DonateLife

BOOK OF LIFE

A collection of life-saving and life-changing stories from people touched by **organ and tissue donation.**

Volume 3

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DonateLife Book of Life

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Her Excellency Ms Quentin Bryce AC
Governor-General of the Commonwealth of Australia

Foreword to the DonateLife *Book of Life*

by Her Excellency Ms Quentin Bryce, AC
Governor-General of the Commonwealth of Australia

As the inaugural DonateLife Ambassador, I have been privileged to observe the impressive leadership of the DonateLife team and agency network in managing organ and tissue donations throughout the country, and in educating Australians about the issues that are central to our decisions to give life.

Inspired by the work of these outstanding professionals, the DonateLife *Book of Life* is a heartfelt appeal to all Australians urging us to find out the facts about organ and tissue donation, to make well informed decisions, and to discuss those decisions with the people close to us.

Here is a collection of stories from brave and thoughtful Australians whose lives have been touched and transformed by a donor's life-affirming decision. These honest and grateful accounts pay tribute to the generosity of lives tragically and abruptly ended: the ultimate act of giving life to another as one's own life passes.

The DonateLife *Book of Life* starts its journey around Australia in DonateLife Week, Sunday 20 to Sunday 27 February 2011, a campaign led by the Australian Government's Organ and Tissue Authority to raise donation awareness among Australians and to increase our donation rates.

It is my hope in 2011 that, as these stories are shared across the nation, many more of us will be moved to think, talk and act on a decision that can help bring life and healing to thousands of Australian lives.

This is a decision for all of us and each of us. We share life and we share a capacity to give life. Our personal experiences of living and giving are most powerfully told through our stories. This book is our carriage and our conduit for ensuring that our decisions bring the greatest good to the greatest number in the Australian community.

We are forever indebted to those Australians who have chosen to give life. They have made their mark in the most profound ways and the DonateLife *Book of Life* bears their courageous stamp.

May these pages travel far and deep across our generous land.

Quentin Bryce

6 February 2011

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The most important thing that helps a family's decision is their knowing the donation decision of their loved ones.

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An 11th hour 'gift of life'

Words cannot describe how I felt when I regained consciousness after my double lung transplant surgery in 2009. As I looked at the nurse I realised: I had been saved with the 'gift of life.'

I had deteriorated very quickly from the affects of idiopathic pulmonary fibrosis (IPF) and had been put on the transplant waiting list. My father and brother died of the disease and I was diagnosed in 2006.

Lung transplantation was the only thing that would save my life.

Already a patient in a hospital intensive care unit when word came through of a possible transplant, I was transferred to The Prince Charles Hospital, Brisbane.

Had the lungs not been a match I would have been placed in palliative care with pain relief. It was just a miracle that the donor lungs were a match.

In the early days of recovery I believed that I must have been touched by angels, but I knew who the angels were: my donor and his or her family and the transplant unit.

Aged 62 at the time of transplant, I was discharged from hospital after just 11 days to start on the road to recovery.

Along with my husband Barry, daughters Kristen and Jacqueline and son-in-law Eric, whose love and support has sustained me, I am a very grateful human being.

Life is precious and beautiful. As I go about my new life with vigour and excitement, I feel extremely special that I walk with the lungs that belonged to another human being.

It's my fervent wish that my donor's family can take some comfort in the fact that the donation of their loved one's organs saved the lives of up to five people that day.

The most special thing about my new life, apart from being with my family and watching my little grandchildren grow up, is being able to breathe freely.

Thank you to my wonderful donor.

Marion

Photo courtesy of Gold Coast Publications

Marion is now able to enjoy her grandchildren thanks to the life-saving generosity of a donor.

Discover the facts
Decide about becoming
an organ and tissue donor and
Discuss your decision with
the people close to you.

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My Hunt

The way I remember Hunter is him being a little ratbag, laughing at the world and thinking that he was the boss. Hunter had my heart wrapped around his little finger. He was and still is the highlight of my life.

Hunter was born in late 2005. Arriving two and a half weeks early, he weighed 8 pounds 6 ounces or 3.8 kilos.

Hunter had a difficult start to his life. When the doctors delivered Hunter he was struggling to breathe and he had to be whisked away and put on oxygen for the next few hours. Luckily for me I had a little fighter on my hands.

Hunter was just such an easy going baby. He was the kind of baby that people are jealous of. I guess I didn't know at the time that I was living with an angel without wings.

I think Hunter knew that he didn't have long in this world. He was in such a rush to do everything. He sat up and got his first tooth at five months, he crawled at seven months, started walking at eight months and was running by nine months! He was always so busy, never stopping for a breath—just go, go, go. He was the reason I got up in the mornings!

The day Hunter died is a day that I would much rather forget. Hunter's death was very unexpected because he wasn't a sick child, so when he was rushed to hospital with a bleed on the brain, I knew that I would never take my baby home.

That day was the day that my heart was broken! When Hunter's father and I were asked to consider organ donation it was not a decision that we had to think about. We decided that we would never want anyone to go through this, that no mother or father should ever have to bury their child and if Hunter could help just one other person or another baby then Hunter would donate his organs.

We had Hunter christened the next morning and we got to give him his last bath, and then we just waited for the doctors to take him for his donation. We did get to spend as much time with him as we wanted after the operation and I think it was the early hours of the morning before I left the hospital.

The doctors who operated on Hunter said that they were honoured to do so as he was the smallest person that they had operated on at that time. We believe what Hunter did was such a beautiful gift and feel that he was given to us to help other people. We have found out that he has helped both adults and babies with his donation and we are so very proud of him. I couldn't have asked for a more beautiful gift in my life than Hunter.

Hunter's mum

Hunter

If you want to donate life, discuss it today, OK?

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The Gift of Life

Two decades on

Twenty years ago I faced a sudden unexpected crisis. I had enjoyed a very interesting and varied life during a career with the Australian Diplomatic Service, most recently as head of our Consulate-General in Noumea. I was in good health and happily married with two teenage sons.

I travelled to Papua New Guinea leading an Australian conference delegation and then joined Foreign Minister Gareth Evans to visit New Caledonia. On the way home, I was struck by acute hepatitis and admitted to Canberra Hospital. As my condition deteriorated, I transferred to the Austin Hospital in Melbourne. The option of transplantation was explained and my wife and I agreed, if my condition worsened, it was the only resort. I entered into a coma with less than a day to live.

The medical team who saved me described it as a miracle—to survive in that condition and to receive a matching liver in such a short time-frame. For me and my young family it felt much more than that. After convalescence, we gradually returned to normal life as a family and I resumed my career. More importantly, it led to much closer bonding between us and with our friends who lent us enormous support during the upheaval.

I worked for fifteen years afterwards and became head of the Australian Consulate-General in Hong Kong. After retirement I decided to do whatever I could to promote greater awareness of the importance of organ and tissue donation. This reflected not only my strong appreciation of the special gift I had received, but also the fact that each year in this country the waiting list for transplants far exceeds the number of organs available and many people die waiting. I am currently President of Gift of Life, advocating organ and tissue donation in the ACT and surrounding districts, which also contributes nationally and organises the annual community DonateLife Walk around the lake in Canberra.

My family is forever indebted to the skill and compassion shown to us over many years by the transplant team and to the extraordinary generosity of the donor family—who remain unknown to us. You have made our lives since immeasurably better. You are never far from our thoughts. Thank you all sincerely.

I hope my story and the fact that I am still able to contribute energetically two decades on will help inspire others to become donors.

David
President, Gift of Life

40% of Australians
do not know the donation
wishes of their loved ones.

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Gary’s transplant

One weekend my youngest son Gary, who was 15 at the time, was unwell. He’d had a headache all weekend and the pain relieving medication I’d given him wasn’t helping at all. On the Sunday afternoon just as I was leaving for work, he told me that his ‘wee’ was a red colour. I asked him to collect a sample next time he went to the toilet and show it to his dad.

A few hours later I received a phone call from my husband to say he had taken Gary to see a doctor who was admitting him to hospital straight away. He was diagnosed as having Glomerulonephritis (which is a kidney disease) and spent about 10 days in hospital.

Several months later the problem occurred again—and again I was at work! This time the doctor wanted us to take Gary to a hospital to see a kidney specialist. Gary went on to have a biopsy and was diagnosed with I.G.A. Nephropathy. This is a disease in which the body’s immune system recognises the kidneys as foreign bodies and over a period of time destroys them.

By the time he was 30 Gary’s kidney function had deteriorated to the point where he was rushed to hospital early one morning in acute kidney failure and placed on a dialysis machine to remove the built up toxins from his blood. During that period the possibility that a family member may be able to donate a kidney to Gary was broached by his doctor.

Although Gary recovered after many days of dialysis, his kidney function tests never returned to normal readings. A year or so after that his specialist suggested to him that he have a fistula (which is a tube connecting the artery and vein in his arm) inserted in readiness for permanent dialysis—which he was really reluctant to do. Around that time he got a job in Perth and moved over there.

A few months later Gary was started on permanent peritoneal dialysis (this is dialysis through a tube into your abdomen) which he hated as it needed to be done four times a day—every day. His new specialist also spoke about the possibility of a family member donating a kidney to him.

I consulted a local kidney specialist regarding the possibility of me being that donor as my husband’s blood group wasn’t compatible with Gary’s.

After many tests of my own general health and that of my kidneys, Gary and I had compatibility tests done and were found to be a match. We flew over to Perth for the last of the tests, which included a third and final compatibility test. I then became the live donor for Gary’s kidney transplant. We were amazed at how quickly he became well again. We hadn’t seen him like this for years. I recently heard him telling someone ‘from the time I realised I was awake after the operation, I was feeling better’.

Gary was really well for two years after his transplant but unfortunately the kidney was to fail due to an unrelated medical condition. He is now back on dialysis while he waits for another kidney transplant.

Carole

40% of Australians
do not know the donation
wishes of their loved ones.

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Seeing is believing

The gift of sight is a precious one that many take for granted. I am not one of those people. When I was born with an ulcer on my left cornea, my parents were understandably devastated. The idea of me not being able to see the world in all its wonder and beauty crushed them. All, however, was not lost. My parents had me placed on the transplant transplant waiting list, and at the age of two I had a corneal transplant.

As a child I was frustrated at what I had to go through. I remember drops that stung my eyes, tedious exercises and again that ugly patch I had to wear until I was school aged. I also remember countless visits to the specialist, and bright lights that seemed to burn through my eyes into the back of my skull.

I didn't realise then how truly blessed and lucky I was. My parents had patiently sat with me, giving me drops and making me do my 'tedious' exercises, trying to make my eye as strong and healthy as possible.

I had a kind and brilliant surgeon who gave me so much of his time on those 'countless' visits—often at the expense of other patients. Most importantly, I now appreciate the miracle that happened. Someone gave part of their eye for me.

I am so very grateful. I am grateful to my parents for their constant love and support. I am grateful to the surgeon who miraculously performed my intricate operation, and I am eternally grateful to the wonderful and generous person who gave me the gift of sight through organ donation.

Ellen

Donors and recipients
vary in age from
infants to the elderly.

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Organ gifts save lives

A Melbourne teenager lost his life when he was hit by a car at Christmas – but his death saved three others.

Andrew, 17, died as he lived – generously.

He was killed by a car, but because he was an organ donor, his heart, liver and kidney saved three lives.

His parents, Lynne and Laurie, said organ donation had helped make a positive out of a tragedy. 'It has got us through knowing that his organs have helped people,' Lynne said.

Andrew was a friendly teenager who lived life to the full, and his generosity lives on through his organ donation.

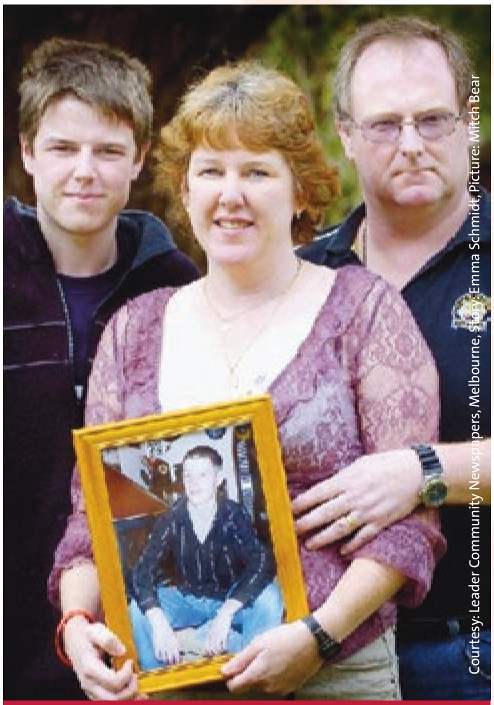
Years before, the family had discussed organ donation with Andrew and his younger brother, Shaun.

'We talked about it at dinner time, and Andrew, being the person he was, said 'yep',' Lynne said.

The family said often people worried that the bodies of organ donors would not be treated with respect, but Andrew was operated on just as if he was a living patient, and his funeral had an open casket.

Laurie also said that more people were eligible for donation than they realised.

The family wants to encourage all people to consider organ and tissue donation and to talk about it with their families.



Courtesy: Leader Community Newspapers, Melbourne, Story: Emma Schmidt, Picture: Mitch Bear

Andrew's family with his picture

Around 1600 people are on official transplant waiting lists at any one time

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Welcome 'back' Maz

My mum's return to health and life!

My mum, Marion, received a double-lung transplant after many years of declining lung health and function. She almost did not make it; the gift of life came just in time from a very special donor and their brave family.

Humanity at its greatest and most selfless. How can we ever say thank you? The Welcome 'back' Maz sign was created by Mum's older brother, John, and erected on Mum and Dad's front lawn in anticipation of Mum's return home after her transplant. He was hugely relieved to have his little sister 'back' – it was truly a family's journey as well.

The word 'back' is indicated as Mum was literally coming 'back', not just returning home. Her health and her life had been restored.

Mum spent 10 days in hospital post-transplant; quite a feat after such a major operation.

She walks with Dad on the beach every morning, continues with her pilates classes, meets with friends and family regularly for lunch, travels interstate to visit her daughters and three grandchildren, gardens, cooks, knits and volunteers for DonateLife to help raise awareness regarding the important issue of organ donation.

She is well and truly 'back' – living, breathing, loving and giving back! Mum thanks her donor and their family everyday by living life well and with gratitude after receiving the greatest gift of all – the gift of life!

The picture was taken by Kristen Walsham on 12.11.2009

A welcome home sign greeted Marion after her life-saving transplant.

Ask and know your loved one's donation wishes

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Silent disease with a donation relief

Kidney disease is a silent disease. Being under the care of a GP that treated me for high blood pressure and suffering headaches, I sought the second opinion of another GP due to overwhelming fatigue and the need for more sleep.

With blood, urine and blood pressure tests he found a possible kidney problem. I was sent to a Nephrologist who arranged for a biopsy of the kidneys. On my return to the 'Doc' his word were 'well old man you're too far gone. You will be on dialysis within six months.' I proved him wrong—it was just three months!

In 1994, I started dialysis at a renal unit, where I was supported by great nursing staff and caring people. I was told by the visiting kidney surgeon that I would be an ideal person for a kidney transplant. I had been asked if someone in my family could be a kidney donor, however being adopted I have no family background or people to turn to.

So I went on the transplant waiting list. I was told the waiting list was at that time was four to five years. I dialyzed and waited for seven and a quarter years! I had a bag packed ready for the trip to Melbourne under my bed for five years. Finally the call came in January to head off to Melbourne with my Dad for the transplant. The plane broke down in Melbourne so we were late getting there.

The operation took around two hours. On waking the next day the bed next to me was occupied by a man, also from Tasmania, who received a transplant on the same day as mine.

My thoughts are always with that donor and their family. In the end it was the family that had to make the final decision to abide by the wishes of their next of kin to become an organ donor and improve or save many people's lives!

It's now many years since that day and I'm still living a healthy life and working thanks to an organ donor.

Kerry

Any day is a good day to talk about organ and tissue donation.

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Something good out of something tragic

At 29 years of age our son was killed in an incident at work. It was an unexpected, preventable death.

On that day, one of the first phone calls we received was from a tissue bank. Our son was not registered as a donor at the time but we had often talked about donation as our other son is registered.

When they rang for our permission it was easy for us to grant it. We gave our consent to use whatever they could, as we knew our son would have wanted to do that.

They were able to use our son's two main heart valves to save the lives of two others, a couple of rib bones for reconstruction of a person's face and some skin from his legs and back to help burn victims.

Although we will never get over the loss of our son it is a comfort to know that he was able to help others to have a better quality of life.

Joy

On average, people on transplant lists wait between 6 months and 4 years.

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Mitchell's dream saved lives

Mitchell's wish was to be a paramedic. When his life was cut tragically short late last year, he lost the opportunity to have his dream job, but he still saved the lives of four people.

His gift of organ donation was the ultimate way of helping people.

He was a normal teenager that loved to do normal things. He was kind and gentle. He accepted everyone and never had a bad word to say about anyone.

All he cared about was family, friends and lending people a hand. He loved to ride his motorbike with his best mate Luke and he was an asset to his football club.

Mitchell grew up quickly when his Dad died—he was only 13. We were a close family and he became the 'man' of the household, even though he was the youngest.

His sisters loved him dearly and so did his little nephews; three and a half year old Harrison and four week old Oliver. We all idolised him. He was more than a 'little' brother, he was a best mate.

Mitchell died when his ute ran off the road during a storm and hit a tree. He was only 18 years old. He hardly had a mark on him when my daughters and I saw him in the hospital.

Nothing prepares you for the news that there is no hope. Then you are asked about organ donation and your brain has to comprehend the question.

The decision that day to donate Mitchell's organs was extremely hard because we were in shock and our minds struggled to process the information. But we all knew in our hearts what Mitchell would have wanted.

Something can happen in a split second. You never ever think this nightmare could happen to you. You need to talk about it with your family, let them know what you want to do, regardless of your age.

Mitchell's heart, lungs, liver, both kidney's and pancreas were all donated.

No parent should ever have to lose a child, but our family's decision gives me comfort every day knowing that Mitchell's organs saved the lives of others. I think about them every day and hope they are okay.

I am humbled to know other people have been touched by the story of Mitchell's generosity and they have now discussed organ donation and registered to be donors.

Sonja

Mitchell

Each year around
1,700 corneal transplants
are performed to give
the gift of sight.

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Notes on a transplant

Six years ago I started asking people to show me their scars. One mid-winter Tony showed his zipped-up ribs. Then Pauline; a diagonal crease across her front. Mary-Jane; a new lavender line over coffee in a restaurant. A kidney; their spare, donated for a daughter, a son, a husband.

It took some doing. There were cigarettes to give up, wine and spirits to cut, kilojoules to burn, and months of testing before they were accepted.

My sources; endlessly repeated their stories on request until the final question, 'Pauline, what will I feel when I wake up?' Her jade irises flashed, 'you will feel terrible. But there's morphine and these days there's no need to feel pain.'

The jacarandas revive exam time memories the day we go in. Our daughter at the wheel of my mummobile, our four kids 16 to 25 braving the knowledge that mum and dad will soon be out for the count.

At 7.30 the kids and I have a group hug and they go to their dad. I went to preop checks; height and weight and blood pressure. Then on to a bed with my unfinished book, along a glass corridor, between trees and sky, into a small room with my back to the main action. I meditate on the last visions held in my mind's eye and hold the kid's hug until cheery staff interrupt, and someone apologises to someone else for missing a vein in my right hand.

Warily I say 'It's my right kidney I'm having removed. Can I mark it?' Someone hands me a purple pen and I make an X on my stomach and scrawl R. I don't care about the size of the scar now. I want enough vein and artery taken so it can easily be reconnected to my much larger husband. The last I remember the surgeon is stuck in traffic and the anaesthetist asks if a phial of milky liquid looks familiar.

Waking up I see their faces all at once, 'my darlings I'm fine'. Down the corridor dad's kidney is working well, 'that's fantastic'. And dinner; plastic tubs of chicken soup, orange juice and red jelly will never, ever taste as good again. Awake all night I thrill to updates longing to see for myself.

He stays longer until finally on our first night home he gets up five times to pee. 'Hallelujah,' I call sleepily, unlikely jubilation for any other middle-aged couple.

Helen

The day before the transplant; taking dad to hospital

One organ and tissue donor can save or enhance the lives of 10 or more people.

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Louise undergoes a heart transplant

Just another challenge in my life and I will win it. These are the words I said after my heart transplant. With my outlook on life and determination there is no doubt that I have won!

My remarkable story begins when I was 30 years young and 26 weeks pregnant with my second child. I had a sudden cardiac arrest in front of the Year 9 students I was teaching. For many years I had been involved in teaching cardiopulmonary resuscitation (CPR) and spreading the work about its importance in the community.

The students were able to revive me with the help of two teachers from the school who performed CPR and kept my blood flow going until the ambulance arrived and I was defibrillated on the classroom floor. I was then flown by the rescue helicopter to hospital where I underwent a caesarean and baby Katy was born while I was still on life support. I woke up about a week later and had no idea what had happened. Katy was very premature but survived her incredible entry into the world.

I was then diagnosed with hypertrophic cardiomyopathy and fitted with an implantable defibrillator as a back up just in case another such incident should occur. A number of other problems started to appear and two years later it was recommended that I be placed on the waiting list for a 'new' heart.

After 11 weeks on the list, I received the telephone call of a life time. Although I had a tough road to recovery, my spirits remained high. I did everything the doctors told me to do and with the love and support of my husband Gary and my two daughters, Grace and Katy, I have overcome another hurdle in my life.

Living a near normal, wonderful life is how I describe myself today. Apart from taking drugs (which I never had to before), I can do anything!

I devote most of my time not only advocating for CPR and defibrillators in the community, but have now added organ donation to my story.

Like many others I am most grateful and humbled by the family's decision to donate at a very tragic and sensitive time. Organ donation is vital so that many more lives can be saved. Remember, one day it could be you who needs another organ.

Louise

Louise

Ask and know your
loved one's donation wishes

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Gift

My twin sister has had kidney disease for the past 17 years and over the last few years her health has had its ups and downs. A few years ago the thought of live donation crossed my mind. Then last March she commenced dialysis three times a week, and without any complaint, she continued working full-time, as well as doing all the things she had done in the past. I still don't know how she did it all! Such an inspiration.

It was then that I got serious about donating a kidney to her. The hospital accepted us and further tests were performed—resulting in the decision to proceed to transplant. The staff at the hospital were very informative and caring and at no point did I ever question my decision, neither did my family.

The transplant went ahead and so far all results have been positive for both of us. We celebrated on Australia Day with her favourite drink. The most emotional time for me was this Mothers' Day when my mother told me how emotional she was at seeing how healthy her daughter was looking following her transplant. I saw her last Saturday and have to agree with my mother. My sister looks very healthy.

It is the most rewarding thing I have ever done, apart from giving birth to my daughter. Without the help and support of my husband and daughter it would never have been possible but the feeling is amazing—to see someone you love have their life back.

Julie

Julie

Start the organ
and tissue donation
discussion today

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A chance diagnosis led to a transplant

I was always registered as a potential organ donor, never once considering that I may one day become a recipient. I knew little about organ donation other than it saved lives and I knew of no one who had ever had a transplant.

Unexpectedly, on a routine visit to my GP, I was diagnosed with high cholesterol and needed medication to control this. A liver function test was carried out before I could take the medication and a liver problem was found.

Several months passed with more GP visits, a referral to a specialist and more tests before a final diagnosis was made. I had a disease called primary sclerosing cholangitis which, due to inflammation and narrowing of the bile ducts in the liver, causes the accumulation of bile in the liver and liver cell damage. It is a disease with no known cause and a transplant was the only cure.

This all sounded a little far-fetched to me as my health was good. After a couple more years, small problems arose such as infections, meaning short hospital stays. My life was on hold and I took sick leave from my teaching career.

I began the wait for a donor—an agonising time for my family. With the uncertainty of a suitable donor being found, I became yellow, more tired and unable to cope with normal day-to-day routines. I felt helpless when I could no longer do my patchwork and quilting.

One year after going on the waiting list, the call came that a liver had been found for me. After a lengthy surgery and recovery period I was back to my old self again, being able to do all the things I used to do. Now retired, I can focus on new activities.

My thoughts will always go to the family who lost a loved one. Their generosity in a time of grief is admirable and 'thank you' does not seem quite enough.

I am now committed to spreading the word about organ donation through my volunteer work with DonateLife and Transplant Australia.

Margaret

Margaret

In 2011
337 organ donors gave
1001 Australians
a new chance in life

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16 extra years...thank you

At the age of 49, our lives took a sudden change forever. After returning home from a beautiful day with friends and family at the local Christmas parade, a viral infection caused me to have a cardiac arrest. A quick thinking new neighbour performed CPR and got my heart and breathing started, after which an ambulance transferred me to our local hospital. Six hours later I woke up in hospital very confused by what had happened, and it was then I was told that the permanent damage to my heart had left me with cardiomyopathy.

I was transferred to hospital via air ambulance for further treatment, and returned home again in time for Christmas Eve. I later travelled for more tests, only to realise due to the nature of my condition I would be unable to return to work.

I was assessed for a heart transplant due to the deteriorating health I experienced. Months later we got a call to notify me that a compatible heart had become available for transplant. We flew to Melbourne immediately and I received my heart transplant.

At this time we were the proud grandparents to three grandchildren with the youngest being one year old. Prior to my transplant, the only way I could hold him was if someone put him on my knee.

We now have four granddaughters and four grandsons. I am so pleased that I have had a further 16 years of life following my transplant that I otherwise might not have had. My wife and I recently celebrated our 50th wedding anniversary—a milestone I just would not have been able to achieve without my transplant.

All this with thanks to our wonderful donor family.

Vern

Vern and Justin

Do the people close to you know your donation decision?

Aaron's gifts

Flying across the Pacific Ocean, the little girl looked down onto the cotton clouds below her and said to her mum, "We're closer to Aaron up here."

That was two years after her mum's best friend had come to her with the news that she could not bear to say aloud. "Leah, Aaron is in the hospital, and he's very, very, very, very sick." Leah could visit him in the hospital when he was better. Anything beyond him getting better had not even occurred to the little girl.

The following few days were a blur in the little girl's mind. A murky sea of flowers, cards, visitors, condolences, tears.

Now looking over the clouds, the girl couldn't imagine the rest of her life without him. Would she survive the first family holiday without the cheeky, playful, energetic, laughing, loving brother she had known to be the cherry on top of the perfect family they had always been? How would anything ever be the same with him just looking over them, not actively participating in this life?

But he WAS participating. Through the lungs that breathed precious oxygen into another. Through the heart that beat inside another's chest. Through the eyes that saw a brighter, more magical world.

Seventeen years later, the knowledge of what those gifts brought to the mystery friends, keeps the little girl (me) going. Aaron's beautiful soul is no longer in need of a vessel, and he was able to offer many gifts of life – I passionately believe that this is the simple duty of all human beings..

Leah

Brooke, Leah and Aaron

Register your donation decision on the Australian Organ Donor Register and make sure your loved ones know your decision.

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Doug’s journey

I had been ‘yellow’ for years, but had no idea the underlying reason was that my liver was slowly dying.

In 2008 I was diagnosed with the end stages of liver failure. A month later cancer was found in my liver.

Over the next year I travelled regularly to Melbourne to monitor my condition and received chemo to ensure the cancer didn’t spread to any other organs.

I became sicker still and, after many tests, was put onto the transplant waiting list for a donor liver.

I do not remember much from the year before I received a transplant, but I do remember the early hours when the Liver Transplant Coordinator rang to tell me a suitable donor had been found.

It was very emotional. My partner, Julianne, even missed the turn off to the hospital. All we could think about was the person who had passed away but was giving me the gift of life.

Julianne agrees, ‘The drive to the Austin Hospital was a very emotional journey. Thoughts of the donor and donor family were heart wrenching.’

The surgery took 10 hours and afterwards I spent eight days in Intensive Care. Now, 17 months later, I have fortnightly visits to the hospital, and my new liver shows no signs of rejection.

Julianne says I looks so well and everyone can hardly believe it is still me.

Before the transplant, I had no energy. I couldn’t do anything. I wouldn’t have seen another Christmas without my transplant.

It changed my outlook and I now see myself as a completely different person.

I still think of the donor and donor family and when the time is right will write to them. Feelings can’t express how much I appreciate the gift. How do you express it? It’s a hard letter to write.

I have been given the go ahead to return to work in the building trade. I now enjoy the simple things like mowing the lawns and helping around the house.

I will always be grateful for the special gift of life.

Doug

Start the organ and tissue donation discussion today

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DonateLife Book of Life

Having life is simply the best

I am about to celebrate my 60th birthday this week—57 years longer than my original life expectancy! I was diagnosed as a child with cystic fibrosis. The numerous hospital visits each year were good because they gave me time to rest from playing and fighting with my brothers—I was the only girl. To me, regular hospital visits, coughing and wheezing was normal. It was all I ever knew.

As life and time went on, so did my illness. I never let it prevent me from living my life. My saying is 'I'm here for a good time, not a long time', and I've done both. After being told that I was not expected to live, I ensured my life was filled with quality, living life to the fullest, partying, spending time with my beautiful daughter and great friends. I felt good pre-transplant when I lived and worked by the ocean. The sea air did wonders for my lungs.

A transplant was the only option to continue on life's journey. I remember one time I was not expected to survive the night. That was until a 6ft gorgeous nurse named Laurie came to look after me. I thought to myself—I'm not going anywhere!

My memories of waiting are positive due to the friendships formed with others waiting too. Not everyone survived and not everyone received a transplant, but the friends I made at that time and the transplant co-coordinator were invaluable to me.

I waited just over two years for my transplant. Surviving afterwards was a concern for the doctors, but not for me. I knew I was going to live. 24 hours after the operation when I was chatting away, the ICU nurses were ready for me to go to the ward. The staff were excellent. I felt free. No coughing, no wheezing.

Eight years ago I was given a new life and a new responsibility. I wanted to look after my new lungs for they belonged to somebody's loved one. I admire and I am forever thankful to the donor family. If it wasn't for them, I wouldn't be here with my beautiful daughter and she wouldn't have her mum.

Having life is simply the best.

Jan

Jan and her daughter Jay.

Ask and know your
loved one's donation wishes

donatelife

DonateLife Book of Life

Even storm clouds have silver linings

My DonateLife story had a different ending than I expected. A year ago my sister had returned from living in the USA for the last 18 years to raise her boys in Australia. She and her husband were in the process of finding accommodation, jobs and schools to start this new chapter in their lives when she became acutely unwell.

My sister had a rare genetic condition, erythropoietic protoporphyria (EPP), which causes sensitivity to ultraviolet light. Rarely does it cause liver failure, but in Jennet's case it did. She spent the last five months of her life in hospital, determining the cause of her liver failure and then the ongoing management of it. It became apparent that Jennet required a liver transplant to survive.

The events over the following months saw my sister's condition deteriorate. At the time, the doctors were also trying to 'keep alive' other patients on the ward who were also waiting for suitable liver donors. This highlighted the fragility of life and the importance of organ donation.

In the end Jennet was placed on life support. Her condition became irreversible and she was no longer a suitable candidate for transplant. It was then the medical team approached her, and us, about Jennet becoming an organ donor herself. Jennet made it very clear that this was her wish. It was then up to us, as her family, to respect this very hard decision.

This was the surreal nature of our experience. Within weeks we had gone from waiting for a donor, to my sister becoming a donor. This was hard to comprehend in the face of our own grief. I had often wondered how I would write to a family to thank them for this second chance at life, but now I face life without my sister.

Knowing that through Jennet's death, the lives of three people and their families have been improved, is the silver lining in a very dark storm cloud.

Lizzie

Ask and know your loved one's donation wishes

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Australian Government
Organ and Tissue Authority

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Enquiries
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Alternative format
The DonateLife *Book of Life* is available electronically on the Authority's website at www.donatelife.gov.au