

15

# POSITIVE PROFILES

***Cystic  
Fibrosis  
WA and  
Connect  
Groups***



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Authors from Cystic Fibrosis Western Australia.

With special thanks to the 15 inspirational adults who have shared their stories.

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Designed by Ruby Pekin-Osborne



# TURNING LIVES AROUND



The Advanced Lung Disease Program was established at Royal Perth Hospital (RPH) in Western Australia in 2005. The program, now in operation at Fiona Stanley Hospital (FSH), is one of four Australian transplant centres known for having the highest transplant survival rates in the world.

More than 2,500 lung transplants are performed each year worldwide. Lung transplantation is a generally accepted therapy for a wide range of severe lung disorders with evidence supporting the primary goal, improved quality of life and survival. Studies have shown significant benefit in certain conditions, one of which is cystic fibrosis (CF), however, it remains a non-curative procedure.

The screening and 'workup' for transplant is extremely thorough and extensive. All body systems are screened and there is optimisation of lung function, nutrition and psychosocial status. Being listed involves a complex discussion of patient information with the transplant team which includes surgeons, lung transplant physician, nurses, physiotherapists, occupational therapists, social worker, dietitian and more. Not all individuals benefit from transplantation.

Transplant is all about the "window of opportunity" with the aim to transplant when the benefit outweighs the risk. The guidelines for consideration of lung transplant in CF are an FEV1 < 30% predicted or a rapid decline, especially in females; exacerbation requiring ICU; increasing requirements for antibiotics; pneumothorax or haemoptysis not controlled by embolisation; and a significant decline in quality of life.

The relative contraindications for lung transplant in the CF community are: a multi-resistant bacteria infection, severe liver or renal disease, nutritional failure, a history of non-adherence or an inability to complete the post-operative regime.

Once a decision is made to add someone to the list the patient must agree to relocate to Perth and be contactable 24/7. They must also agree to participate in pulmonary rehabilitation, which is mandatory, and be compliant with all health appointments and treatments.

Matching donors and recipients is imperative. This involves matching blood group, lung size and the recipient must not have any antibodies that fight against the donor lung otherwise rejection will occur.

The long-term management of lung transplant involves rejection prevention, achieved by lifelong immunosuppression drugs and infection prevention by the use of prophylactic antibiotics and early detection procedures. There is routine pulmonary function surveillance by biopsy, FEV1 monitoring and regular sputum sampling.

**Transplantation improves quality of life and survival in selected patients through careful selection and a complex ongoing management plan involving lifelong immunosuppression and infection prevention and control. FSH continues to perform successful lung transplantation for our CF community bringing a brighter outlook and improved quality of life for many of our members.**

## - References

*Lung Transplantation (PowerPoint Presentation 2016)*  
Sharon Lawrence Advanced Lung Disease CNC, Fiona Stanley Hospital

*Lung Transplantation in Cystic Fibrosis* Jamie Wood,  
Senior Physiotherapist Cystic Fibrosis Sir Charles Gairdner Hospital

# Q

This compilation of positive profiles introduces 15 inspirational Western Australian adults who have graciously shared their lung transplant journey. These stories are relevant for all people considering transplant. Transplant is often an issue for those with cystic fibrosis, raising many questions and in some cases a lot of fear and trepidation. If you would like to discuss any issues that these stories raise for you or would perhaps like to speak to somebody who has had a lung transplant, please contact us here at Cystic Fibrosis Western Australia.

[servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au)



*We hope that you enjoy these stories  
and feel as inspired as we did by these  
remarkable individuals.*

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# A

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HANNAH  
&  
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**Tim & Hannah Bailye**  
**A wife's perspective**

**Five years ago, Hannah was caring for her husband, Tim, who was waiting for a double lung transplant which he received in October 2012. Tim and Hannah have two lovely daughters, Rachelle, five years, and Amy, nine years.**

**Can you tell me a little bit about what it was like when you first met Tim? Did you discuss what the implications of him having CF might mean to you both?**

I first met Tim when I was 13, Tim was 15. I had come from Adelaide for a holiday and we met at Bible school. I had no idea that he had CF. He had a couple of rough patches when he was 15 or 16, but I was living in Adelaide and we had no email then, so I really didn't know what was going on. We did keep in touch and we caught up with each other when I came to visit my family once a year.

When I was 18, I came over for a holiday and we started dating. When things were getting serious, Tim's mum spoke at length to me about what a relationship with Tim could look like. Tim was very open about his disease, and when discussing our future plans, we discussed the fact that it would almost certainly not be possible to have children. First and foremost, CF can cause sterility in the majority of CF men. If we did really want to go down that track then it would probably only be possible if we had IVF treatment. The CF doctors had advised against having children as well because of the risk of infections. Although I always really wanted children, I still wanted a relationship with Tim. As soon as we started dating I had a blood test to see if I was a carrier, so I would know what to expect if we ever did decide to have children.

We have now been married 17 years. We dated in 1999, I moved to Perth in 2000, and we married in 2001. Ten years ago we spoke to the doctor about what the prognosis was for Tim; he advised us that there was no clinical reason not to have children, so we went ahead with IVF. We were lucky. In 2007, we got pregnant with Amy on the second IVF attempt and in 2011, we got pregnant with Rachelle, again on the second IVF attempt.



Tim & Hannah

BAILYE

**Do you feel that your relationship changed much when Tim has been unwell, particularly when he was waiting for his lung transplant?**

Tim got really sick in June 2012. It was a routine check-up. He stayed in hospital for two weeks and just before he was due to come home, he caught influenza A and became extremely sick again. He had a really high temperature. The ICU team introduced themselves advising that he could turn either way. I prayed that I would have a husband in the morning. Fortunately, they brought his temperature and the infection under control and he became better. Unfortunately, this did a lot of damage to Tim's lungs and it wasn't long before they listed him for lung transplant.

Whilst waiting for transplant Tim came home for a week. During that time our daughter had a cold which Tim caught and he went straight back to hospital where he basically stayed until the transplant. We went into lock down, we had very little contact with anyone, only online shopping. We took Amy out of school and avoided public places for fear of catching an infection because we wanted to keep seeing Tim in hospital. We were very careful not to bring any bugs with us; there was a lot of disinfectant hand gel used during this time.

Before that time, we always had regular hospital trips and occasional scares, but it was just part of the journey. In fact, Tim was hospitalised two weeks after our honeymoon. The hospital was really supportive and set up an extra bed in his room so that I could stay over on weekends and hospital trips soon became a normal part of life. I had to learn to be flexible and accepting. The first few times were the hardest because I didn't know what to expect. I would start to know when he was becoming unwell because he would become more tired. Tim probably worried more than I did except for when he got really sick. Overall I am not a worrier, I just went with the flow; however, nothing was a foregone conclusion that we would get through. I did at one point think of planning a funeral in case his lungs didn't come in time.

**Was it difficult taking on a role of both carer and wife, then letting go of the role of carer when he got better?**

I did physio and when Tim was on Hospital in the Home (HITH), I would get his drugs ready and put them through his line. I didn't have to go to his appointments; he was able to manage these. Overall, CF has not affected our relationship. During the six months that he was waiting for transplant, I had to work a lot harder; Tim was unable to move. Even to make a cup of tea was difficult, so sometimes it was frustrating. The experience has made us stronger and more appreciative of what we have. When he was in hospital, I couldn't always be there with him because of the children, which made it hard for all of us.

After the transplant, Tim was out of hospital after three weeks and as the girls were sick, Tim returned home to his parents' house for the first two weeks. We would often drive by and wave to him. It was easy to transition back to a normal relationship. We both felt safer having Tim in hospital when he was really sick. At one stage when he was home, he was on oxygen 24/7 and he woke up coughing, I would have to get up and reconnect all the oxygen tubes from his CPAP machine to the oxygen machine as the CPAP machine didn't allow him to cough effectively and so he had to take it off. Therefore, if I didn't swap him over to the oxygen, he wouldn't have had any. My mum in South Australia had a lot of late night calls during this time, and thankfully she's a good listener.

When we wed, I knew it was highly possible that Tim would have a transplant, but I didn't think it would come so soon. It's very hard to know when things will happen. If it weren't for the particular bug that he caught, maybe he would still be okay without transplant.

When Tim was in hospital waiting for the transplant, we would often meet at Kings Park for a picnic, Tim loves the wildflowers and would show the girls the different types of plants; it's something that our daughter, Amy, still remembers fondly of at that time. The Tim I have now is like the Tim I first met and fell in love with - full of energy and lots of plans.

**“The Tim I have now is like the Tim I first met and fell in love with - full of energy and lots of plans.”**

*- Hannah Bailye*

**What things helped you at this time?**

Faith in God, family, friends and the support of CFWA. The home care workers would assist with physio which really helped because my wrists were weak and I couldn't do physio for very long, and when Tim was in hospital we had home help as well; assistance with the ironing really helped as this felt overwhelming.

**It's been really wonderful to see you and your family able to do normal things again now that Tim has had his transplant. Is there anything that you would like to share with our readers that might help if they need to take on the role of carer?**

It's been an interesting journey. Take all the help you can get and concentrate on your relationship. I was lucky I had a good support network that helped bring meals etc. It's also really important to have some "me" time, go for a walk, and do something just for you.

We have lots of plans to travel around Australia, renovate the house, enjoy life and do all the things we couldn't do before. Tim's lungs are now at his personal best, life is good and the girls can enjoy having their "daddy" back.



*Tim, Hannah, Rachelle and Amy*



# WOMAN SANDI BOWIE

## Sandi Bowie

**Sandi Bowie is a mother, author, librarian and a passionate advocate for cystic fibrosis and organ donation. Sandi denies any and all allegations that her behavior was responsible for turning her husband’s hair grey. She does admit to being guilty of singing along (badly) to Cyndi Lauper songs. Sandi lives in Western Australia with her husband, a disgracefully behaved blue heeler called Pepsi, and a ‘to be read’ pile of books so high that they frequently threaten to cause a "book-a-launch."**

*Sandi was 37 when she received her transplant.*

### What sorts of things did they assess you for to get onto the waitlist for transplant?

There was a barrage of medical tests to assess the rest of my body and make sure that all my other organs could handle the stress of a transplant, numerous blood tests which included my immunity history, followed by updating the required vaccinations. A psychological exam and, finally, a dental clearance were also required.

### What was the decision making process around getting a transplant?

My work-up for transplant took over six months. This was mostly me dragging my heels because I wasn't emotionally ready for a transplant. After I'd done most of the tests/appointments and just prior to obtaining my dental clearance, my husband and I went to Thailand for ten days. There was a moment on the beach when I thought I was coping well, then two elderly people with walking sticks passed me as if I were standing still. That, for me, was the realisation that this time, things were different. Until that point, because I experienced a massive drop in lung function in a relatively short period of time (from 80% down to 25% in under 12 months), I was still fooling myself with the belief that this was just a nasty infection that needed a bit of extra help to recover from. That was the moment for me when I realised that this time my body wasn't going to get better and I was out of options. I got my dental clearance as soon as we returned and went on the list.

### What happened when you were on the list for transplant?

Initially I was sleeping on oxygen, so I carried on with things as normal. I was on summer school holidays, but as my 15 year old son was in the process of moving interstate to live with his dad, it was still a very busy time. By the time I went back to work, I was on oxygen full-time. After only one week back at work I was admitted to Charlies via the emergency department and I began sleeping with Bi-pap at night.



Sandi

I had enough sick leave and long service leave to take extended time off, so I made the decision that this would be best for my health. I ended up doing a repetitive cycle of home IVs three weeks on with one or two weeks off until transplant.

Initially I drove myself to my appointments at Charlies and twice a week to the gym at Royal Perth, but eventually my mum had to become my chauffeur.

### Did you have to wait long when you were listed for transplant?

Five months and one week after being officially listed for transplant, that all important phone call came.

### What sorts of changes happened to your body after transplant?

Lots of changes, but for me, the most significant would be the disorientation. I went from someone who was in-tune with my body, understanding its strengths and weaknesses and understanding my drug regime to being absolutely disorientated. Part of that is the pain relief and massive doses of immune suppressants which can initially affect your memory.

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My son describes my changes succinctly. I am, he says, who I was always meant to be.

- Sandi Bowie

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The other part is learning a different set of symptoms to look out for along with new medications. In terms of both memory and understanding, I had a good grip on things by six months, but to return to the previous point where I was totally in-tune with myself again – that was closer to ten months.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

My son describes my changes succinctly. I am, he says, who I was always meant to be. I think of the changes as falling into three categories:

- How my thinking process/priorities have changed due to being in respiratory failure.
- The difference in my energy levels post-transplant. I spent most of my adult life with an 80% lung function and I have a similar lung function now – but the change in my energy levels is huge.
- Unexplained changes that can only be attributed to cellular memory. I am now rather fond of Lindt dark-mint chocolate (I was a white chocolate girl before transplant, and still am, but I did not like dark chocolate at all.) I also have an intense desire to draw and create arty things.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

I don't recall any trauma at all or dreams. However, while I was in ICU, whenever I closed my eyes I would see kaleidoscope images that would mesh and merge, which were hallucinogenic.

**Where are you now in terms of your health and outlook on life?**

There have been some ups and downs in the last five years. I knew that a transplant would be trading one set of health problems for another. A transplant is not a cure and it's really important to keep that in mind.

But it's a pretty wonderful trade. I've done some amazing things in the last five years; published my first book, written my second. Travelled to Vietnam, Rome, Scotland, Wales, London, Paris and Hong Kong. Married my best friend and watched my teenage son grow up. In my professional life, I've won two industry awards.

I could keep listing things, but the truth is nothing beats the feeling of waking up each morning to take a deep sweet breath without it being followed by the dreaded morning cough and to breathe in without gasping or pain and the knowledge that all day long each sweet breath will be followed by another and another.

As for my outlook, I believe that as a transplant recipient I have three responsibilities:

- Guardianship of something which was once part of another person. I have a responsibility to make informed health care choices.
- I have a responsibility to live my life well and to the full. I wasn't given a second chance to sit around in a bubble.
- To share my story in the hope that hearing how successful transplants can be, will encourage people to join the Organ Donation register, paying it forward someday.

**What are your future plans?**

In the immediate future, I plan to fly to Sydney to celebrate my son's 21st birthday. Professionally, I'm very happy in my chosen career and have no plans to make significant changes.

In my writing life, I have a piece in an upcoming anthology titled "Writing the Dream" which details my writing journey, including the publication of "The Mystery of the Sixty-Five Roses". I'm writing the first in a series of chapter books which feature the continuing adventures of Jeremy and Darcy – where Darcy plays a significant role in helping Jeremy solve mysteries. I'm still looking for a publisher for my first chapter book which features the disgraceful, but sweet-natured antics of my dog Pepsi Parsons, and a publisher has expressed interest in my (as yet unwritten) autobiography.

**What words of wisdom can you offer other people considering transplant?**

Be realistic about your expectations; in particular, you need to understand that a transplant is a trade, not a cure. Push yourself to do some form of exercise each day, even if it's only walking around the house. Ask for help if you need it. Ask CFWA to put you in contact with someone who is a post-transplant recipient so you can ask questions.

Join the post-transplant groups on Facebook – they are not exclusive; people on the wait list or those considering transplant are also welcome. You'll find that many people in these groups are happy to share and they have a range of tips and things they wish they'd done that can make your life easier while you wait. It's also nice to be able to connect to people who understand what you're going through.



## Caz Boyd

Caz is a vibrant and iconic woman in the world of CF, having spent several years on the CFWA board of management in 2010 and once again as a current and active member. She has been involved in several campaigns such as Kalydeco, travelling to Canberra to meet with politicians. Caz has also presented numerous, very moving speeches to continue to raise awareness about CF to the broader community. She has a true sense of glamour, often wearing a touch of red, a wicked sense of humour and tons of resilience. If you can't find Caz in Perth, guaranteed you will find her in her beloved Bali with her loving partner, Chris, sipping cocktails and enjoying a massage.

*Caz was 27-years old when she received her transplant. 22 years ago in 1994.*



*Caz and Chris*

"I guess I was in denial so I spoke to a friend who helped me to decide. She said to me "If I was given a second chance I would take it"..."

- Caz Boyd

**What sorts of things did they assess you for to get onto the waiting list for transplant?**

I had to go to St. Vincent's in Sydney as lung transplants were not being performed here in Perth, however, they started the assessment here at SCGH when the Sydney team visited. They advised me that if I didn't have the transplant I would be dead in two years. When I arrived in Sydney I had to undergo the same assessment which was a bit stressful. I believe I am the longest surviving female lung recipient in WA.

**What was the decision making process around getting a transplant?**

I was in hospital for a tune-up when my specialist mentioned to me that the Sydney transplant team were coming over and that I should see them. I didn't think I was that unwell to need a transplant. I was working, albeit part-time, and had a great social life. My FVC was 0.8, I am not sure what that is as a percentage.

I knew of people who had gone to Melbourne and not survived because transplant was still fairly new back then. It was such a different time, success rates were not so good and I didn't really have any mentors. I only knew of one person who had a successful transplant.

I guess I was in denial so I spoke to a friend who helped me to decide. She said to me, "If I were given a second chance I would take it." Retrospectively, it would have been better to have gone across a lot sooner, before getting so sick. Recovery is so much better if you are healthier.

**What happened when you were on the list for transplant?**

I went over to Sydney in October 1993, the transplant was in November 1994. I was given a pager as mobile phones were relatively new and the size of a brick. I had to attend both Royal Prince Alfred for the CF clinic and St Vincent's for my transplant. I had to attend the gym twice a week at St Vinnies which I really enjoyed as it was very social.

**Did you have to wait long when you were listed for transplant?**

I was listed for nearly 18 months before I got my transplant. The last three to four months were the hardest. I was on oxygen 24/7, so much seemed impossible. Ten days prior to my transplant, I was admitted to RPA with palpitations, shortness of breath and haemoptysis. My body was shutting down. I was given IV antibiotics but was not responding to these. I couldn't shower myself without the help of my mother. I couldn't even make it to the toilet without soiling my pants. Here I was, 27-years old and all my dignity was being viciously stripped from me. Even the simple task of brushing my teeth would render me breathless. I barely had the energy to breathe. I would simply sleep all day scared that this time I wouldn't wake up. I suffered excruciating headaches as my carbon dioxide level was getting dangerously high day-by-day.

A few days later I was put on a respirator. My physician spoke to mum, unbeknown to me, and said that "We've pulled out all the stops for Carolyn, there's not much more we can do. I just want you to know that she probably won't make it to transplant."

**"We've pulled out all the stops for Carolyn, there's not much more we can do. I just want you to know that she probably won't make it to transplant."**

- Transplant team (Caz Boyd)



Finally, just 12 hours prior to my predicted demise, I received the call. I was in the theatre at RPA waiting for the anesthetist to put a PICC line in me as my port had decided it had enough. The nurse and I were chatting and she asked me what I was having the line for. I told her I was waiting for a lung transplant and that I needed to have it before the end of November so I could go home and be a bridesmaid for my best friend, when the phone rang. The nurse said “Yes, yes, OMG yes!”, She then turned to me and said “We’ve got some lungs for you.” I was then taken by ambulance to St Vinnies for the operation. I was so weary by this stage my CO2 levels were dangerously high, I had the worst headache. They only just managed to get this all under control to operate. A few days after the transplant, I saw the anesthetist who was present during my transplant and he said to me, “Wow! Look at you; and to think I thought you would be a waste of organs”.

**What sorts of changes happened to your body after transplant?**

The usual puffy face. I already had chubby cheeks, but after the transplant I looked like Burt Newman’s love child. Taste was different. I think mostly because I had such a long history of coughing and wariness about regurgitation and just wanted easy food. Oh! I love food now. Having so much more energy, that was amazing. I had an extra two hours a day – no physio!!!

My first breath was amazing too. I had pink nails, pink lips. I could feel my toes. I still have a phobia about blue lips, I always like to wear a little lipstick. My best experience was when I took my first shower. I asked the nurse if I could close the door and shower in

private. I was able to inhale steam without coughing; it was so good even though I was still very weak. Before this, I always had to shower with the door and windows open because any steam made me cough.

I also got constipated which, strangely enough, also felt great because it was something I had never experienced before. You have to love the CF bowel. Pre-transplant, my energy requirements were so high everything just went straight through me. I took a lot of drink supplements.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

I think that has a lot to do with, and the fact that, when you feel healthy you’re more willing to try different foods. I had highs and lows mentally from prednisolone.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

I recall being moved from recovery to ICU after the transplant and spitting out the tracheal tube. I was woken up pretty soon after the operation to the nurses scrubbing me to take all the betadine off. I thought “geez, give a girl some rest. I have had a major operation.” During my first bronchoscopy, they discovered I also had some fluid on my new lungs so they had to drain four litres of fluid. But I still felt good, there wasn’t too much pain. The pain was more when I got home, a bit like muscle pain after a full-on gym session.



*Chris, Caz, Mitch, and Anthony*

**Where are you now in terms of your health and outlook on life?**

I have very good health and, yes, I need to get back to the gym. I have a lot of sinus issues, but my lungs are great. I get check-ups as needed at SCGH. My outlook is very good; I have lots of normal plans such as travel and retirement, normal getting old stuff. I didn’t really make plans when I was young such as superannuation, life and health insurance.

**What words of wisdom can you offer other people considering transplant?**

Don’t think you’re immortal, don’t wait until you’re too weak and unwell, don’t leave it until it’s too late. Life is truly amazing after transplant, you have so much more energy. Listen to your body, pace yourself if necessary. Take advantage of your medical team, ask questions and listen to them. Make plans and set goals for after transplant. Most of all, remember you have been given a second chance, take it and enjoy your new found life.

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Life is truly amazing after transplant, you have so much more energy. Listen to your body, pace yourself if necessary. Take advantage of your medical team, ask questions and listen to them. Make plans and set goals for after transplant. Most of all, remember you have been given a second chance, take it and enjoy your new found life.

- Caz Boyd

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DEAN CADWALLADER

## Dean Cadwallader

**Dean lives and enjoys life with his gorgeous wife, Mel, and two children. He also spends a lot of time helping his mum and seeing friends.**

*Dean was 45-years old when he received his transplant. Three years ago.*

"For me it's all about my children and looking forward. Post-transplant living is so much better."

*- Dean Cadwallader*

DEAN CADWALLADER



*Robbie, Mel, Dean and Ruby*

### **What sorts of things did they assess you for to get onto the waitlist for transplant?**

They went through my whole physiology to make sure all systems were okay and that there were no contra indicators. Their biggest concern about me was my occasional non-compliance and my ability to stay adherent to treatment following transplant. There was also a psychological assessment with fairly routine questions about support structures, etc.

### **What was the decision making process around getting a transplant?**

There came a point where I had to stop working. I was too unwell to work, but too well to get a transplant. There was a period of around 10 years of gradually getting worse. Prior to this I had a great job, working lots of hours, however, it was not the kind of work that I was able to do part-time. I entered a kind of limbo state, which was really awful, I was not able to see a future. The work-up for transplant finally came twelve months prior to listing. Two weeks after I was given the pager I got a call, however, the lungs were incompatible. It was six months later when I got my transplant.

### **What happened when you were on the list for transplant?**

I had to go to Royal Perth Hospital (RPH) one to two times a week to do physio and ongoing tests such as the stress test for my heart. Sometimes this was really difficult. I would catch the train from Rockingham to RPH and on one occasion they called a code blue as I was panting so much and was in significant respiratory distress with low oxygen levels. It was a relief to finally get listed, but my anxiety also increased; I kept thinking about my mortality and perhaps, not waking up from the operation. I didn't fear pain or even the operation, I was just really scared that my kids would have no dad. A lot of friends who had been through transplant kept telling me it would be okay and I know the success rate is phenomenal, however anxiety is not always logical and I needed some medication to help with it. I had some sessions with the psychologist, before too, but what really helped for me was writing and drawing as self-therapy. I wrote lots of poems and my drawings I signed off as "CF survivor", not "CF sufferer" which was an important distinction for me.

The other big concern for me was sex. Sometimes it felt like I was going to die I felt so exhausted. I then started to worry about performing for my wife and the anxiety about providing for my kids. I tried really hard to present as a normal healthy male.

“

...but I have these great lungs now and I love to sing, I've been really able to open up, it's been very soul enlightening.

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- Dean Cadwallader

**What sorts of changes happened to your body after transplant?**

My hair has gone thinner and my vision is not as good, but perhaps that's an age thing, too. I got a puffy face and gained weight, but have stabilised. My upper body strength was also diminished. I still feel vulnerable at times. If I have a pain I immediately think "it's my lungs." I fear rejection, however, all good so far.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

Not so much, but I have these great lungs now and I love to sing; I've been really able to open up. It's been very soul enlightening.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

I remember everything about ICU and the epidural. It took them a little while to get the pain under control, but then they gave me a morphine pump. There was no pain after that and the nurses were great.

**Where are you now in terms of your health and outlook on life?**

I'm pretty healthy and have an optimistic outlook on life. You need to have a sense of humour. I wasn't aware of how sick I was; I sometimes remember the look on peoples face when they saw me. They had "look of fear".

**What are your future plans?**

For me it's all about my children and looking forward. Post-transplant living is so much better. There are so few restrictions; I can party harder, longer and better, obviously without over doing it.

**What words of wisdom can you offer other people considering transplant?**

Whilst waiting, keep up your work skills, e.g. education online. Plan for after your transplant. I was really only focused on getting through transplant, not afterwards. Having a transplant is better than the alternative. Children worry about their parents dying. It's important that children and spouses get support because it's a bit of a hard time for everyone.

Doctors need to be upfront and not wrap us up in cotton wool. We need to know what's going on; forewarned is forearmed. Ask your doctor for information. Get out whilst you're waiting, it can become a bad habit just staying home. Force yourself to get out and stay involved with friends and do things; this will help afterwards.



# CRAIG CUTHEL

**Craig Cuthel**

**Craig is now into his 15th year post-transplant, loving life, playing music and living with his gorgeous wife, Katie, and beautiful step-daughter, Verity. Craig is living the life he once only dreamed of. He was born in Scotland and grew up in Perth from the age of two.**

*Craig received his transplant when he was 32 in 2001.*

“I always thought how do you make ‘that’ decision? I don’t think I could make it? Once it was time, the decision was easy.”  
- Craig Cuthel



Jackie Je  
www.jackieje.com.au

Craig

**What sorts of things did they assess you for to get onto the wait list for transplant?**

Lung capacity, oxygen levels, carbon dioxide levels, infection rate and recovery time were the critical markers that said I was ready. My lung capacity FEV1 was hovering between 600mL - 1 litre and at my worst I was coughing up 400 - 600mL of phlegm per DAY. Physio was keeping me alive and I had been doing all my own since I was 16-years old. I pioneered self-physio and did old school percussion on myself. The assessment involved blood type, tissue type, lung size, arterial size, antibody testing (serology) to test for a virus called cytomegalovirus (CMV) which could possibly suppress the immune system.

**What was the decision making process around getting a transplant?**

I always thought how do you make 'that' decision? I didn't think I could make it. Once it was time, the decision was easy. I couldn't walk without looking like I just ran a marathon and I am talking 10-20 metres. I couldn't get dressed. I was on oxygen almost permanently. My saturation was in the 80s but the big one was Bilevel Positive Airway Pressure (BPAP). I used to see people on that machine in the years before and thought I don't care how bad I get, I am never using that. That was until the carbon dioxide intense migraines started.

The build-up of CO2 causes huge problems and BPAP offers relief by pushing the CO2 out of your body...well okay, I will try it. I used it for two years and it was so good to sleep with it on with the O2 being pumped in, It made life a lot more comfortable; not real sexy but what a relief. I was also getting a lot of haemoptysis and some close calls. When you have litres of bright red blood pouring out of your lungs it's quite scary. They tried to seal that through vascular surgery. When you get to that point, the decision-making process is an easy one and once you've made it, you have to go 100% with it.

**What happened when you were on the list for transplant?**

I had to leave all my friends and move to Melbourne for my 'adventure holiday'. That was hard wondering

if you would ever come home. Once there, the whole assessment process started again from scratch. I attended conditioning physio three times per week and other appointments. Luckily the WA Health Department put me and my support team, my mum and dad, up just near the hospital, which was right in South Yarra near Prahran. What a spot. I did see the odd band or ten even when I was on the list.

**Did you have to wait long when you were listed for transplant?**

Once on the list, which took about four weeks, I actually only waited three weeks for my transplant. I am average size and O+ blood so I was very lucky. I was watching the Mel Gibson movie, 'The Bounty'. It was 12:30am (after midnight)...my mobile rang, gulp..."Hello...We may have some lungs for you Craig. Can you be here in an hour?" That's the point where it all hits you. It's a pretty emotional moment. I called my bestie, Dyson, in Perth and all I could do was leave a message "This is it mate, I am going for my transplant...I am going to make it. Talk to you on the other side".

**What sorts of changes happened to your body after transplant?**

I had my CF recovery head on, which was food, food, Ensure Plus and food. I ate the hospital food, my mum brought me meals as well and I ate those and I was still pouring eight cans of Ensure Plus down my throat. That's what I had to do to maintain weight as a person with CF.

I, like everyone, had early rejection and had two 1000mg doses of methylprednisolone (pred) in the first couple of months. I started at 70kg which was a great weight for me, 60-65kg was my usual and I could go to 55kg very quickly when sick. Well, apparently that has a lot to do with your lungs not working as well as your pancreas. In twelve weeks, I was 97kg and unrecognisable, "pred-head" was here. I didn't care. I was alive and feeling amazing. Pred-head is going to happen but it eventually subsides. After a year, I was 82kg and in another year, I was 72kg where I have remained.

Craig



**"Yes, on day one, I thought I was Astro travelling. I could see my flat back in Fremantle; I was flying over it. I flew over Dyson's house, my best mate. I was looking at myself lying in hospital."**

- Craig Cuthel





Craig and wife Katie

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

Yes, on day one I thought I was Astro travelling. I could see my flat back in Fremantle; I was flying over it. I flew over Dyson's house, my best mate. I was looking at myself lying in hospital. I had a rough first day and had to have the resuscitation mask put on me about six times. Apparently, getting my old lungs out because the infections had caused them to fuse to the plural wall, was a long and traumatic operation. Then the epidural moved and I could feel the pain; when I had first woke up I couldn't believe how comfortable I was. That changed. It was pretty rough. My dreams were of bright lights and floating out of my body. But then no I am going back, I wanted to fight.

Day two, I remember thinking I was looking at photos of my family and my surroundings were like an animation...it wasn't photos, it was my family each taking turns standing at the end of my bed. My brother flew straight over and was there when I came to.

I had never drunk wine before. Once I had recovered and was back in Perth, I suddenly had the craving for red wine; not any, but merlot. I loved it...suddenly. The final thing was my hair, it went really curly. It isn't now but in the first year or so it was crazy curly.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant, do you remember anything about this?**

Yes, it was quite intense but all over in two weeks. Mental trauma, yes, that was the biggest part for me. I had a rough start so it was quite worrying in the early part but the staff and nurses were incredible. They were so good at putting your mind at ease, it's all normal. Stuff like taking off your oxygen mask in the first few days and watching the level plummet, scary but normal. My lungs had been a bit damaged from all the handling and it took them about a year to reach their full potential.



Craig

**Transplant wise, a doctor once said to me, "You had your transplant to live...go live your life."**

- Craig Cuthel

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**Where are you now in terms of your health and outlook on life?**

My health today is just amazing. My lungs are 95% predicted. I have a flu right now but you could count the times I have had a chest infection on one hand in 15-years. Compared to an infection with CF, well, there isn't a comparison. I take some oral antibiotics and I am fine in seven to ten days. I remember my first cold, I didn't know what it was. It was so mild it was ridiculous. I have diabetes now but it's pretty mild; I take insulin but I control it well. Eat cake, have more insulin. I still eat whatever I like and don't gain weight, so with good lungs CF does have its advantages. I am all about living my dreams. I am married to my dream girl. I am in my dream band playing the part of my hero and biggest influence Bon Scott, playing to hundreds of people at every show, and love seeing the joy that brings people. I also have my dream job. I am doing very well and I love my life.

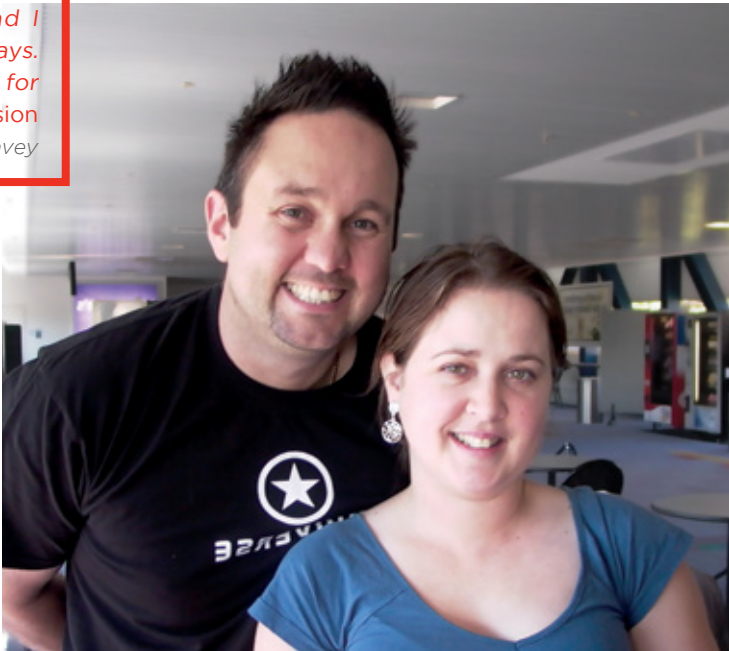
**What are your future plans?**

My future plans are to continue living my dream life. To further my career and improve my skills. My band has a huge year ahead; in its first year it is already Perth's most successful tribute act. We have toured from Esperance to Exmouth and everywhere in between and we are being offered shows in the eastern states. My main plan is to grow old with my beautiful wife, Katie, and enjoy our lives together, so far...wow, so good.

**What words of wisdom can you offer other people considering transplant?**

Stay positive. It sounds cheesy almost but it is so true. It's a battle having CF, fight and fight hard. Never give up. I did three to four hours of physio a day to myself. I vomited and it was just horrible at times but it was what kept me alive. Your biggest threat is apathy. Transplant wise, a doctor once said to me, "You had your transplant to live...go live your life." You can do anything, but just remember balance, everything in moderation. That means you want to have a beer? Have a beer. Would I have twelve? No way. Exercise? Yes, but again, moderation. Don't push yourself too hard in any aspect of life, know your limits and stay within them.

“The actual surgery took 13 hours and was difficult. My oxygen levels dropped and I was in ICU for five days. I was sleep induced for about 48 hours; decision was easy.” Angela Davey



Angela and husband Tim

**Angela Davey**

**Angela is 35, works as a teacher, is married to her loving and supportive husband, Tim, and has a beautiful little two year old girl. Angela was diagnosed with CF when she was three.**

Angela had her transplant in 2008 when she was 27. She was about the 25th person to have a lung transplant at Royal Perth at this time and she was about the second or third person with CF. Angela's health was okay until she was in her early 20s, and then her lung function dropped.

**What sorts of things did they assess you for to get onto the waitlist for transplant?**

They looked at how often I was in hospital, I had chest x-rays, lung function tests and they checked my kidney level function, and my weight. They were checking to see that I would be strong enough to survive the transplant operation.

**What was the decision making process around getting a transplant?**

I wasn't devastated when the doctors told me I would need a transplant, I accepted it. It wasn't always smooth, but I guess there wasn't any other option. I assumed if I didn't do it, I would die.

**What happened when you were on the list for transplant?**

When I was on the wait list I was still working as a relief teacher, between one to three days a week. My lung function was at about 30%. I look back now and wonder how on earth I did that! I still had my regular appointments at Charlies and went to appointments at Royal Perth once a month. I did also start going to the gym at Royal Perth, too.

**Did you have to wait long when you were listed for transplant?**

I was on the wait list for ten months before I got the call.

**What sorts of changes happened to your body after transplant?**

Straight after my transplant my chest felt very heavy. It felt like I had a turtle shell on my back. It took ages for me to get used to the fact that I didn't have to do physio anymore. It would get to 4pm and I would think "I need to do my physio" and then realise with happiness that I didn't have to do it anymore.

I can put on weight much more easily than before my transplant. I also find I have much more energy now. It feels like I was a totally different person to who I was before my transplant.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

No, I don't believe in that. I think it is an interesting subject but I haven't seen the evidence to support it.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

The actual surgery took 13 hours and was difficult. My oxygen levels dropped and I was in ICU for five days. I was sleep induced for about 48 hours. I was out of the hospital after three and a half weeks. I don't feel like it was a trauma going through the lung transplant though. I feel like it was an operation, compared with something like a car accident which is traumatic.

**Where are you now in terms of your health and outlook on life?**

I am just trying to maintain my health and look after my lungs as best I can. It is more important to me now that I also have a little girl who relies on me to look after her. I am also now more aware of things that are harmful to my health, particularly harmful thought processes. I am finding I put more effort into my mind, as how you feel mentally can have a huge impact on your physical health.

**What are your future plans?**

I would very much love to see my little girl grow up and maybe have a second child, or maybe not, it just depends.

**What words of wisdom can you offer other people considering transplant?**

I would recommend making sure you keep yourself occupied while you are on the waiting list, I think that is really important. It doesn't have to be anything strenuous; it could be a knitting group or whatever, but just being part of something keeps your mind directed towards other things. Otherwise you can fixate on the transplant process too much.



DANIEL DI RE



Daniel and Rikke

**“I don’t do words of wisdom, but I guess I would say do it or die.”**

-Daniel Di Re



Daniel Di Re

**Daniel Di Re**

**Daniel is 28 and enjoys spending time with his beautiful fiancé, Rikke. Daniel has a passion for computers and all things electronic.**

*Daniel received his transplant in 2013 when he was 25.*

**What sorts of things did they assess you for to get onto the waitlist for transplant?**

They assessed to see if I was compliant with visits to the doctors, my treatment and physio. I had Lappa (home care worker from CFWA) come almost daily to help me with my physio. They wanted to make sure I wasn’t drinking too much. By the time they were looking to see if I could go on the waitlist, I had actually stopped drinking so much for over a year because it was making me feel even worse, but Dr Musk wanted to be sure. He made me go to an alcohol recovery clinic. I had to go every week.

**What was the decision making process around getting a transplant?**

At first I wasn’t going to consider it because I had been in so much pain everywhere; in my back, chest, and I have lower back sciatica. I thought there was not much point going through having a transplant but still being in lots of pain. But then the doctor prescribed a combination of pain killers that made me feel better; I wasn’t in pain all the time. As I was feeling better with the pain side of things I thought it was in my best interests to keep living by getting a transplant.

**What happened when you were on the list for transplant?**

I had to have vaccinations and go to Royal Perth Hospital to do their physio every morning. I had to work towards getting fit.

**Did you have to wait long when you were listed for transplant?**

I had to wait about two and a half months.

**What sorts of changes happened to your body after transplant?**

I had a swollen face which has gone down a bit now. I put on 15kg but my weight is going back down now due to some medication I am on.

About six months after my transplant, I had pimples which lasted for about six weeks and then went away.

My hair went curly then back to normal. I do get tendinitis as a side effect to one of the medications I am on. I also still get pleurisy in my lungs.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

No, I don’t have anything like that.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

I was really hungry a day after my lung transplant and I tried to eat something but almost choked because of the tube down my nose. I had to ask them to pull the tube out so I could eat as I was so hungry. I was in hospital for three weeks. I had to get used to breathing again as I was on oxygen for about 12 to 18 months before I had my transplant.

**Where are you now in terms of your health and outlook on life?**

Things are still a bit difficult because I don’t always feel so good sometimes after I have taken the mediation I am on. I have to lay down until I feel better. But overall, I feel much better than I did before. I got engaged last November in Bali. I met my girlfriend, Rikke, a year after I had my transplant.

*Daniel’s dad, John Di Re:* "For years before Daniel had his lung transplant he was constantly coughing. I found it very tough watching his health go downhill and had butterflies in my stomach about it. Now, after his transplant, he hardly coughs at all."

**What are your future plans?**

I would like to move out from my parents, but somewhere close by to them, so I can still get free dinners.

**What words of wisdom can you offer other people considering transplant?**

I don’t do words of wisdom, but I guess I would say do it or die.

SHANNON FOX

Shannon Fox

At 30, Shannon has worked as a radio producer and presenter, as a DJ around Perth, managed a band, written music reviews and coordinated communications for music festivals. For the last few years, Shannon has worked on creating her own business, Eclectic Ladyland, which is a boutique in Albany as well as an online store.

Shannon received her transplant two days after Christmas in 2014; she was 28.

“My health is so amazing!  
I LOVE BREATHING!”  
- Shannon Fox

What sorts of things did they assess you for to get onto the waitlist for transplant?

The work up was all encompassing. I had to do intense breathing tests, sleep tests, see the dentist, the gynecologist, a psych... not to mention blood tests and x-rays and bone scans, and basically everything you can imagine, nuclear dyes, CT scans, and ultrasounds. They basically check for anything and everything!

What was the decision making process around getting a transplant?

Once I found out I was eligible, I had to decide whether I wanted one. And I didn't! I was feeling too tired and sick, not to mention my brother hadn't survived his, and I was about to go through a divorce. I was exhausted and prepared to die. But then my family, particularly my niece and nephew, inspired me not to give up. They didn't want me to leave them! And I figured, I either die in a few months or I die trying... or perhaps I'll even live! It's a really hard decision to mak; the mental anguish that comes with transplant is huge.

What happened when you were on the list for transplant?

I had to move back to Perth from the country, which was a huge financial hit as I'd been running a business for less than a year and had to hire full-time staff. It felt like I was at the hospital all the time, it was constant, and I wasn't used to being there that often. Not to mention going from Charlies to RPH (before they moved to Fiona Stanley) was hard. It's such an old hospital, I hated it. I was supposed to go to physio, but rarely got there.

Did you have to wait long when you were listed for transplant?

I only waited six weeks, which is pretty unusual, but I have a common blood type and am quite tall. It was an agonising six weeks. I didn't sleep that well, waiting for my beeper to go off.

What sorts of changes happened to your body after transplant?

Weight gain has been a big one! I'm so hungry all the time, with the steroids, but they also give you more muscle. (My booty is so big now haha!) It can be a bit hard to deal with, going from deathly skinny to 'podgy' in such a short amount of time, although I should have been grateful to my amazing body for getting through such a trauma, I got pretty down about my appearance. My hair fell out and became thin and frizzy, I had to cut it off. My skin also became blotchy and itchy and dry. And I had chipmunk face! Plus the scars are something to get used to, especially in new relationships. I also developed diabetes, which I'd had very mildly before, but after transplant it went nuts!

Some people report weird dreams or other strange experiences. Did anything like this happen to you?

I had loads of hallucinations and dreams in hospital. I actually find a lot of them hard to talk about still as some were really awful. But I do remember thinking my nurse was a kangaroo! I've also gone off meat since my transplant and developed an insane sweet tooth!

There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?

I don't remember any trauma after ICU, but I do remember the whole recovery period being quite traumatic at times. The mental wall you hit is really intense, and the pain killers make life a bit hard.



*“I had loads of hallucinations and dreams in hospital. I actually find a lot of them hard to talk about still as some were really awful. But I do remember thinking my nurse was a kangaroo!”*

*- Shannon Fox*



Shannon



**Where are you now in terms of your health and outlook on life?**

My health is so amazing! I LOVE BREATHING! I have had no issues with my lungs. My FEV1 now is 4.3 instead of 0.8. I can laugh, sing, dance - it's the best. The diabetes is a pain, but I'm getting it under control. Otherwise, the side effects have calmed down now for the most part. The biggest thing recently has been my mental health. I have been on anti-depressants for a while, but I have struggled a lot. I saw a psych for a while, and basically am still grieving for myself and what I went through. It's hard to explain, but apparently very common. You need to give yourself time to process and recover, and I don't think I did! My outlook is positive! I have been working hard and can't wait to have adventures and travel.

**What are your future plans?**

I have just moved back to the country and am working hard on my business. Next step, I have made myself a bucket list and am taking it really seriously! I want to tick off loads of adventures.

**What words of wisdom can you offer other people considering transplant?**

Try not to leave it too late. The better you are, the easier you will find recovery.





Jo

**Jo Giles**

**Jo is currently teaching introductory classes of Tai Chi in Bayswater and attends Edith Cowan University to finish off a Graduate Diploma in Secondary Education. She is the eldest of four and the only one with cystic fibrosis. She writes stories and poetry in her spare time and loves to garden, even though it's not exactly an ideal pastime for a transplant recipient. She owes her good health to her mother, who made her swim relentlessly when she was growing up.**

*Jo was 47-years old when she received her transplant in 2015.*

**What sorts of things did they assess you for to get onto the waitlist for transplant?**

There are a range of tests and procedures that help the Advanced Lung Disease (ALD) Team at Fiona Stanley Hospital assess you for transplant. You don't have to be in perfect health, obviously, but they have to make sure that the transplant won't: a) make you worse, and b) that you are prepared for the responsibility of caring for your new lungs. These are really tough things to try and measure so there are a lot of tests and it can seem to take forever. But the tests are your best chance of enjoying longevity of life as a transplant recipient.

My tests started with an interview with one of the three consultants on the ALD team, Jeremy Wrobel, and I met the Transplant Co-Ordinator, Sharon Lawrence. I was a bit anxious about my first meeting; I was hospitalised at the time and moving around was very difficult. I was badly underweight and exhausted and I suspected I was dangerously close to being too sick for a transplant. I also had CF liver disease and knew that would be an impediment to getting a transplant. I was dreading this appointment. So I took my sister, Christine, and this was a great idea as the amount of information the team offers is absolutely breathtaking. Chris was able to remember things that I'd forgotten and she also asked questions I hadn't thought to ask. By the end of the appointment, the three of us were able to share a little laugh and a smile and that helped.

It's important to realise that the team are being very cautious with you on an emotional/psychological level. They need to be able to discuss the possibility of a transplant but at the same time, they have to be careful not to offer false hope. They need to impress upon you the extensive commitment involved in being a bilateral lung transplant recipient. It's also a good idea to put your best self forward but be honest. Over my 40 plus years of having CF, I have met some doctors who have been utterly repugnant human beings. This has made me wary of new doctors and sometimes

I can be rude and unresponsive in that first meeting. I made myself be polite and friendly, charming and attentive. Luckily, Chris was very pleasant with Jeremy and I think he liked her. That helped.

**What was the decision making process around getting a transplant?**

There were a few major decisions. First, my doctor (Siobhain Mulrennan) made the decision to refer me to the transplant team. This decision was actually brought up several times in the lead up to finally being a transplant recipient. Though my lung function was quite poor, my health was on a plateau. I felt I was somewhat stable and while stable, I didn't want the added stress of adhering to a pre-transplant regime.

***“Secondly, you decide that life with advanced lung disease is untenable. This decision varies from person to person and that can be confusing. Generally, when your FEV-1 is at 30-40% of the predicted mean, it is probably time to look at transplant options. But also look at your quality of life.”***

*- Jo Giles*

Ask yourself some difficult questions, like: When was the last time I looked forward to going out at night with friends? Am I enjoying eating? Am I making new friends or is that just too tiring? It might be the case that you have a good quality of life but your lung function is very poor. This can be difficult as you seem fine but if you came down with a nasty virus, you could become dangerously ill. The decision to "go for it" is probably the biggest decision you'll ever make but it is important you make it one way or the other. You don't want to be struggling for breath before you decide to meet the transplant team.



**What happened when you were on the list for transplant?**

People always talk about "lists" for transplants as if there are queues and when it's your turn, boom, transplant time. Someone told me it's more like a pool and all the people eligible for a transplant (you've met the team, you've had the tests at FSH, you've talked to your family and organised your support team) are swimming in the pool like human-shaped fish. Some lungs are donated. Then the team considers ALL the potential recipients in the pool, even if you were only accepted the day before, and tries to find the best match possible. They do this by looking at several things, like blood type and the size of the lungs. They also consider the health of each "fish". So your lung transplant can happen any day once you have been accepted into the pool.

This can be a really difficult time, a really anxious time. And you have your regular CF appointments to attend as well as your regular ALD appointments at Fiona Stanley. You'll be encouraged to exercise as people who exercise are fitter and stronger. It doesn't have to be a marathon but if you can manage about 20 minutes each day, that will go a long way in helping you recover from surgery. Your physiotherapist will probably have some suggestions regarding exercises to help you maintain some of your muscle strength. I spent the eight weeks before my transplant in hospital at SCGH. I was too sick to leave and for a long time I was too sick to even walk. I had to be fed via a nasogastric tube as I couldn't swallow properly. I was on non-invasive ventilation almost all the time and only came off occasionally to have a cup of tea or a lemonade, a juice or milkshake. It was terribly hard work and then I had to exercise as well. Fortunately, the ward at SCGH, G54, had just acquired a portable NIV (or bi-pap) and I used that to exercise. No matter what your pre-transplant regimen is, most of it is hard work but I guarantee it will be worth it.

**Did you have to wait long when you were listed for transplant?**

I did not wait long for my transplant. The work-up (the pre transplant testing and so on) took time, but once I was in the pool, I only waited about six weeks. There are people who have waited for over a year and people who have waited less than a day. There is no way of knowing how long you'll wait. If you are the type of person who thinks meditation might help, then do that. Go to a class and learn. I learnt Tai Chi and in the year or two before my transplant, one of the instructors decided to start a special class for people with health problems. I was their first student. It was extremely soothing and it helped me to relax.

**What sorts of changes happened to your body after transplant?**

Be prepared for your body to change - a lot. At first a lot of the changes are to do with the surgery. Your chest will be both tender and a bit numb for months and months after your transplant. My liver and kidneys had a lot of difficulty coping with the intense medication administered immediately after transplant. I was still very thin but my body swelled and became very painful in the abdominal area. I had four drains coming out of both sides of my chest and a catheter. I felt as if someone had beaten the stuffing out of me. Every time I tried to move, the tubes attached to me pulled and it felt as if the scar was being ripped apart. Eventually, everything settles down and you start to enjoy breathing.

Breathing with non-CF lungs is absolutely amazing. I must have used that word "amazing" hundreds of times a day. I would occupy myself breathing in and out, in and out. Then I would hold my breath and count how long I could last. I kept staring at the monitor that recorded my oxygen saturation (98-100%) and my heart rate. I could not believe how good the scores were and I took a picture with my iPhone.

I coughed and a tiny bit of mucous came out but it was so light I remember thinking it was like silver. Long term body changes include putting on lots of weight and, for some people, significant water retention. Be prepared for your body to change because now you can breathe, your body will have more energy and you will need to fuel it properly (no more chips and Coke diet, for example). It is all worth it even though, at times, you feel strange.

**Some people report weird dreams or other strange experiences**

During my time at FSH I had several hallucinations but they were fairly manageable and did not bother me that much. I also had vivid dreams and would often tell people strange stories about what I had done "the other day" and half way through the story I would realise that I was talking about a dream or a confused long-ago-lived event. I know of people whose hallucinations can turn into scary or frustrating events in their minds. Some patients, while in ICU, think their nurse is trying to kill them or hurt them.

**"Breathing with non-CF lungs is absolutely amazing. I must have used that word ("amazing") hundreds of times a day. I would occupy myself breathing in and out, in and out."** - Jo Giles

Luckily I did not experience these kind of scary hallucinations or paranoid delusions. I don't think I inherited any likes or dislikes from my donor via their lungs. It's hard to tell. Most of the time I'm discovering the things I used to like doing and, it seems, I still do. I did wonder, however, how my lungs voted in the last federal election when it was time to vote early July. I wondered which party my lungs voted for. But most of the time I have had an overwhelming sense of these lungs being my lungs,



Jo

the lungs I was meant to have and the lungs I finally believe I deserve. I often think about the donor and their family, but I can't say I feel as if I inherited any personal traits from him/her.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

Transplant surgery is serious surgery. It can take around six hours to complete and when you wake up you are pretty sore. Bad dreams, hallucinations, crying fits and feeling unworthy - they are all part of the process. My "trauma" was mostly centred around the time before my transplant so I probably didn't feel the trauma from the transplant as much as I could have. But many do. Because of this, the ALD team has a psychologist you can talk to, a social worker and many of the nurses have seen many. Many transplant recipients go through exactly the same thing. The best thing to do is talk about it.



**Where are you now in terms of your health and outlook on life?**

My transplant was approximately 11 months ago. During that time, I've watched others have their transplants and they are going back to work or going on holidays. I hadn't worked or studied (I had started writing a thesis at university about eight years ago but had to stop as I became more unwell) for a long time and I don't know if the plans I had ten years ago are the plans I want to resume. I have become more involved with the Tai Chi Society, of which I'm a member, and I recently became (re) accredited as a "beginners" instructor (kind of like a junior instructor). Resuming interests and past-times I haven't been able to do for many years has been one of the best things about the transplant. I've also had to work on developing social skills as I had become very socially isolated and used to spending a lot of time by myself. I've been very lucky that many of my friends have patiently been waiting for me to get better and are happy to just pick up friendships where we left off. So I'm still working on where I'm at with my recovery but each week I look at what happened during the week and how things are improving.

**Where are you now in terms of your health and outlook on life?**

Future plans. I have a million of them. Initially, my main plan was to cook myself a meal I actually looked forward to eating - as we all know, hospital food smells like feet and tastes like vomit. I wanted a steak and some rice salad. It was delicious! Some of my plans seemed normal: like returning to university and studying teaching or social science or perhaps doing a creative writing PhD. Some of my plans are probably not incredibly realistic; become stars in a reality show with Holly (also a transplant recipient) about our adventures as CF/transplant women with attitude. Last week, my plan was to make a living from knitting dog jackets. This week I'm thinking of going back to writing so the PhD option is coming

back into my plans again. Like I said, every day I have a new plan and sometimes I think I'm just in love with being able to make plans because I couldn't before my transplant.

**What words of wisdom can you offer other people considering transplant?**

I guess if I have to come up with something it would be this: having a transplant is one of the hardest and most amazing things you'll ever do. So take as many pictures as possible, make your family and friends video you - even if you don't feel like it. If you're into writing, write stuff down (you and your family and friends will laugh, and laugh about it later). Also, transplant meds take a bit of getting used to so you might need to enlist a "drugs buddy" to help you remember to take everything. I was really surprised by how confused I was with all the different meds until I realized that some of the meds have side effects that fuzzy up your thinking a bit. You'll get used to it just as you are used to your CF meds.

The other piece of "wisdom" is simply this: take your time. Transplants, in general, take about a year from which to recover. Bilateral lung transplants are no different and may take a little longer depending on your circumstances. So be patient. Every day people will tell you how well you look and some days you may feel dreadful and wonder what it is they are seeing or why your exterior isn't matching your interior. Other days you will feel so excited and grateful to be alive, you'll want to take on the world. A (not too old) friend whose transplant took place over east in the 90s told me the first year is like a roller coaster and I guess she wasn't wrong. For me, this transplant reminded me how precious everything is and how lucky we are to be here. I know some people curse CF and all of its debilitating symptoms and I guess I have also. But I also know that without my CF genes, I wouldn't be me, I wouldn't have had some truly awesome people in my life and I wouldn't have had this transplant.

**"I wondered which party my lungs voted for. But most of the time I have had an overwhelming sense of these lungs being my lungs, the lungs I was meant to have and the lungs I finally believe I deserve."**

- Jo Giles



Ingrid Laing

**Ingrid has worked in scientific research for many years, taking a break prior to having her transplant and returning back to full-time employment at the Telethon Kids Institute about 12 months post-transplant. She has a very close family, a long term partner (Mario) of 18 years and two gorgeous nieces with whom she and her partner take a very active role.**

*Ingrid received her transplant at 38-years of age.*

**What sorts of things did they assess you for to get on to the waitlist for transplant?**

- Lung function (how bad were my lungs?).
- Kidney function (were my kidneys working well?).
- Gastrointestinal health (did I have any difficulties with my digestion related to my CF?).
- Dental health (did I have any dental infection?).
- Skin health (did I have any skin cancer?).
- Breast health (did I have breast cancer?).
- Heart health (how healthy was my heart? (Probably checking if I were prone to developing a stroke).



INGRID LAINING

**What was the decision making process around getting a transplant?**

I had known for many years that a double lung transplant was probably my only way of surviving with CF past about 40-years of age. I was just too old for the new CFTR treatments that were on the horizon. Even if I had survived until they became available, my lung function would have been pretty poor.

The year before my transplant, I had six respiratory viruses and each had resulted in a permanent loss of lung function despite hospitalisation and IV antibiotics. The antibiotics were becoming less effective. At the end of that year, I saw the transplant team and they were of the opinion that I would be okay for about a year before I would need to be listed for a transplant.

The year of my transplant, I caught a cold on a trip and kept holidaying. Three weeks later, I caught an aeroplane flight and my oxygen saturations nose-dived and didn't recover. I had ended up with the bacteria from my lungs in my blood stream and I was extremely sick. I was in hospital for six weeks and came out of hospital on oxygen. This fast-tracked the decision that I would need to be listed for a double lung transplant as soon as possible.

**What happened when you were on the list for transplant?**

The main things I had to work on were trying to put on weight and maintaining my physical fitness as much as possible. This meant taking about one litre of protein supplement in milk three times per day in addition to my usual meals. I wouldn't recommend starting with adding the protein to milk as I developed severe pain in my diaphragm from lactose intolerance due to the lactose in the supplement added to the extra milk.

**Did you have to wait long when you were listed for transplant?**

The longest part for me was getting listed – three weeks. I had my transplant two and a half weeks later and I was really starting to worry if I would make it. This is quite a short wait compared to many people, but I had such a sudden deterioration that I started on the list close to the top of those most needing one.

**What sorts of changes happened to your body after transplant?**

So many, but the best of all – I could breathe and laugh without coughing. And this has led to such a change in my life. Early on there are lots of side effects from all the medication. I was much more sensitive to hot water and this has lasted to some extent. My feet felt like I was walking on big jelly beans. I had some trouble sleeping in the early hours of the morning. I was affected by vertigo. My face swelled and I put on weight. My hair grew – everywhere. I craved meat and couldn't tolerate sweet food at all. I was completely hyperactive and couldn't stop talking ALL THE TIME!

After transplant I held onto Mario like a lifeline. I was manic after transplant even though I was doing really well. There was so much anxiety before and after about are my organs going to be okay. I had a fear of failure, and it took about two years to adjust mentally to a new life; how to feel about things like retirement, superannuation and getting old.

Now the side effects are less. I still cannot tolerate the hot water temperature in the shower that I used to. I still, occasionally, have trouble sleeping in the middle of the night, particularly if I am stressed. But I often feel tired during the day. I still can't tolerate steep heights as my head spins. My face and weight have normalised to the best face shape and weight I ever had before my transplant and this means that the lines on my face I should have due to age are still pretty faint. My hair is now a little thinner. I still occasionally have food cravings, but they aren't so severe.

*“It takes quite a long time to adjust to your new life – a life with no predictable end. But there are quite a lot of us now who have been through it who would be happy to talk with you as you go through it. Don’t be shy.”*

*- Ingrid Laing*



*Ingrid*



**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

Well, I lost my sweet tooth for a while, but I didn’t have any other new traits that people often attribute to their donor.

**Where are you now in terms of your health and outlook on life?**

I don’t have to worry about weight anymore. I’m pretty happy and I’ve been pretty healthy three years post-transplant.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant, do you remember anything about this?**

I didn’t have an epidural, so I had a lot of issues with pain from the beginning.

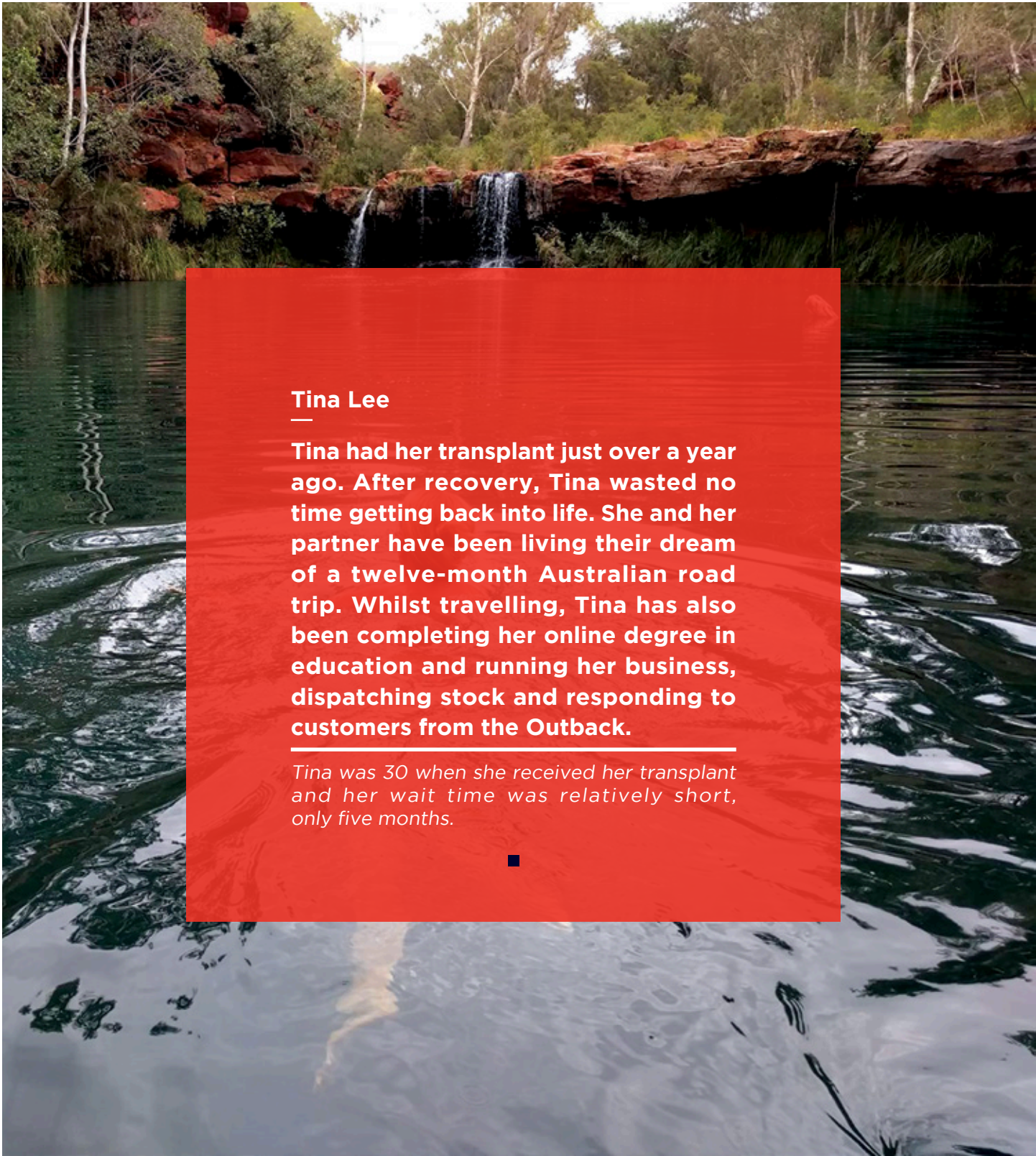
My breathing rate did drop very low (four breaths in a minute) which prevented them giving me more pain killers even though I was in a lot of pain. Other than that, I was lucky enough to have a good recovery. I felt some guilt for surviving in the place of someone else.

**What words of wisdom can you offer other people considering transplant?**

Transplant isn’t a walk in the park, but the rewards of living with healthy lungs are endless. It really helps to have people who love you there to support you and help remind you of all the things you have to look forward to. It takes quite a long time to adjust to your new life – a life with no predictable end. But there are quite a lot of us now who have been through it who would be happy to talk with you as you go through it. Don’t be shy.







**Tina Lee**

**Tina had her transplant just over a year ago. After recovery, Tina wasted no time getting back into life. She and her partner have been living their dream of a twelve-month Australian road trip. Whilst travelling, Tina has also been completing her online degree in education and running her business, dispatching stock and responding to customers from the Outback.**

*Tina was 30 when she received her transplant and her wait time was relatively short, only five months.*



Tina

**What sorts of things did they assess you for to get onto the waitlist for transplant?**

- Compliance to existing treatment and medications.
- Lifestyle factors, i.e. smoking, drugs, drinking.
- The capacity of my other organs; were they strong enough for transplant treatment?
- The transplant team do regular blood tests to check for any possible diseases, cancer, STDs, STIs to make sure they have the full picture of my overall health.
- Dental check
- Pap smear
- Bone scan
- Skin check for cancers
- Psychology evaluation to ensure that I was mentally prepared.
- Liver and kidney scan
- Have all vaccinations

**What was the decision making process around getting a transplant?**

The transplant subject had been spoken of occasionally with my doctors over the years. Once I started to deteriorate to a point where I was struggling to maintain a good quality of life due to frequent hospital admissions, Dr Mulrennan, Sue Morey and myself had THE talk. We discussed options regarding new treatments and trials that I could participate in to no avail. I was simply too weak to even qualify for any trials. We agreed to look at the transplant prospect and a referral was made for me to see the team at RPH. The journey had begun.

**What happened when you were on the list for transplant?**

To get on the list is a marathon event. Once you are there, life becomes much simpler as most of the tests have already been completed. Once listed, it was a matter of attending weekly physio appointments, meeting with the surgeon, seeing the transplant team once a month for check-up, and blood tests.



Tina

TINA LEE



“

The transplant process can be tough, but the outcome and the life you have afterwards is better than you can possibly imagine. It really is the most incredible gift of life.

”

- Tina Lee

**What sorts of changes happened to your body after transplant?**

Quite a few that I was not expecting: my face was no longer bright red due to lack of oxygen, I no longer had blue lips. Initially I was very puffy, like the Michelin man due to the steroids but it went away after about a month or two. My skin started to peel like I had bad sunburn. I have a constant tremor due to the tacrolimus; this has improved over time. However, it gets worse if I'm anxious. My hair started falling out, partly due to tacrolimus and stress (I had a few complications plus an extreme needle phobia). I learnt how to cope with some really difficult situations. I set aside twelve months for any complications to occur, that thought process got me through. Luckily, twelve months on, all seems to have settled down.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

I'm not sure if it's relevant but I've developed a love of the gym and fitness. To be able to complete a class with the healthy folk is an incredible feeling. I love the fact that I have little muscles now instead of just being skin and bone like I once was.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

No I didn't. My only trauma was that I was only allowed to eat ice!

**Where are you now in terms of your health and outlook on life?**

I'm very happy; quality of life has improved dramatically. For me, life began at 30. Health has

been wonderful for the past six months; I maintain regular contact with the transplant team which helps to alleviate any concerns. Keeping healthy is definitely a team effort.

Currently, 13 months post-transplant, I'm traveling around Australia which will take approximately 12 months. Prior to transplant, this would never have been possible. Loving life!

**What are your future plans?**

At the end of the year, I will be graduating university after completing my Bachelor of Education degree. Next year, I plan to return to work full-time and start our surrogacy journey to have a family. I'm sure this will be followed by more travelling and, hopefully, building a new house! It's a wonderful feeling being able to make plans now. That was once a cruel thought.

**What words of wisdom can you offer other people considering transplant?**

The transplant process can be tough, but the outcome and the life you have afterwards is better than you can possibly imagine. It really is the most incredible gift of life.

Surround yourself with strong people - you will need to lean on friends and family more than ever as you make your journey through the process.

Start setting goals NOW... It helps to have a visual motivator!

I hope this helps.

Tina

**Matthew Maartensz**

**Matt is an extremely fit young man, happily married for two years to a gorgeous young woman who also has cystic fibrosis and has had a transplant. Matt and his wife have also bought a house; they have lots of future plans and two energetic dogs to keep them busy.**

*It was in 2014, at 25-years of age, that Matthew received his transplant.*



Matthew and Kaila



Matthew

**"I was hungry. I love food and was eating pancakes by Tuesday"**  
*- Matthew Maartensz*

**What was the decision-making process around getting a transplant?**

It was about quality of life; I was getting sick and not bouncing back.

**What happened when you were on the list for transplant?**

Pre-transplant the physio team seemed to have low expectations, probably because I was already working out, doing strength and conditioning work twice per day. I was on the way to the gym when I got the call for the transplant.

**Did you have to wait long when you were listed for transplant?**

Believe it or not it was only three days!! I went in on Sunday night had the operation and was eating on Monday. I was hungry, I love food and was eating pancakes by Tuesday. I was reasonably well prior to transplant even though my lungs weren't so good the rest of my body was okay.

**What sorts of changes happened to your body after transplant?**

Anti-rejection tablets affected muscle tone and strength. This took a couple of weeks to restore. It probably wasn't too bad because I already had a high level of fitness.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

The first breath wasn't easy; my lungs were tight. Everything is foggy, you don't know what's going on. The medications can cause hallucinations. I thought the TV was going to get me and that I couldn't trust the nurses. Things started to stabilise about day three or four. My memory was also affected and sometimes still is.

At hospital, my lungs collapsed around one week. I went onto a ventilator because I couldn't breathe and couldn't see. I went into ICU. I was intubated and had my chest cut open to drain fluid. At 19 days I was due to return home and, due to the trauma of this incident, was scared that it could happen again, but everything was okay.

**Where are you now in terms of your health and outlook on life?**

My health is good; my lung function is around 90% and my exercise tolerance is very high. I watch my diet, having about six meals a day, around 4,000 calories as I have some malabsorption and take Creon and insulin. I had diabetes before transplant and the transplant made the diabetes a little more complex, however, it's manageable.

**What are your future plans?**

Nothing is off the agenda. I'm loving work as a personal trainer. I have my own business, Pro-Fit WA, and my own gym, including mobile personal trainer service. I would like to travel around the world with my wife now without getting sick.

**What words of wisdom can you offer other people considering transplant?**

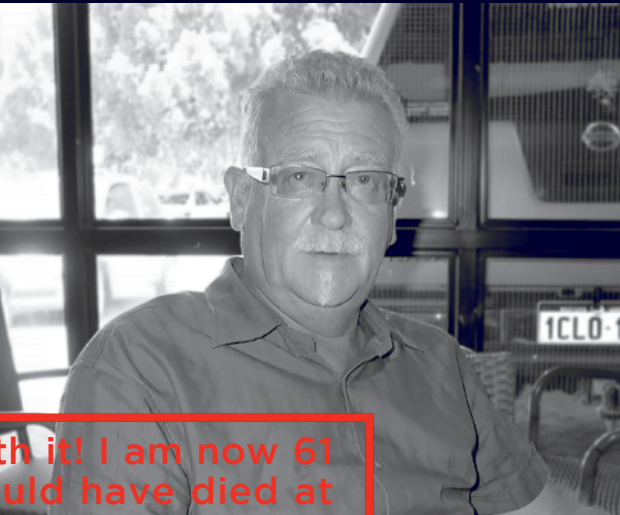
It was important for me to keep fit pre-transplant. If feeling low, exercise always helps to pick up my mood. Having goals and rewards both pre-and post-transplant are really important.

# MARIO PALANDRI

## Mario Palandri

Mario is now 61-years old. He recently retired due to a few age-related issues, however, spends lots of positive time with his two grandsons, long term partner, Ingrid, and their dog. He has also spent lots of time travelling the world and has enjoyed a full and interesting career.

Mario was 39, nearly 40 when he received his transplant.



Mario

**“It’s worth it! I am now 61 and I would have died at 39. I have lived to see my son grow to be an adult and to meet my grandsons. I went back to work full-time soon after my transplant and I am now retired.”**

- Mario Palandri

### **What sorts of things did they assess you for to get on to the waitlist for transplant?**

Lung function, drug screening, medical and social support history, can’t remember if there was anything else.

### **What was the decision making process around getting a transplant?**

I was short of breath all the time. My physician told me I had a maximum of one year to live. I knew some of the people who had already moved to Melbourne for a transplant. I could arrange employment while I was in Melbourne (two days per week). My employer was happy to let me compile all my leave from work to go and I could afford to go while still supporting my family in Perth.

### **What happened when you were on the list for transplant?**

I had to try and keep up my fitness, which I mainly did with walking. I had to attend gym sessions. I had to carry a pager. I worked two days per week carrying my oxygen on my back and I had to be treated for chest infections

### **Did you have to wait long when you were listed for transplant?**

Eleven months

### **What sorts of changes happened to your body after transplant?**

I was able to walk long distances and up a lot of stairs. When I came home, I was able to play cricket and I gained weight.

### **Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

I had to wear my watch on my other arm.

### **There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

My epidural broke and when they finally found out, I had a big dose of morphine and then some strange dreams.

### **What words of wisdom can you offer other people considering transplant?**

It’s worth it! I am now 61 and I would have died at 39. I have lived to see my son grow to be an adult and to meet my grandsons. I went back to work full-time soon after my transplant and I am now retired.



Ingrid and Mario



**Gavin Pearce**

**Gavin is a family man with a lovely wife, Trish, and three children. He is also highly motivated and a keen swimmer, having swum the Rottnest Channel Swim three times and done several triathlons.**

*Gavin was 40 when he had his first transplant. While waiting for transplant, his wife and mum thought it would be funny to put 40 candles on his cake. He had trouble blowing out one. Eventually, he was rejected after five years. He was in hospital and not particularly well when the transplant coordinator came in and said "Happy birthday, we've got lungs for you." Presents don't get much better. Happy 46th.*

GAVIN PEARCE



*Gavin  
Cottesloe to Swanbourne Swim*

**What sorts of things did they assess you for to get onto the waitlist for transplant?**

The main criteria for selection is height and blood type, so tests around that. There were many others involving breathing, infections, etc.

**What was the decision making process around getting a transplant?**

This was tough. I was torn between going too early and being too sick to survive the waiting time for new lungs. I had run out of criteria to assess that. I eventually decided to take three months off work and commit 100% to health and fitness. It was a dramatic failure but gave me total clarity about needing a transplant.

**What happened when you were on the list for transplant?**

My first transplant was in Melbourne, so no distractions with total focus on surviving and being prepared for transplant. It was quite convenient as we lived a couple of blocks from the hospital. I spent a lot of time as an inpatient in hospital. I was there with my wife and two year-old son.

My second transplant was in Perth. Very different as I could be around friends and family! I used to go to my local gym but with lots of visits to the hospital. I was the first person in WA to have a second lung transplant so the transplant team were pretty intense about making everything go right.

**Did you have to wait long when you were listed for transplant?**

My first transplant I waited nine months. It seemed like I would never get one, and an incredibly long time. While my focus was all on transplant, I tried to enjoy Melbourne as much as I was able to, to take my mind off it.



“There is nothing more to say other than I could breathe.  
No more chest clearance physio.  
I suddenly had five hours of my day back.”

- Gavin Pearce

My second transplant I waited six months. My breathing was heading south at 3% a week. After three months, I stopped doing breathing tests as it was pretty much accepted that my breathing was screwed at 18%. I spent most of my time in bed and on oxygen, not a great existence.

**What sorts of changes happened to your body after transplant?**

There is nothing more to say other than I could breathe. No more chest clearance physio. I suddenly had five hours of my day back. Very odd transition to deal with! I turned pink from a dull grey, my appetite improved and I gained weight. Generally, my state of wellbeing improved dramatically.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

There was no sudden change about liking beer, this was a well-established habit already. However, my favourite colour was always green, but it changed to yellow. Very weird.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

I was very nervous about leaving the security of ICU, but the post-transplant staff are amazingly diligent and switched on. I was very well looked after. In Melbourne, I had a lot of pain from infection, so I was looked after by the pain team. I gave them a case of wine on departure, so on subsequent admissions I was the best looked after guy in hospital. Just to add, I had absolutely no pain on my second transplant here in Perth.

**Where are you now in terms of your health and outlook on life?**

I continually keep my health and fitness on a fairly short leash. Balancing CF, transplant, Type 1 diabetes and life can be difficult to navigate at times, but one of my mottos is “plan for the worst, expect the best”. Keeping a baseline level of fitness is crucial as the medication can deteriorate muscle mass.

Daily training bores me silly so I need goals to motivate myself, which involve sporting events. Six months after my first transplant, I started doing triathlons. I ended up doing three seasons, I loved it. After my second transplant I had a “why not” moment which led to having done the Rottneest Channel Swim three times.

**What are your future plans?**

I'll keep doing these events as long as I can. Exercise, while great for physical improvement, does amazing things for the mental state. My career plan is to retire from “dollars for hours’ style work” and replace it with investment returns. I want to lie on a beach in Thailand drinking a cocktail and looking at my balance sheet on my laptop.

**What words of wisdom can you offer other people considering transplant?**

Strike that balance between waiting too long and being fit enough to do well after the transplant.

Always have a goal. Times will be tough. To get through and absorb the lumps and bumps, you need a strong, clear goal about where you're heading. Do lots of sit-to-stand exercise while waiting for transplant; you have to be able to get out of bed after the op.

I've had two double lung transplants, with very different experiences. The last one I virtually had no pain with a very quick recovery... no physio... Onwards...

# THOMSON

## Stacey Thompson

**Stacey is 31 and has a 13-year old son, Jack. She enjoys watching her son play sport, going with her family to the movies or out for dinner or shopping with friends.**

*Stacey received her transplant at the age of 27. Her son, Jack, was nine at the time. It's the biggest thing she has done in her life and she says it was more full-on than having a baby.*

# STACEY

## **What sorts of things did they assess you for to get on to the waitlist for transplant?**

When I was being assessed to be put on the waiting list, they looked at my oxygen saturation levels, how often I was needing antibiotics, how often I got admitted into hospital or needed IVs at home. They checked how quickly I was desaturating and I had to do the six minute beep test to check my fitness levels.

## **What was the decision making process around getting a transplant?**

The doctors came to a decision that I should be put on the transplant list due to the deterioration of my lungs and the antibiotics were no longer doing their job. My body was becoming immune to them and I was getting sicker and sicker. I decided to also do it for my son.

***"My future plans are to become a grandmother and to be the longest living transplant recipient and make history - ha ha!"***

*- Stacey Thompson*

## **What happened when you were on the list for transplant?**

When I was on the list there was one main thing I had to concentrate on and that was my weight. I had to put on more weight before I got my new lungs. I also had to attend heaps of appointments and physio sessions. I didn't have to go on oxygen, as my oxygen saturation was still at 95%, and the transplant team were amazed.

## **Did you have to wait long when you were listed for transplant?**

When I was on the list, it took me about two and a bit years for me to get a call.

Stacey







Stacey and Jack

**What sorts of changes happened to your body after transplant?**

Not much really happened besides more scars and developing a lazy eye, which is more noticeable when I'm tired. They checked to see if I had had a stroke, which I hadn't. They don't know why, maybe it's to do with a nerve. For a while my laugh changed, which my mum and husband both noticed. It might have been because I was sore and didn't want to hurt myself.

I had the typical round face that you get due to the steroids, which people call "moon face". But that's gone now as I am not on as many steroids. I have got cystic fibrosis-related diabetes now as a result of the steroids, which is tricky because I really like sweet things.

**Some people report weird dreams or other strange experiences. Did anything like this happen to you?**

Yes, I had weird dreams that were not nice. I also woke up suddenly due to jumping a lot in my sleep. This was because of some of the tablets I was on; it didn't last for too long.

**There is some evidence that people experience some trauma after coming out of ICU after the transplant. Do you remember anything about this?**

No I did not have any trauma that I know of after coming out of ICU. I was ready to come home a week later but had to stay in the hospital for the minimum time of two weeks.

**Where are you now in terms of your health and outlook on life?**

I am doing really well; my health is better than ever. I have had no problems as of yet with my new lungs. My outlook on life is that I'm happy to be here, knowing that I will be around for a lot longer to see my boy, Jack, grow into a young man.

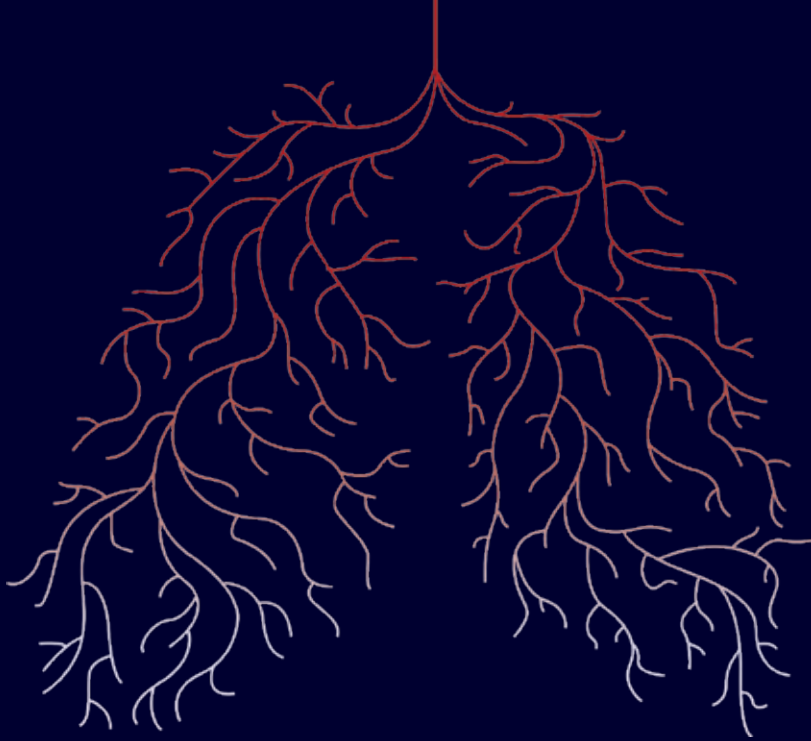
Throughout the time when I was waiting and then having the transplant, my husband, Michael, and son, Jack, were really good. Jack had days where he was worried but he doesn't talk much, but he knew what was going on and he knew it was very serious. After I had my transplant Jack was amazed. He said he was looking forward to running a race with me once I was better. He is champion boy at his school in running. Well, anyway, a couple of weeks ago we had a race and I beat him!!

**What are your future plans?**

My future plans are to become a grandmother and to be the longest living transplant recipient and make history - ha ha!

**What words of wisdom can you offer other people considering transplant?**

My words of wisdom are to be positive and never give up because everything works out in the end. A very wise man said: "Your health is your wealth and you never know how strong you really are until being strong is the only choice you have".



**Turning Lives Around.**



# POSIT



POSITIVE . PROUD .

*15 inspirational Western  
Australians share their  
story on their lung  
transplant journey with  
cystic fibrosis.*



# -LIVE

