



Donor Families  
AUSTRALIA

# Donor Families Australia NEWS

Summer 2017, Edition 18

## HIGHLIGHTS

Uniting consenting donor families and recipients

Facing Christmas and the Holidays without our loved ones

Reflections on the Donor Families Australia AGM and Dinner

*Share your story*

## MATTY, OUR HERO

**My brother Matthew “Matty” was born 11 June 1982. He entered the world in a rush and left us at high speed, living his dream – racing his motor bike, a Suzuki GSXR 600cc at Eastern Creek Raceway on 14 February 2017.**

As a young boy growing up, Matty loved anything with two wheels. At the tender age of three, our parents bought our first motor bike, a Pee Wee 50CC. Every afternoon you would find Matty riding the jumps and tracks our Dad built. As we got bigger, so did our bikes. Then when Matty was old enough, nothing held him back to get his motor bike licence. As a family, we would hit the road for scenic trips around the country side.

Matty certainly loved his sports from an early age. He enjoyed the fun of sports, the adrenalin and achieving goals. He would give anything a go and loved following in Dad’s footsteps. When he was nine years old, he started road cycling. Matty became so dedicated to his cycling that road racing wasn’t enough, so he tackled track racing as well. As a family, our Dad, Matty, and I would head out for training sessions. It was always a race to see who would get up the hill first and of

course it would be Matty—with us hot on his heels. Over the many years of Matty’s cycling career, he won many state titles on the road and velodrome. Matty made everlasting friendships as he would always be the first to help if you were stuck on the side of the road with a flat tyre and no spare tube during a race or training ride.

After road and velodrome cycling came mountain bike racing. Matty competed in races that were over 12 and 24 hours. He went in races individually and at times in a team. Other races included kilometre and downhill races. Most mornings at the crack of dawn he’d be out training on one of his push bikes to improve his strength for the weekend of racing whether it was on the



~continued page 2



*A life that touches others goes on forever*

# MATTY, OUR HERO

~continued from cover

road or in the bush.

Other sports that Matty played included a bit of squash with our parents, swimming competitively and achievements in athletics. When he wasn't competing, he loved to ride the surf in his wave ski. His passion for surfing started during the many trips to Crescent Head where our family had been coming to since Matty was six months old. Crescent Head became a magical place for our family,



and from that time on we had annual family holidays there which were always exciting and enjoyable.

Matty's love of water also extended to canoeing and kayaking. When Matty was 17, he and our Dad built Matty's first racing K1 Kayak. Matty paddled in the State Schoolboy championships at Grafton and he also loved white water races. His biggest paddling achievement was competing in the Hawkesbury Canoe Classic 5 times in a double Kayak with our Dad. This is a gruelling overnight race covering 111 kilometre

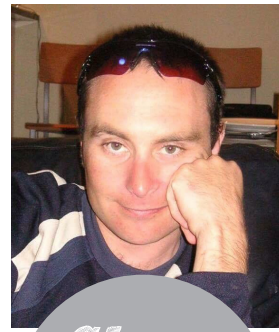
nonstop; just to finish the race is an achievement. Matty didn't just take on the challenge of completing the race, his goal was to finish under eleven hours which they achieved every time.

After many years of competitive kayaking Matty hung up his kayaks and hopped back on his push bikes. He got back into cycle racing on the road, at the velodrome and mountain bikes as well.

On a more personal note, the week before Matty's accident, our Dad was heading out for a training paddle when Matty asked Dad to put a Kayak on the roof of the car so Matty could join Dad on the river. Even though he had not done any paddling for years, within minutes Matty had the racing Kayak gliding through the water. He still had it!

This paddle was one of many special things Matty did out of the ordinary during his last few weeks. Matty was also out surfing his local break that he loved so much at Crescent Head just days before the accident that killed him.

Aside from his many sporting achievements, Matty loved to share his life with family and friends, especially his best mate in the world – his little pug dog 'Princess Gemini'. He lived for his Princess Gemini and they were inseparable. Gemini would come to the push bike racing events and cheer Matty on from the sidelines. Their adventures would also take Gemini to the beach for swims and walks. They really were best buddies. Every day when Matty would come home and park his car, Gemini would be sitting on his lap helping to steer it into the garage. But it didn't stop there. Matty would put a towel on the tank of his motor bike and sit Gemini on the tank and would take her for rides around the backyard. The rides around the backyard became even more fun when we had a baby jogger that Dad and Matty converted to a side car and would attach it to the side of the motorbike. Gemini loved it and



*Share  
your  
story*

 *A life that touches others goes on forever*

didn't want Matty to stop.

About 2½ years ago Matty decided to get out on his motor bike at Eastern Creek raceway in Sydney to try circuit racing on his Suzuki GSXR 600cc. His motor bike was his pride and joy, every week you would find him in the garage washing and polishing his motor bike. Frequently, Matty would head to Eastern Creek for practise rides. I remember when Matty came home from his first ride day, all he talked about was how much fun it was and all the new friends he made. Then it was on – he wanted to convert his road bike to a circuit race bike. Dad and Matty spent countless hours converting the bike. It was a great achievement they accomplished as a team. Matty continued many more practise training days; he was pumped and ready for racing.

Every afternoon when I got home, all I could hear coming from Matty's room was the sound of a motor bike. He would be on the internet watching anything and everything to do with motor bike racing. Matty was always honing in his skills.

Then came his first race meet. Matty had all the gear and was ready to race. Even though Matty loved speed, he would not exceed his limits and would take it nice and steady around the race track. As the race meet continued, Matty would try and improve his times from the previous race without exceeding his limits.

It was on 10 February 2017, the day of my birthday, that I got to spend my last day with my brother as a cheeky, happy and outgoing fella.

Together with our Dad, Matty was all packed and ready to leave early the next morning for a weekend of racing at Eastern Creek race way, the weekend of 11-12 February 2017. The weekend was hot, and even hotter on the race track. On Saturday 11, Matty got out on the race track and gave it all he had, improving his times each race. As the day went on it was getting hotter and so many riders were falling off in races that the committee cancelled

racing for the rest of the day.

On Sunday 12 February 2017, as per usual Matty gave it his best in all races. Around 2 pm I decided to give our Dad a video call to see how Matty's racing was going, also Matty's dog Princess Gemini wanted to say hello. Dad headed down to the track garage so we could chat to Matty as he was getting ready to head back out to race. We laughed and joked around, Matty was living his dream. We watched him ride to the start line, he waved good bye to us as he lined up for his final race. About 30 minutes later my mother and I got the dreaded phone call from Dad saying Matty has had a bad fall and it didn't look good. Mum and I hopped in the car for the 2½ hour drive to Sydney.

On arrival at Westmead Hospital the Neurosurgeons told us that Matty will not survive due to the severe head injuries. We sat by his ICU bed for four days. On 14 February 2017 at 12:34 pm, my little brother was pronounced brain dead. From that



# MATTY, OUR HERO

~continued from cover

moment the organ donation team started the process. It was a long night. The next morning at approximately 5 am, we walked Matty to the operating theatre doors and said our final goodbyes. It was devastating knowing that it would be the last time we would see Matty's face.

The next day we received a phone call from the Donor team to tell us that five different people had received Matty's organs. A twelve year old boy received part of his liver. We later received a letter from his family. A 37 year old lady received the other part of his liver. We have been lucky enough to meet her family, thanks to them making contact with us through social media and they also received our letter. A person received Matty's heart and we have received a letter from them. One person received a kidney and another person received the other kidney and his pancreas. We have sent those recipients letters but have not heard from them as yet. I hope one day they are able to reply.

It was remarkable that about a week before Matty's fatal accident, he and Mum were sitting on the lounge and what seemed to be very out

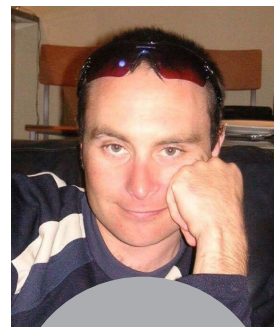
of the blue had a conversation about funerals, organ donation and their personal wishes. Little did we know what was about to happen. It was Matty's wish to help others and to donate his organs. Matty last amazing gift was to give life to others. During organ donor week our local newspaper, The Newcastle Herald, ran a story about Matty as an organ donor. It was an amazing article that touched many people.

So please, talk to your family to discuss each other's wishes.

One of the ways we chose to celebrate Matty's life was by scattering some of his ashes in the surf that he loved so much at Crescent Head. That magical place will always hold a special spot in our family's heart.

Matty was an amazing, talented, caring fella who loved life, followed his dreams and accomplished everything he strived for. He was taken away too soon.

**BORN TO RIDE 182**



*Share your story*



Donor Families AUSTRALIA

## AROUND AUSTRALIA

**Donor Families Australia** is a nationwide independent support and advocacy network comprising families who have donated their loved ones' organs and tissue.

Membership is free and gives donor families a voice:

- To speak with and to support each other;
- To let those who formulate organ and tissue donation policy know what is important to Donor Families; and
- To connect the community to a group that knows the experience of donation so they might come to a true understanding of what it is all about.



*A life that touches others goes on forever*

# NEWS ON MATTHEW'S RECIPIENTS

Matthew Brown's transplant happened during the early hours of Wednesday 15 February 2017.

Gosh, it's been just eight months since Matty's accident and we have had correspondence from three of his organ recipients which is so overwhelming and exciting. We are ever so grateful that those three have made contact with us.

We received a beautiful letter from the family of a part liver transplant recipient. The recipient is a 12 year old boy who happens to be the youngest of a lovely family of 13 children. We wish him well as he grows into a wonderful healthy young man.

We also have had contact by telephone and have met the family of Matty's other part liver transplant recipient. Suzanne was a beautiful 37 year old woman – wife to Hasan and mother to two gorgeous children. Suzanne was the same age as Matty's older sister Michelle which was an amazing coincidence in its self, but also by chance we found out Suzanne and her mother were good friends of our old friends Noel and Margaret. Such an incredible world we live in! Sadly Suzanne passed away just days before we met with her beautiful family at Eastern Creek. It was a very sad occasion as other issues with her health had caused her death not related to the liver transplant. May you rest in peace Sue.

We had a gathering to honour Matty at Eastern Creek Motor Racing Circuit where we placed a

plaque, with a photo of Matty on it, in motorbike Garage 42. We invited Suzanne's family to help us celebrate Matty and Suzanne's lives. It was very touching to meet Suzanne's husband, children, mother and their extended family and friends. We'd like to extend our heartfelt thanks to Suzanne's family for the lovely flowers.

Recently, Matty's heart recipient sent us a moving letter. Miracles do happen and they are going very well. In the letter they said one of the

things they missed the most before the transplant was taking their little Pug "Baxter" for a walk. This just brought tears to our eyes as Matty's best mate was his little Pug "Gemini". Again we are amazed at

the incredible world we live in – it really seems that things in this world are meant for a reason. Someday we hope to be contacted by Matty's other recipient. It means a lot to us to hear from his recipients and we are hopeful that the last recipient will also respond.

When we wrote to all of Matty's recipients we included in a beautiful card the story about Matty's life. On the front of the card which shows a young child's foot print in the sand, it says "Life is Beautiful" and we also placed a lovely feather in it.

Thank you for letting us tell our story and if anybody's transplants connect with this date we would love to here from you.

*Christine and Russell Brown, Matthew Brown's parents*



# CHAIRMAN'S MESSAGE

## Welcome to our special Christmas edition of DFA news.

To all those who have lost a loved one, we share your grief over this special time. Perhaps more than any other time during the year, the Christmas period focuses on the family. Whilst others may be very excited, those that have lost someone invariably see that empty chair and place at the table. Look after yourself over this period and know that you are in our thoughts. Please refer to the article as provided by the OTA/Donate Life.

Since our last newsletter, we have held our AGM in Melbourne. A big Thank You to Kevin Green who hosted a meal for Donor Families. It was a wonderful night and we have included some pictures of the night in this edition of our Newsletter. As a result of the AGM our committee comprises of:

- NT- Helen Day
- Qld – Kelli McDonald
- NSW – Jann Eastley and Graham Harrison
- Vic – Leanne Campbell and Kevin Green
- Tas- Rebecca Free

- WA – Philippa Waldron and Bruce McDowell.

I wish to extend, on behalf of all donor families, gratitude for the enthusiastic and dedicated work they do to advocate and support other Donor Families. We have noticeable gaps in our committee make up that being two members for SA and one more member for Qld. Any Donor Families from those states who would like to be on the committee to help further our cause: please make contact via our webpage so we can discuss the prospect of joining the committee.

I have been fortunate to have recently attended 'Controversial Conversations' held at Deakin University in Melbourne and shortly after the annual Tissue and Eye Bank Conference in Auckland. Both conferences discussed topics that are very important to our membership.

Controversial Conversations featured our own, Robyn McCanna. Robyn featured on a panel that discussed consenting Donor Families and consenting Recipients meeting. By the time the session finished, it would be fair to say there wasn't a member of the audience who didn't agree with Robyn that consenting Donor Families and consenting Recipients should be assisted in being able to meet.

As a Tissue Donor's Dad, I found the conference in Auckland particularly confronting. To hear how human tissue from unknown parts of the world is now being used in our Australian hospitals is a very disturbing trend. Our government and public sector has allowed for human tissue



Bruce with President of the Biotherapeutics Association of Australasia, Gavin Van Der Meer, AGM, Auckland

to enter our country without knowing how it was acquired (ie: ethically or from where).

The other side to this worrying story is that the tissue is being provided by international companies making a profit. These tissues are now available and are competing with the tissues that Australian Donors and Donor Families have so generously donated.

A very worrying trend is that while organ donation numbers are rising, that can't be said for tissue donation. Here in my state of WA, tissue donation has dropped dramatically thus leaving it open for these international companies to provide our hospitals with their human tissues. This whole side of donation, it has to be said, is not what Australian Donors have agreed to or signed up for. I would suggest it really needs to be looked at as a matter of urgency by the government or the Australian public could start asking very serious questions.

In this politically correct society we now live in, language has become very important. This holds good in organ and tissue donation. If we want the Australian public to register and families to say yes we really need to improve our language. Just recently to promote the Thank You Day here in WA a news article was headed "WA on path to be organ 'exporter'" and the first paragraph included "'an exporter' of body parts". As a Donor Dad I don't really appreciate

the idea that my daughter's donation can be so-called, exported. Nor do I appreciate the disrespectful reference given to my daughter's donation. We are dealing with humans here not iron ore. This does seem to be forgotten sometimes.

November 19 saw our third Thank You Day. For the first time, the OTA included with its "thank you" to Donors and Donor Families that we should now "also take the opportunity to acknowledge our donation and transplantation specialists, joined by many other health professionals, who care for our donors, recipients and their families."

DFA was very disappointed with this and formally moved away from this concept. It was meant to be a day to thank Donors and their Families. If the public servants and medical staff feel that they are not being acknowledged enough through their remuneration and the remembrance services, then surely they could organise their own day and leave this day for the hero, the Donor.

To our membership and readers all the best for Christmas and we look forward to coming back all go next year, fully reinvigorated to continue to advocate and support our members.

*Bruce McDowell*



## A WARM INVITATION TO JOIN US

### Share your experience

with similar people to support those making life changing decisions.

**Help us to build a caring community** and to shape the future of this caring national network.

If you would like to find out more about

**Donor Families Australia** and how to become a member please visit our website

**Individually we do great things and affect those around us.  
Collectively we do great things and affect a nation!**

[www.donorfamiliesaustralia.org](http://www.donorfamiliesaustralia.org)

# AMONG DONOR FAMILIES: REFLECTIONS ON THE 2017 GENERAL MEETING AND DONOR FAMILY DINNER

**My husband Terry, a cornea recipient and I, Anna, a double lung recipient, had the privilege of being asked to speak at this year's annual Donor Family Australia dinner. We also attended the Annual General Meeting for Donor Families Australia prior to the larger dinner held on 16 September 2017.**

Terry and I were both impressed with the organisation and dedication of all of the volunteers present for the general meeting. They discussed important uses of funds and budget, as well as goals of the future of Donor Families Australia. At the conclusion of the meeting Bruce McDowell announced the launch of the new website. Being more user-friendly and making the process of becoming a member, volunteer and making donations much easier, we saw how they are moving towards the future with the website.

The members in attendance were from near and far, including Western Australia, Queensland, Northern Territory, and Victoria. As observers, we experienced a strong sense of community and dedication to the mission.

We were welcomed with open arms to the meeting and to the dinner. The room was filled with Donor families and we were the only recipients along with Kevin Green. Kevin organized a great dinner held in Melbourne at the Limerick Arms Hotel. We had a tremendous spread in a private dining room.

Before we were to speak to the room, we shared in the stories of the donor families and got to feel a strong camaraderie within the group. I myself, was new to the group and was welcomed with those open arms. We all had great conversation, deep sharing, and appreciation for each other's experiences. Terry and I are honored every time we get to be surrounded by donor families. Neither Terry or I know who our donors are, or have had the opportunity to meet the families, despite having both reached out with thank you letters. It is immensely important and special for us to be able to express our gratitude to donor families.

We also appreciate and value the opportunity to share our experience and hear the stories and experiences of donor families, as it helps us to heal and to complete the circle. We appreciate being accepted by donor families and in return, we hope that, for those donor families who don't know their recipients, we can act as a surrogate to share the experience and thankfulness we so deeply feel.

Not only have our lives been saved and enhanced by our donors but Terry and I found our love story. Being new to Australia, I am building a new network of friends and family here, and my friends I have made through Donor Families Australia are some of the most important and supportive people to me. I have experienced that donor families are some of the most giving and loving people, and I am so honored to be involved with this group. Terry and I both realize the hardships everyone has suffered and we never want to minimise that, but rather to remember the family members who have been lost and honor their heroism and memory.

Thank you all for allowing us into your lives to share our story of organ donation. Merry Christmas and Happy Holidays to all Donor Families, with love from Anna and Terry.

***Anna Modlin & Terry Holyoak***





# INCREASING CONSENT TO ORGAN DONATION BY ENABLING DONOR FAMILIES AND RECIPIENTS TO MEET

**Holly's  
Insight**



The movement that has arisen within the DFA community to support the meeting of consenting Donor Families and Recipients is highly significant for efforts to increase organ donation in Australia.

The rules and regulations that pertain to meetings

between people who have received transplants and families who have donated their loved ones organs have historically been managed by transplant coordinators and physician gatekeepers. Fear that Donor Families or Recipients will suffer disappointment or 'behave badly' if they meet- have driven the organisational practice that has seen many Donor Families hidden or silenced behind policies that demand anonymity. These ideas are largely unsubstantiated by published evidence.

Likewise, recipients are provided with limited and inconsistent information about their donor. Across the globe, information about donor – recipient correspondence is minimal and may vary in practice from one centre to the next. This lack of clear communication about what to expect with regard to communication and meetings is a surprise to many consumers involved in the donor-recipient relationship. The silencing of these healthcare consumers has been considered normal practice for many years across organ transplantation organisations. As we move into the 21st Century, and consumer rights and ideas of social justice gain traction in our policy and legal practice; and social media changes the way we communicate- it is timely for organisations involved in caring for organ and tissue donation decision-makers and recipients to revisit their policies and practices.

There is plentiful circumstantial evidence that the

community view of organ donation is enhanced when the community are provided with clear evidence of positive donor recipient relationships that occur when consenting people meet. The opportunity to see bereaved families have their hopes, needs, and sometimes sacrifice of a peaceful death of their loved one -addressed by the tangible proof that someone has benefited from the donation, is vitally important for healing. Further, many Recipients yearning to meet the Donor Family may have a psychological need to connect and honour the experience to help in their own healing. The media seek out opportunities to record these meetings that are seen as special and positive events by the community.

There is limited research into Donor Family–Recipient relationships and the impact blocking or facilitating them may effect on the wellbeing of all involved. It is clear that the conservative approach we have used in Australia is not meeting the needs of many Donor Family/ Recipient healthcare consumers or community expectations. DFA plans to undertake research in this area in 2018 to enable a clearer understanding of the issue. In the meantime, I would like to highlight the research of Lewino, Stocks & Cole (1996) who found, "Donor Families and Recipients not only desire contact, they think they have a right to meet even if the transplant professional advises against it" (p.193). Lewino et al (1996) quote a respondent who stated, "If both parties are willing to meet, I just don't see a bad outcome except not to meet at all" (p.195).

I look forward to 2018 and the hope that we will all positively touch the lives of others.

Reference:

Lewino, D., Stocks, L., & Cole, G. (1996). Interaction of organ donor families and recipients. *Journal of Transplant Coordination*. (6); 191-195.

*Dr Holly Northam, Faculty of Health,  
University of Canberra Pundam*

# TREE PLANTING & THANKSGIVING CEREMONY

HEART & LUNG TRANSPLANT FOUNDATION, SATURDAY 7 OCTOBER

The Bendat Parent & Community Centre in Wembley, alongside Lake Monger WA was the perfect venue for a beautiful service and tree planting ceremony to honour our Hero Organ and Tissue Donors.

The welcome address given by Nicole Cox was followed by 3 songs from the WA Variety Youth Club Choir, which included a beautiful and emotional rendition of "Amazing Grace"

Sharon Lawrence, Clinical Nurse Consultant, spoke of the benefit of transplants and the transplant status in WA. This was followed by a moving story from Mum, Sue Lambert, about her son Danny and what organ and tissue donation meant to donor families.

Brett Dressen gave the recipient address and this was followed by Thanksgiving from Father Thomas Mankuthel.

A prayer and candle lighting exchange from donor families to recipients took place in remembrance and thankfulness for organ donors and their recipients.

At this point we all walked across to Lake Monger Reserve where a remembrance tree had been planted in acknowledgement of donors.

The afternoon concluded with a delicious afternoon tea and fellowship in the Community Centre.

Donor Families Australia were very kindly invited to be a part of this Ceremony and it was very special to meet other donor families and we sincerely thank the Foundation for our invitation.



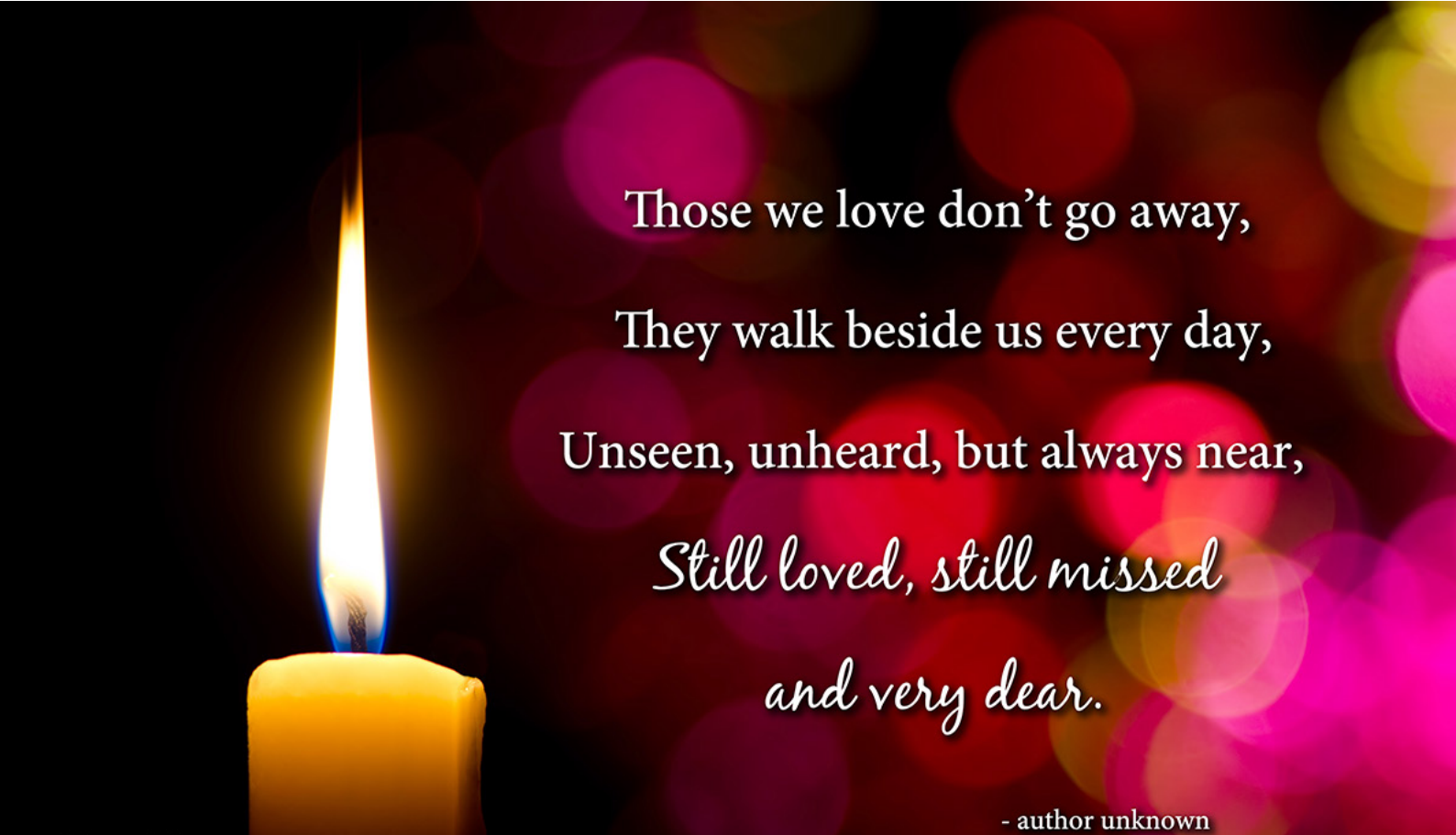
## Upcoming Events



DFA News is distributed throughout Australia each quarter.

If you have a public event planned in relation to organ and tissue donation, please let us know and we can publish your event details.\*\*

To advertise an event, contact us: <http://donorfamiliesaustralia.com/contact-us>

A photograph of a lit yellow candle on the left side, with a soft, out-of-focus background of colorful bokeh lights in shades of pink, purple, and yellow. The text is centered over this background.

Those we love don't go away,  
They walk beside us every day,  
Unseen, unheard, but always near,  
*Still loved, still missed  
and very dear.*

- author unknown

# DONOR FOUNTAIN SAVES LIVES



The Donor Fountain in Geraldton can be credited with directly saving lives. Sadly, Julie Nelson, a local, recently passed away, and in so doing, saved many lives becoming a Donor when her husband Peter and her family of four boys said “Yes” to organ and tissue donation.

Peter said: “Julie and I would walk by the Fountain three times a week.”

Peter confirmed that the awareness brought about by the Fountain definitely helped prompt that all important conversation between them both, and their boys.

Peter was surprised or perhaps, fair to say, stunned that something similar to the Fountain is not done in Perth or the other capital cities. The awareness factor created is immense and is there as a constant reminder not like once a year events or set advertising campaigns. It is in your presence every day.

Peter is seen at left, with Jason Keals, our volunteer who places all the plaques on the board for DFA.



Being a Donor Family is forever a unique and changing experience.

Our organisation is a place for Donor Families to go. We want to hear from all Donor Families -their stories and experiences assist all Families with what they are going through.

Donor Families be treated with the utmost regard and considered throughout the process.

We have a role to play by working to help educate the public on the system from a Donor Family perspective - understanding it is not a simple process - celebrating and honouring our loved ones' gifts.

Donors and their families are special enough to be heard and consulted on organ and tissue donation policy.

We give those in a position to influence policy - politicians, bureaucrats, media and other agencies - somewhere they can find out what this most important group in the process think.

90 per cent of Australians support the idea of organ donations, yet many have not let their next of kin know, or get the opportunity to do so.

We believe there is much we can do to improve the Donor Family experience and help many more in need because the community trusts and understands the process.

The community discusses donation without the knowledge and input of those who have lived through this experience.

We connect the community to a group that has the experience of donation so they might come to an informed understanding of what it is all about.

We are the only organisation in Australia, dedicated to Donor Families.

**Join the conversation**

[www.donorfamiliesaustralia.com](http://www.donorfamiliesaustralia.com)



Donor Families  
AUSTRALIA

# DONOR FAMILIES AUSTRALIA BRING CONSENTING FAMILIES TOGETHER

DFA has now taken it upon itself to assist consenting Donor Families and Recipients to meet. Already via DFA's facebook page, there have been at least 30 pairings of Donor Families and Recipients' Facebook page 'Donor and Recipients Group Australia:

<https://www.facebook.com/groups/219966401436603/?ref=bookmarks>

DFA has been very conscious of the increasing interest being expressed by Donor Families and Recipients and their families to have a formal process that will enable consenting parties to communicate and/or meet in person. Our Facebook page is full of comments made by Donor Families and Recipients about their dissatisfaction with DonateLife's communication process.

"How do we even know our letters have been passed on?" is a common comment. We, at DFA, are planning on getting far more involved in the whole communication process to take away this dissatisfaction and uncertainty and also help with facilitating consenting parties meeting.

This desire to communicate with each other has been gathering momentum in countries around the world and has been trialled within Australia for a period of a few years during the early 2000's within Transplant Australia resulting in thirteen successful meetings. More recently during the past twelve months there have been two forums, both held in Melbourne, discussing the topic of Donor/Recipient contact by consenting parties. DFA members attended both and it was gratifying to note that a consensus near to 100% in

agreement of those in attendance supporting donor/ recipients meeting—provided that both parties have consented.

At the recent 'Controversial Conversations' two day conference, we heard from the surgeon who heads up an American state health system, that they employ staff specifically to assist Donor Families and Recipients who wish to make contact. Unfortunately the OTA/DonateLife has demonstrated that it is not in favour of this happening in Australia despite the overwhelming desire of those involved. Perhaps in the current climate we can compare ourselves with the same sex marriage movement and just need to maintain our stance and eventually force a change in policy.

DFA is now in the position of establishing a Donor/Recipient Contact Registry with the assistance of fellow Donor Family sibling Mei Ling Clucas Egan who has already commenced a registry of her own. By combining resources and strengthening internal procedures and processes, DFA will be in a strong position to undergo any scrutiny. Our approach will be to open up the registry to all DFA members and DFA Associated members.

During January and February, details of our registration process will be available through the DFA website at [donorfamiliesaustralia.org](http://donorfamiliesaustralia.org). Meanwhile, we encourage those that are interested, to register as a DFA member (Donor Family) or a DFA associate member (Recipient or Recipient Family).

**Graham Harrison, Secretary DFA**



# REFLECTIONS ON LESSONS LEARNED

**Michelle Skinner from the Organ and Tissue Authority, generously shares with us, her reflections on the lessons learned from spending time with bereaved family members over the festive season.**

These moments are drawn from the thoughts and feelings expressed by family members in my role as a bereavement counsellor. Names have been changed to ensure confidentiality, and permission gained for any part of a story that might be identifying.

## Roy and June's Story

As with many women of her generation, June was an integral part of her family's Christmas celebrations. She shopped for gifts for her three children and five grandchildren and had everything wrapped and ready by the middle of December. When Christmas was held at the family home on alternate years June was like a "small Sargent Major" in the kitchen.

In the lead up to Christmas and on the day, Roy said he pretty much just "followed orders and stayed out of trouble." Roy said this with great affection.

June's accidental death was sudden and unexpected. She was a youthful, healthy grandmother and her family were left shocked and confused by this loss and by the terrible circumstances of her death. June was also an organ donor.

Roy had attended counselling on two occasions and his third was prior to his first Christmas without June. These are some of the moments Roy spoke about in the week leading up to the day.

It was four in the morning when Roy woke and was filled with dread and anxiety; he was used to this feeling now and he had learned how to manage it. He took slow deep breaths and let the sadness wash over him. There were no tears this time and he was relieved. Although he had stopped fighting the tears, he found these moments exhausting.

It had been five months since June died and Roy felt that was getting "a bit better" but now he felt worse. Some days the pain of her absence

was so heavy and unbearable that he couldn't believe he was still carrying it around. Others he felt empty and insubstantial, his 'better half' gone. He thought perhaps he should have told their children that he couldn't face Christmas day without her but that would require talking about his feelings, something he had never really done before. The other problem was that he couldn't face the day alone.

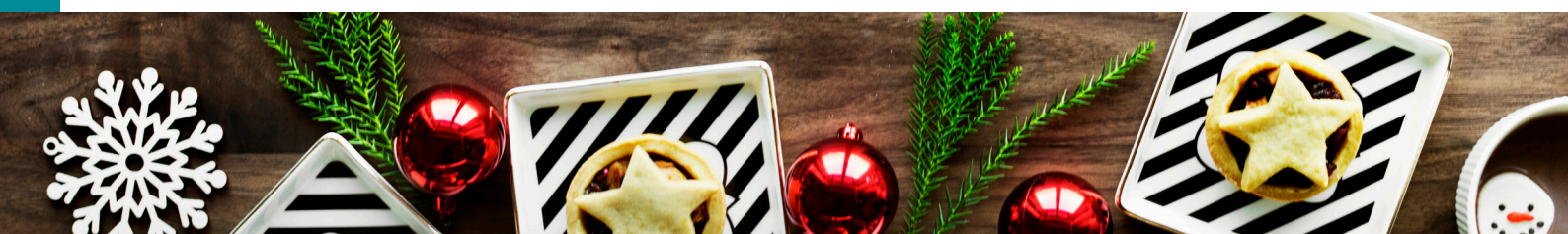
The people closest to the deceased commonly report increased feelings of anxiety, particularly following a sudden and unexpected death. The intensity of the anxiety is influenced by a number of factors including the person's own mental health history. In the lead up to many of the 'firsts' after someone has died, these feelings of anxiety can increase.

Like Roy, many struggle to make sense of a first Christmas without their loved one. In the month of November, I commonly hear people say "I'm dreading Christmas."

When someone dies, our grief response is shaped by many things including the intensity of the relationship with the person who died. People on the periphery of the deceased person's life will have a very different grief experience to those who were central.

The strategies for managing anxiety in grief are similar to those when grief is not part of the picture. These include: self-care, eating well, limiting alcohol and caffeine, getting enough sleep, taking deep breaths and calming self-talk. It is also important to accept that grief is normal and that you are doing the best you can under the circumstances.

Roy and June had settled into their new life without children living at home, working part time and spending more time travelling. In addition to having a deep and true love for each other, Roy and June were great friends. After five months, he began to feel the increasing isolation of grief while other people were





'moving on'. This feeling of being alone in his grief intensified during the festive season. He couldn't blame people for their excitement. At the same time he still had trouble believing that the world could go on without June; it seemed wrong somehow and at times it made him angry. During these moments, Roy did what he always had done when he "was not right"; he spoke to June.

In his first counselling session, Roy told me he had been talking to June when he was at home alone. He was concerned that this meant he was "losing it". He was relieved to know that many people found this comforting and that it didn't mean he was losing it.

For some people these feelings of isolation can be tempered by talking to those who have had a similar experience. Support groups, when facilitated well, can be useful and comforting, particularly in the months and years after the initial busy time after a person's death.

To help Roy manage his feelings leading up to Christmas, we spoke about what he needed to do to help him feel calm and as though he had some control over what was happening. On one hand he wanted to be there for his children and grandchildren. On the other, he also wanted to stay in bed and wait until the day had passed. He did acknowledge, however, that he had never been a person who would lie around in bed all day.

We spoke about a plan, a way he could feel he was honouring June and still feel he was engaging with his family. We also spoke of the people in Roy's life who "just got it". His daughter-in-law and he had never been closer, she seemed to always say the right thing and know when to be silent. She wasn't fearful of upsetting him and spoke about June and how much she missed having her around.

Having a plan for Christmas Day helped Roy feel more in control. We agreed that it didn't really matter if he decided on the day to not follow through with his plan.

Roy had a project in mind and he believed working on this would help on those days when everyone else was busy preparing for

Christmas.

While he was clearing out his garage, Roy came across part of an old wooden bedhead. It had been made from beautiful wood and he had always planned to "do something with the wood." The bedhead was from the couple's first bed, given to them by June's parents. Roy spent the next two weeks making a flower box for June. He planned to take it to her grave on Christmas Day - it was his gift to June.

He spoke to his daughter in law and she let the rest of the family know that he would not arrive until later in the day. This would save him from the task of explaining his needs to everyone and fending off the offers of people wanting to come to the graveside to provide support. He wanted a moment in the day where it was just him and June.

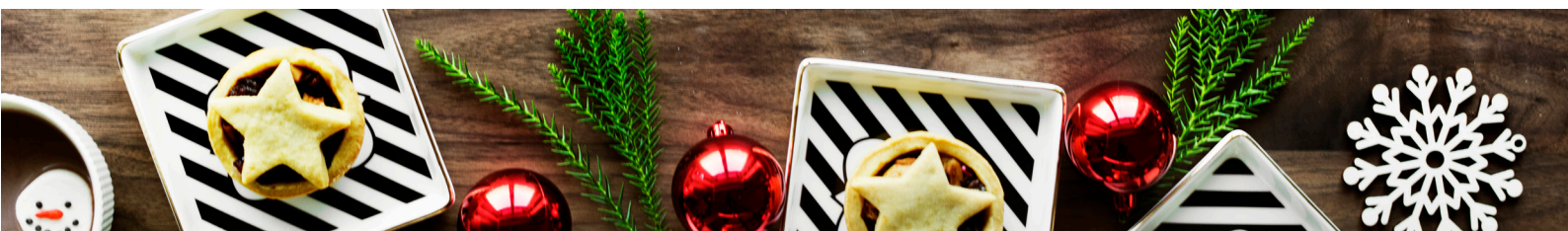
For Roy, Christmas Day played out the way he hoped and was punctuated by tears and laughter. He was comforted by the presence of a loving family who also missed and remembered June. They drank a toast to June and to the people she had helped through organ donation and wished them well.

Planning for eventful days can provide a sense of calm and some feeling of control. There is no pressure to carry out the plan but it's there as a safety net. Engaging in meaningful rituals gives us the opportunity to remember the person we love and the space to express our feelings of loss.

There is no 'one size fits all' way of coping with Christmas. For those in the midst of grief it is frequently something to get through rather than something to look forward to. Trying to manage the rollercoaster of feelings that come with grief is difficult when we are confronted with the overwhelming presence of parties, tinsel, other people's stress and joy.

Bereaved friends and family members need love, compassion and support at this time and they need to be able to make their own choices without the pressure of expectation from others.

*Michelle Skinner*





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and support families who have donated their loved ones' organs and tissue

## Educate

the wider community about the benefits of organ and tissue donation whilst emphasising the very important role of Donor Families in this process

## Advocate

and give donor families a voice in all aspects of organ and tissue donation

## Share

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**We want to assist all Donor Families with what they are going through**  
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