





© Organ and Tissue 2015 DonateLife **Book of Life** Volume 17



Australian Government Organ and Tissue Authority

### Foreword

By Yael Cass, CEO of the Organ and Tissue Authority

The DonateLife Book of Life is an important resource for all Australians.

This inspiring collection of more than 300 stories is written by people whose lives have been changed through organ and tissue donation. In sharing their stories, we are compelled to think about the importance of becoming an organ and tissue donor.

Since its launch during DonateLife Week in February 2011, the DonateLife Book of Life has travelled across the country and featured in schools, libraries, workplaces and community events.

Through the generosity of more than 300 Australians, we can read about those Australians who tragically lost their lives and in doing so gave the ultimate gift of organ and tissue donation.

We can read the stories of those who have benefited from the gift of a transplant, as well as those who as living donors have helped a friend or family member.

We can be inspired by the dedicated people who work in the organ and tissue donation and transplantation sector.

As you read these inspiring stories, I hope that you are motivated to decide and register your donation decision on the Australian Organ Donor Register and, most importantly, to discuss your donation decision with your loved ones. It is a conversation that can one day save lives.

<u>DonateLife Book of</u>

I thank all who so generously choose to share their story and in doing so help this wonderful growing collection of stories continue to inspire us all.

yael Carro

Yael Cass

Chief Executive Officer Organ and Tissue Authority

### Do you know the donation decision of your loved ones?



### Angel

Angels walk the earth. My Angel saved my life and gave me the chance to see my daughter grow up.

For 20 years I was a type 1 Diabetic. After constant hospital stays and dangerous complications my world came to a crashing halt six months after my daughters birth.

Kidney failure was going to end it all. Dialysis wasn't working and I was running out of time.

Thanks to my donor and their sacrifice my girl is about to turn seven with her mum by her side. My transplant was a kidney/pancreas and I will forever be thankful for the gift I was given.

I only wish I could do more to thank that wonderful person and their family for giving me my life back.

Louise



### Louise celebrating her beautiful daughter's birthday

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



# <u>DonateLife Book of I</u>

### **Maureen** Our darling wife, mum, mother-in-law and grandmother

### Our small family consisted of Mum, Dad, two daughters, partners and one granddaughter.

We are a strong loving family who love spending time together doing family things. Mum and Dad worked hard to raise us in a loving and supportive home, and allowed us to do the things we loved.

Mum's taxi worked hard of a weekend, running us from sport, to horses, to friends—all whilst supporting her own parents who needed ongoing care. Mum was an only child and spent many of her years (with Dad) supporting her own parents as they grew older. Mum just loved to care for and help others.

One Tuesday night we received a call from Dad who told us that Mum had possibly suffered a minor stroke. Mum was taken to hospital, where we were advised that she had suffered a catastrophic aneurism (not a stroke) which was irreversible.

Of course, this came as a massive shock to our family. We were asked about the possibility of organ donation. We didn't know Mum's wish, as like most families we never talked about death, let alone about organ and tissue donation. So we discussed what we thought Mum would want.

Mum was the most loving generous, compassionate woman, who always put others before herself. As a family, we made the Receiving cards from two recipients of Mum's organs has also given us strength through this journey.

It gives us great peace that Mum's organs have been received by these recipients and it gives us further strength to know that Mum would be so proud of our decision.

We are now passionate advocates promoting organ and tissue donation awareness to as many people as we can. We attend the annual DonateLife ceremonies every year which gives us an amazing feeling of support and empowerment—being together with others who have shared the same experiences as our family.

Cassie



decision to proceed with the donation.

The retrieval and gifting of Mum's organs occurred on a very special day for our family. It was Mum and Dad's eldest daughter's 39th birthday. 39 years from the day Mum gave life to her first born, she was again giving the hope of new life to five others around Australia.

Maureen

### Australia is a world leader for successful transplant outcomes.



### **Hearts of Gold**

was introduced to kidney disease at the age of 15 when my father died of it. Subsequently four family members were diagnosed, with two of us fortunate enough to have had transplants. The day I was told I had kidney disease I drove around aimlessly thinking the sky had fallen.

Twenty odd years after being diagnosed I was told I needed dialysis. I was tired but nothing else was outwardly evident.

After six weeks training with a machine for peritoneal dialysis I suggested to my husband that we go and book a trip so we had something to look forward to. I felt a pang as my machine went down the oversize chute at the airport but was happy to have a direct flight so it had to come off with us.

Looking at the machine during those first weeks was very confronting as I realised that life was only possible with it. It was such a frightening thought that I blocked it out. Then we humanised the machine by christening him 'Charlie'.

Charlie developed a distinct personality. He would play up at times and I would say to my husband "you had better come, he wants your attention". Sure enough he then settled down and started properly! Charlie and I became very close as we spent nine hours together every night.

Having a sense of humour helped enormously. After naming Charlie we decided the nurses were Charlie's Angels. They were delighted and although there were four of them, they all wondered in turn which of the three they were! Their support and care was so outstanding that we entered them for a hospital award – and they won!

The call to go to hospital for my transplant came at 1am on a Saturday.

I had retired from work four months earlier and was preparing for the transplant by thinking positively and exercising. On arrival at the hospital I even asked one of the doctors when I could start exercising again!

I have a very positive attitude – if you think you can, you will. Underlining everything is awareness that this is only possible because someone has given me this gift. There is a sense of accountability that never goes away.

I think about my donor and know the best I can do is eat healthily, exercise every day, drink plenty of water, keep appointments and take my tablets.

A Heart of Gold rose – red with a yellow centre – was planted to honour South Australia's donors for 2013. That is how I view the donor families – you have hearts of gold to give this gift at such a time of grief. I am indebted to you for allowing me the chance to live a normal life again. Words can never express my gratitude.

Suzette



Suzette and husband John holidaying in Vancouver, Canada

### Do the people close to you know your donation decision?



### A life's journey – the waiting

diopathic Pulmonary Fibrosis. That diagnosis defined my future. A disease lacking cause or reason and without a transplant I had a relatively short future.

With urgency my specialist began pre-transplant testing and I was fortunate to be listed.

Like many other potential recipients the wait had begun. The hope of a suitable donor, the wait for another to give an indescribable bequest, the wait for that intangible gift and the worry. Would this insidious disease take my life first?

The challenge to friends, family and especially in my case my spouse, was to remain positive. They are so very helpless as they watch in silence while you gasp for breath. You struggle to carry out the simplest of tasks.

The sadness shows when you have to say 'sorry' to your grandkids who just want you to play with them. This journey touches, impinges and changes many around you. There was no guarantee of a future, just informal plans in the hope all goes well. The wait goes on.

The first call from the transplant team and with 30 minutes to get to the airport, you give thanks. Shortly after arrival the reality hits. It was evident that this was a false start, as regrettably the lungs were not suitable. We had been advised that this is often the case, so sadly back home to wait once again. Serious deterioration was now taking place in my body and I was hospitalised locally. Things were starting to look very grim.

Positivity, trust and faith are the key for this miracle to take place. We had absolute trust in the wonderful medical teams and had absolute faith we would see this through.

The weeks, the days, the hours, the minutes go by. The wait goes on.

It is now seven months since the late night call and a successful transplant. I am beginning to return to a semblance of normal life. Family and friends have been freed of their collective burdens.

I have had my 60th birthday, seen the birth of our eldest daughter's first baby, and hugged, played, and loved each of our grandkids.

Just being able to spend time with family and those special friends is life itself. Without them I could never have seen this journey through.

I have one person to thank for all this, a person that I will never meet, one who gave a gift of unimaginable generosity, and a gift that their family provided at a time of their own incredible sorrow.

I thank them sincerely for you have donated life to us all.

**Erickson** 



### The majority of Australians support organ and tissue donation.



### Grateful doesn't even begin to describe how I feel

As a teenager I became unwell and Was diagnosed at 16 with Schlerosing Cholangitis. Twenty years and two life saving liver transplants later, I'm finally healthy!

The first liver I received gave me 15 years many of them fantastic! I was able to travel, study and live a very happy and full life. I would not have had this otherwise and am hugely thankful.

The enormity of that moment when the doctor asks to talk to your family outside the room, telling them there won't be a tomorrow for you unless ... is so very confronting—particularly at such a young age.

I may have been unlucky to have this disease, but I'm very lucky to have my strong family, friends and partner. They were the only way I was going to survive any of this. That and the faith that I was in God's hand no matter the outcome.

Once it was apparent my first transplant was failing, I waited almost two years for the precious, perfect liver I have now. Within days of the transplant my skin was pink, my eyes were white and I was out of bed. It had been a long haul for all of us.

Now, three months down the track and I'm fitter and healthier than Ive ever been.

To my donors, and their families, I will never be able to express the enormity of my humble gratitude and thanks. The selflessness required to make this decision in the midst of your grief is incredible and I will hold that close in everything I do.

Because of your gift, life is very different for me now. I've just had my first birthday out of hospital in many years, I'm back at uni studying nursing, I ride roller coasters, I travel, stay out late, lift heavy things and open jars. I can do all the little things we take for granted and every single day is better than the last!

My focus now is this wonderful third [!!!] chance at life and what I can do to make the most of this gift. I will never lose sight of this thankful, humble feeling. Thank you!

Heidi



Three months [to the day] after the transplant we went to the Gold Coast and did all the roller coasters to mark the occasion

69% of Australian's have discussed their donation decision with their loved ones.



### Callum

My son Callum was born with a congenital heart defect. He was operated on at the age of 18 months and was a very healthy child until he became breathless and blue at the age of eight.

One day he collapsed while running around with his brother. We saw his cardiologist who gave us the news his mildly leaking pulmonary valve was now a severely leaky one!

We were told Callum would have to go through another surgery to replace the valve and his doctor felt a donor valve was Callum's best option. The medical team wouldn't know if a donor valve was available until just before the surgery—which was scheduled a week later.

Callum's surgery went really well and we were delighted to be told Callum had a lovely new donor valve. It came from an older woman and I'd like to thank her and her family for giving my son a wonderful active lifestyle.

He's now 15 and a sports crazy young man!

Rebecca





### Around 1,500 people are on official transplant waiting lists at any one time.



### Pamela – An artist from the start

From the earliest age Pamela showed great aptitude for all things artistic. At school she excelled at English and Literature with a special fondness for the writings of Dorothea Mackeller and A. A. Milne—able to quote from their works at will.

Pamela also showed skill in athletics, hockey and tennis, playing the latter well into her forties, and was acknowledged as a talented pianist.

As an artist though she excelled—beginning to sketch from an early age, encouraged by her parents and her art teachers. As the years went by she also painted and produced wonderful leadlight works, complicated tassels and intricate mosaics. Surprisingly it was not until 2008 that her artwork was first publicly shown, with collectors joining the ranks of family, friends, colleagues and admirers who prized her originals.

Pam's abilities and interests led her to work for over 30 years as a teacher's assistant, starting in the country then working for 29 years in a suburban primary school where she specialised in helping children with learning difficulties.

She married and was the proud mother of three children. Her marriage to Ken lasted for more than 21 years and included numerous holidays, travelling around the Kimberley region enjoying the comforts of great train journeys across Australia. Trips through England, Italy and France gave Pam the opportunity to enjoy the marvellous architecture, music and artworks of the old world. Retiring from her final school posting Pam concentrated on her close and fulfilling relationship with her family—as daughter, wife, mother and nan to the youngest generation of the family.

Her usually good state of health took a downturn when she was diagnosed with acute pancreatitis and admitted to the Royal Adelaide Hospital—and although receiving the best of care and attention she passed away. In death she gave the gift of sight by donating her corneas.

Pam was an intelligent motivated woman with a great sense of purpose—intensely involved in everything and who lived a full and very vibrant life. She is greatly missed.

Ken





Pamela

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



### Kai

When we got the call that Kai had been admitted to ICU, I hoped that he would be alive until we could consent to organ donation. As a nurse I understood the reality but prayed for a miracle. We had 700 kilometres to travel to be by his side.

35 years earlier, I had nursed an 18 year old male in the same ICU, as we waited for his parents, who were on vacation to be contacted for consent for corneal donation.

Two days before Kai was admitted to hospital I sang at a funeral for a 16 year old girl who had donated organs and the comfort her mother portrayed in her grief was palpable.

My five year old niece and 46 year old brother both died suddenly and therefore were unable to donate organs. Kai was registered for donation and I wanted him to have that opportunity.

Kai was an active healthy child who enjoyed many adventures with family and friends. He matured into a strong and physically fit adult who achieved at many sports.

He was nominated for Australian of the Year, recognising his commitment to basketball, both as a player and a coach.

Kai was 22. He was struggling with life crises and decided to take his own life.

Four days later when Kai was confirmed 'brain dead' the decision to donate his organs gave us a 'positive' to think about in an otherwise desperate situation. It gave me something that I had control of beyond being an onlooker. I am used to being the nurse, not the nursed, and it gave me a focus. But I also quickly realised that this was a family decision which included his father, sister and brother. It was not mine alone to make. To know that recipients and their families have been given the opportunity to turn their distress into joy and renewed life with the organs of such a beautiful strong fit young adult provides us with comfort in our grief and healing.

Kai lives on in others, what could be more precious.

One of Kai's favourite sayings...

'Good, better, best, never let it rest until your good is better, and your better is best.'

Rest peacefully my beautiful boy.

Angela



Kai

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



### The gift

When I lost my little sister during DonateLife Week, I was privileged to see V how the donor team worked silently behind the scenes.

I was lucky to be there when it was announced that there was a recipient for her liver, and then later her lungs had also found a new home.

The joy in that doctor's eyes when he was telling me this was enough for me to realise that this was the best gift any one could give. Without a doubt, for some families, the next day or so would be like Christmas.

Through our loss there were people finding the joyous present.

I will now be registering as a donor and encouraging friends to become registered donors as well.

I know I will miss her every day and on some days more than others but there will be people out there who will thank her and love her as much as my family did.

FMC



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



### **My brother Danny**

n February my brother Danny passed away. He went into a diabetic coma a few days earlier.

I can remember one day I asked him about organ donation should anything ever happen to him.

His answer was, 'Well if they can find anything useful, they're welcome to it.'

When Danny passed away I contacted the organ donation coordinator in Queensland to

arrange for the donation. The lady who I spoke to was so caring towards me and explained all the procedures involved.

Danny's donation has changed or saved five people's lives so my Brother Danny lives on.

I know when it's my turn to depart this life I also want the chance to save or improve someone else's life, so I carry a Australian Organ Donor Card with me at all times.

David



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



### My second corneal graft in 25 years

My first corneal graft occurred in the late eighties after I was diagnosed with Kerataconus. The difference in my eye sight was remarkable.

Things don't last forever though and in the past few years I had noticed that my eye sight was deteriorating again.

My original surgeon had since retired, so I was referred to another corneal specialist. He confirmed that my original graft had failed and was significantly deformed.

Whilst I could live with the vision loss to a degree the pain and discomfort was a concern.

I made the decision to go on the waiting list and within two months I received my second life changing phone call. It is early days since my operation but the signs are positive.

I am so grateful to my donors for giving me the chance for a better quality of life.

Thank you from the bottom of my heart.

Gaynor



Gayn



### Organ and tissue donation for transplantation is based on the concept of altruism.



### **Living large**

was born with Cystic Fibrosis. Although my life was never defined by my disease, by the time I reached the age of 26, I could no longer escape its grip.

During that year I consistently contracted pneumonia. I seemed to experience an acceleration in my disease and I was declining fast.

Upon examination, my lungs were extensively scarred from a lifetime of coughing. My doctor visited me and said that I would need a double lung transplant within the next couple of years. I was devastated by this news and refused to believe it.

Meanwhile, my life changed considerably. I was forced to give up my work and I was put on oxygen. My attitude also changed during this time, and I now wanted the operation to happen. This was just ten months after my doctor's diagnosis.

I was placed on the waiting list and miraculously I only waited a matter of weeks.

I became one of the earliest double lung transplant recipients in Australia. I remember asking one of my doctors how long I might live? He responded cautiously, "Nobody knows but you may live a year". After receiving my transplant, my life changed positively in almost every way. I felt limitless and euphoric. My gratitude towards my donor was very emotional. I've always felt that the best way to re-pay my donor's gift was to live my life the best way possible at all times.

I have since lived every day with purpose and have achieved some pretty amazing things. I felt that what I was given is "bonus life" and a unique opportunity to live life large. Most healthy people cruise through life without ever having the opportunity to truly live.

Today I am a proud long term survivor of a double lung transplant. My life has been nothing short of challenging, exciting and beautiful...and a great story to tell in the pub!

Organ donation and transplantation are true miracles. I will always be extremely grateful.

Jeff



leff with wife Sue and their daughter Olivia

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



### DonateLife, donate me A poem

Yesterday, I slipped away and I couldn't say goodbye. Now I rest, in this hospital bed and tears fill your eyes. With not a scratch on my face, or a mark on my skin. It's my time to leave this life.

Today you'll choose, as angels do, to give and not to beg. With prayers done, the heartache comes, you'll still do as I have said. With pain in your chest, and black sorrow within. You choose a chance to change others' lives.

Let them use all of me, because I don't need me anymore. Then I will live on, in more than just memories of yours. Let them use all of me, I will be wasted in the earth. Let me unburden others from the grief of the hearse.

You'll never hear my heart beating, but beat again it will. You'll never hear the breath drawn into my lungs as they fill. You'll never again look into my eyes, but see you know they will. I won't ever tread this earth again, because of us, someone will.

Somewhere, someday, someone who is loved like you love me. Will hold their Mother, Father, Daughter or Son, because we set them free. I can now rest in peace.

Alex



### DonateLife Book of I

Much loved Richard with his little niece Caitlyn

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



### Azza – A life well lived

ur boy Aa<mark>ron was</mark> a loving young man, full of life and fun. From a very young age he showed a lot of spunk and was into everything.

These are the bricks that went into building Aaron's life. He:

- Loved bikes, camping, fishing, surfing and 4-wheel driving
- Was generous, loving and loyal; treasuring • his family and friends
- Always knew what he wanted, where he was going and how he would get there ... via this toy and that toy
- Loved dancing from a young age, which started by waltzing with his sister, jazz ballet lessons, then the Riverside High School Rock Eisteddfod and later when he was out on the town
- Was passionate about Lego, fantasy novels, manga and building
- Enjoyed drinking with 'the boys'
- Had an infectious giggle and a cheeky smile
- Was adored by our cat Mishee.

Aaron was the type of young man every family would want to call their son or brother. He always demonstrated a social conscience and at the age of 18 he registered to be an organ donor. This decision displayed his genuine love and compassion for others.

The first communication with the recipients of Aaron's organs was like a spark of light, of hope, of something bigger and brighter than our grief.

The spark that we hold so dear is forever growing the more we communicate and learn about the life of these amazing people. The recipient's immense gratitude and renewed life after facing such a long journey of illness, juxtaposed by the descriptions of their now wonderful life, is a catalyst for a warm glow that spreads within us, producing genuine smiles that were initially so rare following our loss.

To think of and know that four people are loving life because of Aaron's last generous act brings us so much pride, admiration and happiness. A positive focus after our devastating loss.

Michele, Rob and Cara



Aaron was in a car accident which resulted in a brain injury. This led to the question of 'Have you considered organ donation?' Knowing his wishes made it easier to say, 'Yes'.



### Do the people close to you know your donation decision?



### Organ and tissue donation: a family on the same page

### Sue remembers her Dad Michael as someone who was 'always there for us'.

'He was keen for us kids to toe the line and was even a bit authoritarian, but if we needed anything he was the first to offer assistance,' she says.

Michael had been a hospital orderly and had been married for 55 years to Fran, an enrolled Nurse. They had three children, nine grandchildren and three great grandchildren.

As he aged, Michael's sight and hearing deteriorated but he was otherwise healthy. Then one day at home with Fran at the age of 76, he suffered a massive brain haemorrhage.

'The ambulance took him straight to hospital,' says Sue, a Registered Nurse.

'Dad was on a ventilator but we knew that night that he was not going to survive. Just knowing him, and the conversations we'd had as a family, we had no hesitation when DonateLife approached us about organ and tissue donation. 'He was surrounded by his family – there was no disagreement – we were all on the same page.'

Michael's liver and kidneys helped to transform three people's lives.

'Dad was always keen to ensure nothing was wasted – if there was stale cake Mum had to make it into a pudding,' says Sue.

'We said, 'he's still not wasting anything.'

Sue's commitment to organ and tissue donation remains strong.

'More people should do it,' she says.

'It's not a hard thing to say yes to – if there's not going to be any quality of life.

'It's vital people discuss it with their families – donation needs to be talked about.'

Sue



Michael and wife Fran with their first grandchild

### The majority of Australians support organ and tissue donation.



### **Our daughter Kaylene**

Our daughter was a caring and sharing person. She was an only child but she always shared her things with her friends and family. She loved life, enjoyed travelling and played sport including swimming and Highland dancing.

After completing school in Year 10, she commenced work in the banking industry and in December 1990 she was married and had a family.

The household was always busy. Like their mum, her children loved playing sports. Her daughters played hockey and her son played basketball and soccer.

After coming back from a hockey tour of South Africa she had a massive brain bleed. Our whole family was devastated.

Despite this, we honoured her wish to be an organ donor and now she lives on in four others. It has helped us to know that someone else is living a better life now and I feel that she is still with us.

We have received letters from two of the recipients and they are doing well. We wish all of them a long and happy life. I miss my daughter's smiling face and knowing that I will never hear her calling my name... 'Mum, how are you today?'.



life



### Around 1,500 people are on official transplant waiting lists at any one time.



### Brendan's story by his parents Marlane and Ray

t was early on Father's Day when Brendan's family left Jindalee to head down to the Gold Coast Motocross Club's track for a practice day prior to the final round of the Queensland Junior Motocross series. Brendan was leading his class in the series and wanted to familiarise himself with the track prior to race day.

Even wearing full protective gear, including one of the best helmets, Brendan suffered a serious head injury during practice. That night, following multiple tests in the hospital's ICU, We were confronted with the reality that our son, at the tender age of 16, would not be coming home. Asked about organ donation, Ray's initial reaction with all the emotions of the situation was bordering on no.

Brendan was passionate about music and since early childhood had been taking drum lessons. One month before the accident, on his way to lessons, Brendan asked his mum Marlane what the 'y' on her driver's licence meant. On being given the explanation by Marlane, Brendan commented to his mum...'That's a good idea, I also want to do that when I get my licence. Why take them with me if I can help someone'.

The question of donating his organs had been answered by himself and when Ray was made aware of Brendan's position, the family honoured his wishes.

Four people were given a second chance at life because of Brendan as his heart, liver and two kidneys were received by grateful recipients. consider organ donation and most importantly ensure individual wishes are properly registered.

Brendan was a lovable, somewhat cheeky character who was always patient and caring. He liked helping others and hated seeing anyone unhappy. He loved a good joke. "He had beautiful brown eyes, he spoke with his eyes. He was my brown-eyed handsome man" quotes Marlane.

After his death Marlane discovered amongst Brendan's favourite songs was, like he will always be, "UNFORGETTABLE".

Be at peace Brendan, fly now with the angels.

Love Always Brendan's Family



Organ donation did not make Brendan's death acceptable to our family, but it did provide us with some element of sense from the tragic sporting accident that claimed his young life. Consequently, we ask family and friends to

Our son Brendan

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



### **Cassie's story**

My name is Cassie and I am the recipient of two corneal transplants. When I was 20, I received a corneal transplant in my left eye. Two years later I received a corneal transplant in my right eye.

My vision first started to deteriorate towards the end of high school. I was diagnosed with a condition known as Keratoconus. At first I was able to manage with glasses and contact lenses. My vision however continued to deteriorate to the point where I was having a number of near misses with cars and was getting lost when I went out. I soon stopped going out and if I did I would rely on someone to help me get there. A corneal transplant was recommended.

The day that I received the phone call to say there was a cornea for me is a day that I will never forget. So many thoughts and emotions were running through me all at the same time. While I was in shock and trying to work out what I needed to do next, I was also feeling sad. A family had just lost their loved one and while they were grieving they were consenting to donating their loved one's organs and tissues. I can't imagine how tough that would have been. At that time there was nothing that I could do, however I made sure that I wrote to them afterwards to say thank you.

Since the transplants I have regained my independence. I have purchased a unit and have moved out of my Mum's house. I am back to joining in on activities and going out with friends. I have started studying again and have been giving my friends a challenge when playing sport. In May 2014 I completed one of my goals of climbing the Sydney Harbour Bridge. I look forward to the new challenges and activities ahead.

With each new day I say thank you to my donor families – I wouldn't be where I am today if it wasn't for them.



With my mum Carolyn at the top of the Sydney Harbour Bridge

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



### **My Sally**

There is something that all donor families have in common – a loved one who showed kindness from the heart and thoughtfulness for others by signing up for organ donation.

Sally and I first met as teenagers living in the same neighbourhood. We married in 1963. We found out that our grandfathers were the best of mates in Perth before they and their families moved back to Adelaide around 1910 where their friendship continued.

Sally was full of life, a sports woman and held strong Christian principles, but it was her spirit for life that captivated me.

She was full of good ideas, for our wedding saying, "we must learn our wedding vows and say them out loud so people in the church can hear them without prompting, then the vows will come from our hearts." It was interesting how many wedding guests commented on it. After a couple of years of marriage she gave birth to the first of three beautiful little boys then 10 years later, to complete our family, a beautiful little daughter.

Sally was a gorgeous, fun-loving wife and mother. She was very artistic with a good eye for design and colour which helped me with property developments. She loved watercolour painting – mainly of flowers and sailing boats, photography of beach scenes and birds and woodcarving. She was very versatile and I considered myself a very lucky man.

Sally exercised twice a day, ate the right foods and looked after herself well. At age 70, out of the blue, Sally lost consciousness due to an aneurism. They immediately put her on life support and kept her on it until the following night, when she became an organ and tissue donor. Five organs and tissues in all were donated.

After 52 years with 'the girl of my dreams' her sudden loss was very hard to take but reading the letters from the recipients of her organs, was enough to warm my heart and bring tears of joy in a time of grief.

When we signed on to be organ donors, neither of us knew the strict criteria that donors have to meet before their organs can be used. This means only a small percent of donors qualify and more people are needed to sign up! I'd like to thank the DonateLife representatives who've cared for us and treated us with care and compassion.

Tom



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



### **Our daughter**

n May 2011 my partner and I welcomed our little girl into the world. To our devastation, at 30 weeks gestation, she was diagnosed with Autosomal Recessive Polycystic Kidney Disease, a rare genetic condition which destroys the kidneys and lungs.

Our little girl was born six weeks premature and was very unwell. When she came into the world there was no sound, we saw her for less than 30 seconds before she was rushed away to the neonatal intensive-care unit on life support where she spent the first three months of her life. During this time she had her kidneys removed and a peritoneal dialysis catheter placed in her abdomen. On several occasions we were told she would not survive.

Over the next six months, she underwent several surgeries, infections and hearing loss. Up until a few months ago she was hooked up to dialysis for 13 hours every night. This was her life support.

Our beautiful girl has now received the gift of life, a brand new kidney. I donated my left kidney in the Australian Paired Kidney Exchange and in return my daughter received a kidney from an amazing stranger. Being in a different hospital to my daughter and not being able to be by her side was one of the hardest things I have ever had to do. Although the kidney exchange is anonymous, I truly hope the individual who received my kidney is doing as well as our little girl is. She is now a completely different child with a huge amount of energy and a desire to learn.

After reading my story, I hope you are inspired by my amazing little girl and have the chat that saves lives.



Alexis





Australian Government Organ and Tissue Authority



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### Alternative format

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

