically told me to bugger off and mind my own business."

Far from 'bugger off', this was just the beginning for Andy who has since founded the website [givelife.org.nz](http://givelife.org.nz), made two



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documentaries regarding his organ donation campaign, appeared on numerous talkback television shows and even gained the support of Hollywood heavyweights.

“With my constant lobbying I was making friends with a few big name people who were supporting my campaign including director Peter Jackson. I was on the talk shows, Holmes and Campbell Live and two documentaries have been made on the work that I’m doing. Another family supporting me (and have made a generous donation) is the family of Hollywood actor Robert Redford. His son needed a liver transplant also, yet there has been no mention of this in the NZ or Australia media”.

Andy poses the question to every person regarding organ donation, challenging us to think about why each of us should consider giving life. On his website, Andy states his plea, “There are currently around 400 people in New Zealand waiting for

a transplant. Some will die due to the lack of available organs. They need not die. You can help. We are not a charity asking for money. Whether you’re rich or poor, all we are asking you is to consider giving ‘The Gift of Life’”.

Andy believes there is a combination of reasons as to why New Zealand’s donor rates are at such a record low. He states that although some reasons are legal the majority are because of lack of education and public ignorance of the real organ donation situation. A large amount of blame is sheeted home to the New Zealand government:

“The government has neglected the area of organ donation in all ways, from funding for the transplant co-ordination centre to training of doctors, from nil advertising to the public of the need for organs to non-education of the process becoming a donor involves”. Andy has continued to petition the government and



has just issued an amendment bill with the help of National MP Dr. Jackie Blue. They are anxiously awaiting its results.

"As the donor rates are at an all time low there is a need for change," acknowledges Jackie Blue. "There needs to be a provision made for an organ donor register and after many public submissions we have put forward an amendment for change. However a donor register will only ever be as good as the world behind it that makes it work, with doctors buying into it and a strong social marketing campaign".

Andy initially submitted a petition to parliament that, he says, "caused a bit of a stir", primarily because he says that it revealed to the public a lot of information that they didn't know.

"For instance, 'donor' on your licence means nothing, it is not checked in the event of your death. Having a living will etc is also not legally binding, it only takes one family member (including distant relatives) to say 'no' and you won't become a donor. If you have no family, or your family is not contactable (maybe you live in NZ but your family is from the UK) and you have donor on your licence you will still not be a donor, because there is no family to ask... even though you have given your permission already.

"I also pointed out that there was not one single piece of promotion or advertising about organ donation. Even the organ donor service was not listed in any NZ phone book. I pointed out that a computer search revealed that the *British Secret*

*Service*, the *CIA* and even the Russian *KGB* were listed with phone numbers but the NZ organ donor service was not..."

The common misconception that you are a donor if you tick the box on your licence is just one of the problems confounding the lack of organ donors. With a success rate that can be up to 97% and donors accepted up until the age of 85, there is no reason why people should be dying due to lack of organs. Andy points out that one donor can save the lives of up to 10 people but once you become a donor you consent to give all your organs, it's an all or nothing scenario. However all organ donors may not be suitable as donors only come from intensive care, however the more donors the greater chance of organ compatibility.

Cindy is waiting for a liver. She writes of her situation on the Give Life website.

"I am a non-practicing registered nurse as I write this. I learned while working on a surgical floor at a small community hospital that I have hepatitis C. By the time I was diagnosed, the disease had progressed so much that within a year of finding out I have Hep C, I was placed on a waiting list for a liver transplant. Professionally speaking, I understood what was happening to me, but I felt like I had no one who could understand what I was feeling.

"As I write this, I have been on a waiting list for a liver transplant for 20 months with a probable additional one to two years of waiting (unless I get sicker faster than that). I had seen "The Kindness of Strangers" produced by the James Redford Institute and posted to the website. I was contacted by one of the families featured in the documentary, Pete and Laurel Wiley. It has been my blessing to have met Pete; his daughter, Laurel and I e-mail several times a week. It has helped to know someone who has been through the waiting period and who is now five years post-transplant and living a full, productive life.

"If I could say one thing to people, I would stress that they make their wishes to be an organ donor known to their families before that situation arises. I think most families would honor their loved one's wishes and it would be easier to do so if they know in advance".

Currently in New Zealand, the only way to inform everyone of your wish to be an organ donor is to register on your driving licence. Presently 42% of drivers are listed as donor on their licence (1.1 million people) yet a recent New Zealand death audit showed that only 38 people out of a possible 104 were donors in 1999-2000. As people like Cindy wait, Give Life urges that changes need to be made and the crucial one is that public awareness is raised.

Andy states, "The most important part of being a donor is to discuss your wishes with members of your family, so that they are aware of your commitment. You've made the commitment, now have the conversation!"

Until then all we have is hope for people in need of organ donations and their families. The words of Sherry, the mother of a heart recipient, provide hope to a situation that desperately needs to be given life. Sherry writes, "My daughter Joi (age 10) has received organ donations for three open-heart surgeries. She was born with a congenital heart defect that was diagnosed at age 3 months. I am forever grateful...tell everyone...Give Life."

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