



DFA NEWSLETTER

March 2014 EDITION 4



HIGHLIGHTS

-  *Experience in ICU*
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-  *Donor Families Support Services*
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-  *Save the Dates*

MY STORY -

EXPERIENCE IN ICU

One hot February night 5 years ago I was going to Sir Charles Gairdner Hospital, Perth, after my husband Peter had suddenly collapsed at home. I had asked the ambulance paramedics to be honest with me and they were - I knew it was very bad. At 3am, approximately 5 hours after Peter collapsed and after many tests, x rays etc I was taken into ICU to see him.

That waiting in the hospital was one of the worst times, not knowing what was going on.

Over the next 3 days, many staff members, doctors, nurses, specialists and more came in to see Peter. The shock I and my family experienced was huge. The care, understanding, empathy was amazing, nothing was too much trouble for any staff member. Every move, procedure and test was explained, mind you I did ask a lot of questions!!! The nurses had contacted my family in UK and daughter in Spain who immediately flew out to Perth arriving at 2.30am, we drove straight to the hospital and the staff were brilliant, saying we could go in any time, ask questions, sit with Peter and if there was anything they could do, just ask.

A Warm Invitation



We would like to offer you the opportunity to connect to an independent support and advocacy group Donor Families Australia

The Aims of Donor Families Australia are:

- * To provide care and support to families who have donated their loved ones organs and tissues.
- * To advocate on behalf of these families and give them a voice in all aspects of organ and tissue donation.
- * To educate the wider community about the benefits of organ and tissue donation whilst emphasising the very important role of the donor families in this process.

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A Life That Touches Others Goes On Forever



Connecting Donor Families

I was the one who asked about Peter being a donor - in retrospect I now realise how quickly things moved along - we met a lovely young man, a co-ordinator from DonateLife who explained everything to us in detail, answered all our queries, even got a copy of Peter's old drivers licence from the days when you used to tick the boxes if you wanted to be a donor and what you wanted to donate. This made it easier for me, my son and daughter and other family members to come to the final decision, knowing that Peter wanted to help other people, he was that sort of person all his life. The coordinator, Daniel spent a long time with us, he had to ask me questions privately, at some of the questions, I burst out laughing, Daniel too had a great sense of humour which eased the seriousness of the situation. Peter was on a respirator for 3 days, he was declared brain dead on the Friday afternoon. He had suffered a massive aneurysm.

I was told about the tests that confirmed there was no hope and I was asked if I wanted to be present, which I declined. It was our decision as to when the respirator was turned off. On the Saturday early morning we all trooped to the hospital again and were given the family suite on the top floor of the hospital overlooking the river and park, a beautiful view.

This I believe was a very special time. The family suite had easy chairs, beds, fridge (coffee/tea making) phone and lots more, I mention all this as families need somewhere private and comfortable to absorb what they've been told and to cope just a little better. Throughout the entire Saturday, we all at some time (often many times) went down to ICU to sit, talk or just hold Pete's hand, again the nursing staff were wonderful, gave us privacy when needed, took great care of Pete, making him comfortable, talking to him, putting cream on his lips and eyelids, even having a laugh with me over something I had told them Pete and I had done in the past, we included Pete in the conversations which may seem odd but it was comforting somehow.

They all showed great respect to him.....and they cared.

Without going into too much detail now, we left the hospital for the last time that evening, I was the last to say my 'goodbyes' and did not want to return after organ donation although I was invited to come back, there are only so many 'goodbyes' once can take.

Daniel from DonateLife had sent me a lovely message at 3am telling me all had gone well. He assured me that Peter had been treated with respect and dignity and was now resting with the Funeral Directors.

I wanted to share a fraction of my experience with you all as some of you have not been as "lucky" as I consider I was looking back on everything. In the face of tragedy and shock, there was compassion, caring and understanding which made a huge difference to me and all my family. Nursing ICU Staff, doctors, DonateLife and everyone involved were amazing and I will never ever forget them.

If every hospital in Australia and ICU staff and doctors were like the wonderful people I encountered then I believe Organ and Tissue donation would follow as a natural progression to help others live - education and training to help these caring people cope with communication with bereaved families is vital - that is why I am a part of the DFA family and we as an organisation hope to get the recognition we all deserve, help others and hopefully along with DonateLife improve future organ and tissue donation.

Philippa Waldron

Everytime a life is touched by the gifts of organ and tissue donation, a new journey begins.



Connecting Donor Families

CHAIRMAN'S MESSAGE



It is incredible to think we are already three months into the new year. Even so it is worth looking back at 2013 at what was the year that gave us the largest number of Donors in our Australian history. On the face of it this is a good result and one that we hope continues. The reported rate was 16.9 donors per million population. It would be fair to say that Australia has been making steady progress towards improving our poor donor rate when we have so many people depending on our generosity.

Like all improvements, the rate should be steady and sustainable. We are very keen to see this increase continue into 2014. Part of Donor Families Australia objectives is to assist with this to happen.

The response from our December 2013 Newsletter was a very positive one. So much so we have welcomed on board Donate Life head office Canberra through Eva Mehakovic, Director of Clinical Programs. We appreciated the expertise from Donate Life's Sean Dicks in our December Newsletter and we encourage similar contributions from Donate Life about how Donor Families can and are being supported. We at DFA look forward to working with Donate Life's Canberra office.

I must congratulate Donate Life's Thankyou and best wishes to Donor Families on its web page over the festive season. This time of year is a difficult one for all Donor Families and it is always nice to know that we are being thought of.

It's great to have an article from Kevin Green, the Chairman of the Victorian branch of Transplant Australia. Kevin and his committee have a big task in front of them with the Transplant games scheduled for 26/9/14 to 4/10/14, we at DFA wish them every success. Kevin mentions a function in September for Donor Families. What a fantastic gesture and one I hope many Donor Families will be able to attend. Kevin has told me he wants to do this as a thankyou to Donor Families.

I want to include the web site of the Road Trauma Support WA featuring an Organ/Tissue Donor Memorial. This organisation is about supporting those who have suffered road trauma. There can be a cross over with this organisation and Donor Families as many Donor Families have suffered road trauma. I congratulate them for including this Donor Family place of reflection on their site. It is important for Families who have experienced trauma to have a place to go.

<http://www.rtswa.org.au/content/page/donor-awareness-fountain.html>

We have included two Donor Family stories of their personal experience at the time of having to make that life changing decision, please read them and get a better understanding of what it is like to be placed in that situation. It is these people and those like them that have so much to offer policy makers as they know exactly what it is like at that terrible but crucial moment.

As we head into 2014 I hope the donor rate continues to show improvement, we will be doing our best to help that along. We really want this year to see Donor Families get behind DFA and join up. The larger the membership the more notice will be given to our advice. Which is only good for Donor Families and all those involved in this area.





Connecting Donor Families

australian
**transplant
games**
MELBOURNE 2014



the
celebration
of **life**
continues...

My name is Kevin Green and I'm the state chairman of Transplant Victoria/Tasmania. Around 7 years ago I got given the Ultimate Gift of life from someone very special who looks down on my every move. Along with so many other recipients of an organ and tissue Transplant we Thank You So Much.

About 2 years ago I started the Donor family's group Australia page on Facebook. And let you me tell you it shook a few at the top level into the lack of Group support that donor family's really needed. As a recipient I took it upon myself to set up something that was much needed so other donor family's could seek support with each other in this special group.

This year we are holding the Australian Transplant games here in Melbourne from the 26th of September until the 4th of October around the Albert Park area. The games go for 8 days with 24 sports it's a Great time for all recipients, Donor family's and supporters to come together and enjoy the week. I would like to see as many Donor family's as possible at the opening parade on the morning of the 27th of September at the athletics track at Albert Park. Details to come.



On the night of the Tuesday the 30th of September I'm holding a Donor family Dinner in honour of all Donor Family's. It will be a great night to come together and share some Amazing stories. The night is still in early planning and we are trying to fund the dinner as much as we can. Details are to follow as to the venue. I have taken this upon myself to hold this Dinner because this is a much needed night. There will be NO transplant recipient's at this Donor family Dinner It's a night for Donor family's only. I know it will be hard for family's from interstate to be at the dinner but I would love for them to be there.

australian
**transplant
games**
MELBOURNE 2014

A big thank you to the Yarrambat Junior football club for allowing me to run BBQ'S over the month on March with all money raised going to hold the Donor family dinner.

Also my footy club is letting me hold a Charity football day on Saturday the 7th of June in aid of Donor family's and Cystic Fibrosis. It will be held at the Yarrambat Junior football club Ironbark Road Yarrambat.

I honour all Donor family's for their ultimate gift. And I will keep on supporting this special group.

Kevin Green
State Chairman
Vic/Tas
Kevin64green@gmail.com



Connecting Donor Families

Sharing Our Stories

BRAIN DEATH as experienced by a donor father

My wife and I entered the intensive care unit to find our young son appearing to be sleeping peacefully on the bed. The only concern being the ventilator assisting his breathing. He displays all the outwardly healthy signs, a beating heart, his skin pink and warm to touch, and his chest rising and falling. The doctors say his situation is not all that good, the next 12 to 18 hours will be critical.

Hours pass. We hold his hands, hoping and praying that he will suddenly open his eyes and say hi. Each hour the nurses come and care for him, bathing him, cleaning the ventilator tube, bathing and checking his eyes. His beautiful sparkling eyes. Why are they so sad, where is that twinkle, why are they so empty? The expression that the eyes are the windows to a persons sole enter my mind. Is he still there? Hour after hour no change. The heart monitor shows irregularity. Medication is provided. Two more hours and yet again more medication to try and control the swelling within my little boys head.

Many people consider that one is not dead until the heart has stopped beating, but for me, the body is but a vessel that supports and sustains the brain. It is my son's brain that has made him an individual expressing a spirit for enjoying life that has made him so special to us.

I am losing my only son. He is dying. A parent's intuition tells me he is brain dead. His spirit has left, he has gone and only his body remains.

Two independent doctor's openly involve my wife and I in observing the barrage of tests carried out over the next six hours. The first of three tests involved the placing of a skullcap that monitors electrical impulses from the brain referred to as an EEG (electroencephalogram). The results are transferred to a graph which displayed flat lines except for one that showed the smallest flicker.

The second test involves a brain scan after a dye was injected into Ben. The CT scan showed us that there is no positive blood flow within Ben's brain as shown in the comparison photos.



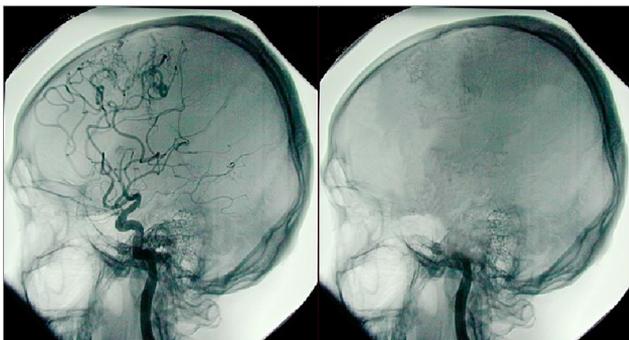
Ben 2 months before the fateful operation.

Finally they conduct a series of reflex tests (in our absence) involving; the placing a swab on the eye, placing a throat depressor to the back of the throat, placing an ice cube into the ear, using a pin to prick the forehead. All these actions would produce a distinctive reflex reaction within an individual with an active and responding brain. There is no reactions forthcoming from Ben. The evidence provided officially confirms he is brain dead, but we had felt this was the case long before. The kindness, compassion and care expressed by all the medical staff, has helped us through this terrible period.

In our greatest moment of grief, having just lost our only son, we realise we hold the ultimate power of saving several stranger's lives by offering our son's organs for donation. We have the ability to save other families the immense grief we are experiencing. Donating our son's organs would add a further dimension to his short life and greatly assisted us to move through the dark abyss that surrounds us.

Twenty years on and occasionally I am asked whether I think he lives on in the organs that are sustaining the lives of several recipients. The response is a definite NO. We have only donated organs from his body. However, I feel that Ben is still very much alive in another sense. He lives on in my mind and those of his recipients, in the photo's that adorn our house, in the every day conversation that occurs when talking of family, of when I am asked to speak about organ donation. I am a very proud dad when speaking about my little mate Ben.

Graham Harrison, Donor Dad



Brain death photo illustration showing blood flow at left and no blood flow at right. © Fusionspark Media Inc.



Connecting Donor Families



Pathways to Understanding

Reading Graham's deeply moving account of the death of his son Ben, and the decision he and his wife made to

donate his organs was a powerful reminder to me of how important it is for donor families to have clear understandings around the treatment and care of their loved one.

I thought it might be helpful to touch on this area from a 'clinical view. I encourage anyone with questions to chat to Donate life staff or their doctor if they wish to know more. In Australia families who are asked to donate their loved ones organs may have the donation process discussed following two different pathways. For instance, Graham and his family made the decision after death had been declared by doctors using tests to confirm the signs of brain death. The other time when donation may occur is when death has been declared after circulation has irreversibly ceased. This is referred to as donation after circulatory death (DCD).

The laws in Australia state that death can be declared when a doctor conducts tests that show conclusively that either the persons brain has ceased to function and will never function again, or the circulation of a person has ceased and this is irreversible. In most circumstances when people die the breathing or circulation stops first, then without oxygen to the brain the brain stops functioning, and once irreversible, death is declared.

The question of organ donation usually arises when a terrible brain injury has led to a patient requiring intensive care. The treatment involves having their breathing performed by a ventilator machine. Specialist doctors and nurses try to save life which includes keeping organs working and trying to protect the brain. Despite all these interventions they may be unsuccessful, and as Graham described there are signs that a patient has died while on the breathing machine, this is known as brain death.

As Graham described there are a range of strict requirements to legally confirm that a person has died on a breathing machine whilst their heart is still beating. The death is legally recognised because with no blood flow or oxygen to the brain, the brain function has been lost forever. The law demands two specialist doctors to independently check there is no brain function using a rigorous testing process and the time of death is documented as the time when the second specialist declares that the person has died, remembering that the deceased person has a beating heart only because of the breathing machine and skilled care.

Treatment has to be stopped after this because morality requires us to respect the body of the deceased. The decision to stop treatment and the time when the treatment is stopped is usually made in consultation with the family. If a decision has been made to donate organs the breathing machine is kept going until the donation surgery can be performed; and the breathing machine is removed in the ICU. operating theatre after the family have

HOLLY'S INSIGHT

farewelled their loved one in ICU.

The other process of donation is more uncommon and also usually involves someone with a critical brain injury, who is severely injured but not brain dead. In this circumstance the decision to stop 'life sustaining' treatment and remove the breathing machine is made by the specialists. This is decided when they believe they can do no more to help the dying patient. In these circumstances the patient's family makes a decision about organ donation before the death. But of course the donation cannot take place until after death is legally confirmed using circulation criteria.

The decision to stop treatment requires a discussion about the end of life wishes of the dying patient. This includes finding out if the patient and their family wish to donate and if it is medically possible. A decision about organ donation may be made and arrangements put in place before the treatment is stopped. It is impossible to predict the exact time when someone will die which means the doctors cannot be certain how long the dying patient may survive without the machines. In most cases death occurs quickly.

If a family has agreed to donation, there are two possible outcomes. The first is that it is possible that once the breathing machine is removed the death may not occur for some hours and donation will not take place. The second possible outcome is that death occurs quickly; following which the doctor performs all the tests that show the person has died (irreversible loss of circulation) and signs the death certificate. Then, with legal and family permission, the deceased person is farewelled by the family in the ICU and taken within minutes to the operating theatre for urgent donation surgery. A truly gracious gift.

Although families sometimes feel that they have made a decision to stop treatment, and the family view is very important; it is in fact the specialist caring for the patient who is responsible for the decision. Intensive care specialists and others involved in the care of critically ill people in Australia are very well educated and are required to follow strict legislation and guidelines when deciding to stop treatment, declaring death and also when allowing organ donation to take place.

To summarise, organs need circulation of oxygenated blood to survive (like the brain). The organs die very quickly without oxygen which is why there are tight time frames involved in donation. This fact explains why brain dead patients are taken to the operating theatre on the breathing machines. Even with all the specialist skills, once the circulation to the organs ceases, the transport to waiting patients must be rapid. For instance the heart must be transplanted into the recipient within only 4 to 5 hours. It is a skilled and complex process and requires specialist skilled teams of doctors and nurses to give expert care of the dying and deceased, and other teams to care for those desperately in need of transplant; and still other teams who complete the connection between them all

Organ donation is a rare and incredibly important gift. The gift can never be underestimated, the donors must be honoured and families thanked; for some families the donation requires a significant sacrifice. It is a medical and nursing duty of care and privilege to provide respect, dignity and peace to the dying, the deceased and their families. It is also a duty of care for health care professionals when they know they cannot save their patient, to think of the deep hopes of the dying and their families and of other lives that may be saved.



Connecting Donor Families



DonateLife Donor Family Support Service

by Diane Murphy
Queensland Donor Family Support Coordinator

In 2010 the National Donor Family Support Service commenced to provide dedicated support for families who have graciously made the decision for their loved one to become an organ and tissue donor. This support service is now provided nationally and is led by the Organ and Tissue Authority in partnership with the DonateLife Agencies in each state and territory. Similar services were provided before 2010 and have been strengthened with the national service now offering support to all donor families across the country.

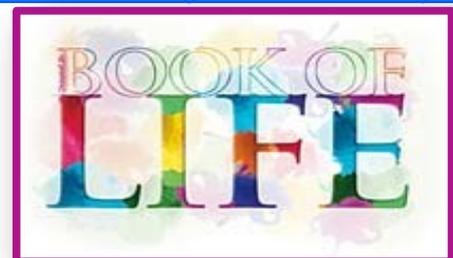
As part of the national service, there are Donor Family Support Coordinators and Donor Coordinators who work within the DonateLife Agencies in each state and territory who have a wealth of knowledge and experience in offering bereavement care or services and can assist families through the provision of ongoing contact and provision of support resources. Their role is to provide follow-up support initially by phone with the family following the death of their loved one and offering to either link them with support services or when possible providing services directly. The Donor Family Support Coordinator writes to each family to provide information following donation and provides an update on the recipients who received the generous gift of donation. An information pack is provided to families about two weeks after donation that includes booklets on grief, the process of organ and tissue donation, information about potential anonymous correspondence between the recipient and families, details about the Annual Services of Remembrance and a special lapel pin. Families are given the pin to wear with pride and in memory of their loved one, it signifies the generosity of the donor and their families in making the decision to donate. It is dedicated to all organ and tissue donors who have agreed to

the generous gift of donation.

I would like to focus a little more on the DonateLife Annual Services of Remembrance which are held across Australia usually in May and June. This year, there are 22 services being held in each state and territory in different shapes, sizes and formats but with common elements to the program deemed symbolic and inherent. The Annual Service of Remembrance provides an opportunity in a public forum for the acknowledgement of the personal journey and generous gift of all organ and tissue donors and their families. Services are attended by donor families, transplant recipients and health professionals. It is an occasion where donor families meet with other others who have experienced donation and includes not only other donor families but also transplant recipients. It is a symbolic ritual at the same time interweaving gratitude, mourning and remembrance of those who have given such a gracious gift to help others.

A donor family's experience is unique with many dimensions of emotion which may continue to arise for many years to come. Learning from these experiences provides valuable insight and ideas on how donor family support services might be strengthened for families in the future. The Organ and Tissue Authority is now building on previous studies of the experiences of donor families and has engaged a research group to seek feedback from 2010 and 2011 donor families in an effort to more closely identify family needs to inform professional clinical practice and training that focuses on how to provide the best possible support for families. This study will be finalised by the middle of 2014 with findings available soon after that time.

In conclusion, I would also like to touch on the fact that DonateLife also has a 'Book of Life' which is a collation of stories about the way organ and tissue donation has touched the lives of both donor families and recipients. It pays tribute to the generosity of donors whose lives ended suddenly. You are able to read and submit your own story, and access Donor Family Support Coordinators in your state or territory by going to the website: <http://www.donatelife.gov.au/donor-family-support>





Connecting Donor Families



2014 DonateLife Annual Services of Remembrance

Jurisdiction	Central	Regional
SA	Sunday 1 st June, 10.00am Anzac Hall, Prince Alfred College 23 Dequetteville Terrace, Kent Town	Nil
WA	Sunday 13 th April, 10:00 – 11.30am Lake Monger Reserve Dodd St, West Leederville	Bunbury – 14 th September
ACT	Saturday 17 th May, 11:00am Old Parliament House – Members Dining Room Canberra	Nil
NSW	Saturday 31 st May, 2:00pm Wesley Centre, 220 Pitt St, Sydney	Wollongong – 22 nd February Newcastle – October 2014 (TBC) Royal Prince Alfred Hospital – 28 th February
TAS	Saturday 31 st May, 2.00pm Quamby Estate 1145 Westwood Road, Hagley	Nil
VIC	Saturday 31 st May, 2.00pm RMIT Storey Hall Auditorium, Building 16 336 Swanston Street, Melbourne	Nil
QLD	Sunday 1 st June, 3:00pm Brisbane City Hall King George Square Brisbane City	8 regional
NT	Sunday 15 th June, 9:30 – 11:00am Borassus Lawn, George Brown Botanic Gardens Darwin	Service usually held in Alice Springs but not in 2014

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 new and exciting network.

If you would like to find out more about Donor Families Australia and how to become a member please visit our website:

www.donorfamiliesaustralia.com

Individually we do great things and affect those around us.

Collective we do great things and affect a nation!