



Donor Families
AUSTRALIA

Donor Families Australia NEWS

Autumn 2017, Edition 16

HIGHLIGHTS

Donor Families Australia looks back - and to the future

Biotherapeutic Association of Australasia

Communication and Consent - discussions from the Community Consultative Forum

Health Professional Workshops

DFA Out and About

Share your story

SHE, TOO, WOULD HAVE CHOSEN

In 2010, the Absolom Family lost its beloved wife, mother, and grandmother, Maureen Kaye. This is the story of this remarkable woman, and the experiences of their family, as told by daughters, Rebecca and Cassie.

Our very small family consisted of our Mum and Dad, their two daughters, our partners, and one granddaughter at the time of Mum's passing. We shared a strong and loving bond and always enjoyed spending time together doing family things.

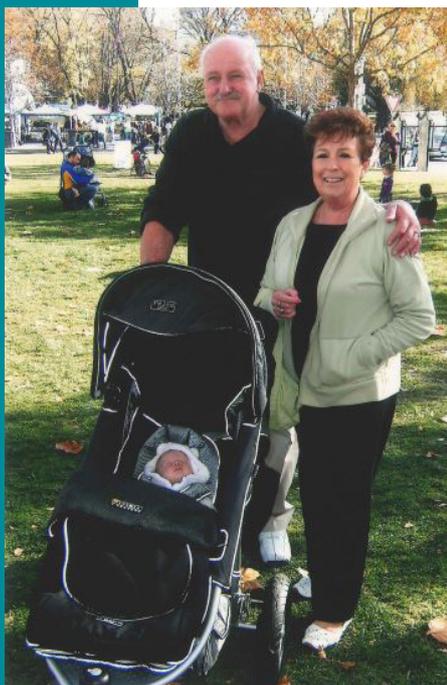
Mum and Dad worked hard to raise their girls in a loving and supportive home, allowing us to do the things we enjoyed.

"Mum's taxi" worked hard of a weekend, running us girls to and from sport, horses, friends' houses – all whilst supporting her own parents who lived with us and needed ongoing care. As Mum was an only child, she spent many of her years, along 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 suffered what was thought to be a minor stroke. Mum was taken to the Royal Hobart Hospital, where we were advised that she had suffered a catastrophic aneurism – not a stroke, which was irreversible. This came as a massive shock to our family – it was so sudden and so unexpected.

As the hours since Mum took ill grew longer, we were asked about the possibility of organ donation. We had no idea of Mum's wish, as like most families we never even talked about death - let alone organ and tissue donation. So, we as a family 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 decision to proceed with the donation believing if Mum



Maureen Kaye Absolom with husband and granddaughter.

~continued page 2



A life that touches others goes on forever

SHE, TOO, WOULD HAVE CHOSEN

~continued from cover

were able to make that decision, it is what she too would have chosen.

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 Cassie'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 the country.



Receiving two cards from recipients of Mum's organs has given us strength through this journey. It gives us great peace to know that Mum's organs have been accepted by these recipients, and it gives us further strength to know that Mum would be so proud of our decision.

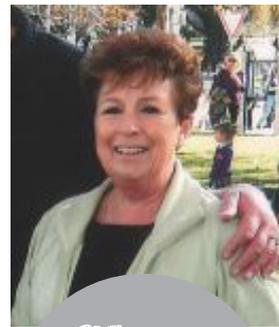
Over the years since Mum's passing we have become passionate advocates for promoting organ and tissue donation to as many people as we can. Being part of Donor Families Australia brings a great feeling of support and empowerment as we share our journey with others who have had the same

experiences as our family. It's one thing to lose a loved one, but to be part of a Donor Family takes things to a completely different level. There is comfort in being part of a group where everyone understands – and where you don't feel so alone in your journey.

Only three short months ago, we lost our dear Dad. Unfortunately, Dad was unable to be an organ donor due to his illness. Dad too was a strong advocate for organ donation and attended many events with us over the years. He was so proud of his beautiful wife, and our amazing Mum, and the gift that she left behind.

We were blessed to have amazing parents – and the fact that Mum was able to assist five others with a greater quality of life gives us so much comfort and pride. We know they are now reunited, and that they will hopefully watch over us for the remainder of our lives too.

Rebecca Free and Cassie Absolom



*Share
your
story*



 *A life that touches others goes on forever*

ROADMAP TO THE FUTURE



It is a privilege to work with a wonderful group of dedicated members that make up the DFA Board. It is timely to look back from where we started our humble beginnings to where we are aiming to ensure that Donor Families views are heard and are taken into consideration within the Organ and Tissue Donation System.

The launch of Donor Families Australia in 2013 provided a wonderful opportunity for Donor Families to improve community acceptance of organ and tissue donation and the care of families who make organ and tissue donation decisions. The generosity of donors and their loved ones transforms the lives of others, both at the time of the donation decision and long afterwards, because donor families are the best advocates for organ and tissue donation.



Many health care professionals have been fortunate to have witnessed the courage and kindness of families who have made donation decisions at times of great sorrow. The members of Donor Families Australia continue to provide energetic inspiration, advocacy, guidance, compassion and care to ensure Australians receive the information and support they require to make donation decisions they never regret.

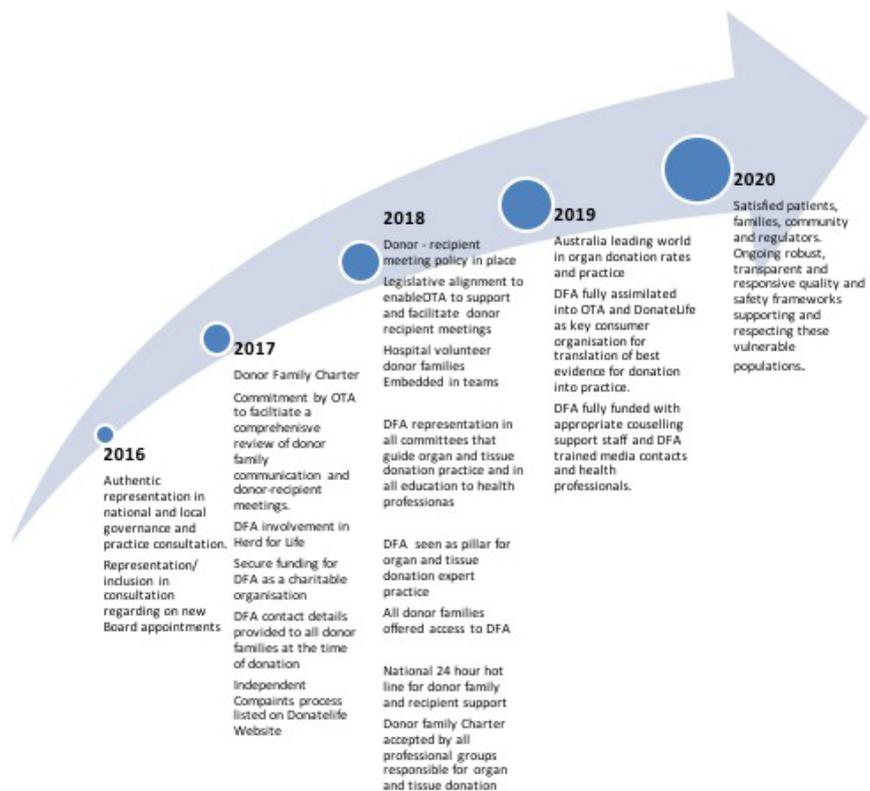
Many in our community are confused about the process of organ and tissue donation. DFA provides opportunities for discussion, education and collaboration about a range of matters that impact on Australian donation practices including the need to properly care for and acknowledge live donors, tissue donors and their families as well as organ donor families. The gift of donation is truly extraordinary and builds our humanity.

If Australia is to achieve equivalence with international

leading practice it is important to make organ and tissue donation normal. A conversation about donation should be a part of expert end of life care for every Australian. Understanding the donation process and knowing loved ones wishes are just so important to helping to save lives and providing meaning from what are often tragic circumstances of unexpected death. This is, because most people wish to help others and to honour the wish to donate. Despite this, many families never have the opportunity to have those wishes properly considered because either donation isn't mentioned, or the person conducting the conversation at the time of death lacks the knowledge and skill to properly support the family making those decisions. Donor Families Australia helps to identify and fill these gaps.

In 2016 the DFA Board met and formulated our Strategic Roadmap and Plan for our future direction.

Dr Holly Northam, Faculty of Health, University of Canberra



CHAIRMAN'S MESSAGE

Donor Families Australia (DFA) has had another busy quarter. As a result of our discussions with the Minister of Organ and Tissue Donation, the Hon. Mr Ken Wyatt and the CEO of the OTA, a Forum discussing whether consenting Donor Families and Recipients should be able to meet was held in Melbourne. This single topic is by far the most discussed on our facebook page and overwhelmingly both families and recipients are in favour of consenting adults having the opportunity to meet.

Our own survey, that included 544 respondents, probably the largest survey respondent number for an Organ/Tissue donation topic ever held in Australia, had only 6 people say “No” to the question: “Should consenting Organ/Tissue Donor Families and consenting Recipients have a right to be supported to meet?”

DFA had three of its committee members attend this Forum. We have included Lizzie Mazur’s report in this edition. Thanks to Leanne Campbell (Vice Chairperson), Lizzie Mazur and Kelli McDonald (committee members) for representing Donor Families. Our representatives came back from the Forum keen to see what the OTA will do as a follow up. They said it was clear that Recipients and Donor Families at the Forum were in favour of consenting adults meeting.

Since the last edition we have seen the discussion of how our Organ and Tissue donation system should work. The Hon. Mr Ken Wyatt raised the topic in a recent news article stating that *Opting Out* needed to be discussed. There are also those in the community that feel *First Person Consent* should be included. At DFA we realise this topic will always be an on-going discussion point. We need however to understand what the proponents of alternate donation systems mean by these terms before any informed debate can take place.

First and foremost the OTA has advised DFA that regardless of the system in place, it will always be the

‘soft’ option - i.e. the family will always have to give consent. So whether it be *Opting In*, *Opting Out* or *First Person Consent*, the family has to give consent before transplantation can take place.

After much consideration the committee of DFA has voted on this topic and unanimously agrees that:

1. The family must always be treated with the utmost respect and give the final consent;
2. The best way to improve on our current rate is to leave the system where it is now i.e. *Opt In*.

With *Opting Out*, the question has to be raised: will it cancel out the conversation? The public will assume they are Registered, so why discuss it? *First Person Consent* conversation with the family needs to be more focused on respecting their wishes.

I have included with this Editorial, a couple of recycle photos I picked up on my recent trip to New Zealand (at left). Interesting one country uses this symbol for advertising recycling rubbish and beer cartons and another uses it for Organ and Tissue Donation. I hope the new board of the OTA, that will be in place come July 2017, reflects on the current DonateLife Logo and considers a more thoughtful way of portraying Organ and Tissue Donation here in Australia.

We at DFA wish the Minister Mr Ken Wyatt all the best with his selection of the new board that will take Organ and Tissue Donation forward into the future. We hope it will be an approachable, informed and a representative board. Hopefully the two objectives and the nine key elements, as devised back in 2009 are revisited and a new more inclusive momentum is put in place.



In recent weeks, Ann Smith has taken over as Acting CEO of the Organ and Tissue Authority. On behalf of DFA and its members, we wish her all the best in her new position and look forward to a productive working relationship with the DFA committee to help promote an inclusive approach to the system.

This edition has included an article from the Biotherapeutics Association of Australasia. This association incorporates all the Tissue and Eye Banks in Australia. We hope to include more Tissue and Eye Donation discussion in our future editions of the DFA Newsletter. As a new member of their board, I am looking forward to learning more about this very important part of transplantation and sharing with the readers in future editions.

On a personal note we at DFA would like to wish Kelli McDonald, our Queensland committee member, all the best to her and her family, after cyclone Debbie's destructive forces went through her community.

Bruce McDowell



OUT AND ABOUT

DFA members are always doing their bit to help promote organ and tissue donation.

Here (pictured at right, top image), Lizzie Mazur has been presenting to the Lions Club of Adelaide.

The Donor Awareness Fountain in Geraldton was the scene for the 115 Year 11 students from Nagle Catholic College in Geraldton a few weeks ago (see picture at right, below). Bruce McDowell was able to address them on the importance of The Conversation about donation.

As a follow up to the May Forum on whether consenting Donor Families and Recipients should be supported in meeting (where DFA had three representatives), we will have four representatives attending the DonateLife May Forum on *Where To From Here?* Look for our report in our next edition.



TOWARDS COMMUNICATION AND CONSENT: COMMUNITY CONSULTATIVE FORUM

As mentioned in the Chairman's Message, following discussions with the Minister of Organ and Tissue Donation, the Hon. Mr Ken Wyatt and CEO of the Organ and Tissue Authority, a Community Consultative Forum was convened in Melbourne on 17 March to discuss the issue of contact between donor families and transplant recipients. DFA's Lizzie Mazur was in attendance and we provide a summary here (full report available from our website).

Among the 37 people in attendance, there was a good mix of donor family representatives (11), organ recipients and supportive others (12), those within the organ and tissue sector (10) along with some independent / Department of Health policy advisors and/professionals (4).

Transplant Australia and LiverKids joined with Donor Families Australia to present feedback on behalf of their members. Attending for Donor Families Australia were Lizzie Mazur, Leanne Campbell, and Kelli McDonald, who presented the findings from our recent survey – with 544 responses, this was a remarkable response.

The purpose of the day itself was to establish what individual perceptions lie behind support for, or against, donor families and recipients meeting. Participants were reminded that discussions were not about whether contact between donor families and recipients should occur, but should focus on the current system and what considerations would be needed if changes are to be made. For example: what supports might recipients and donor families need if they decide to pursue contact or are approached with a request to meet; and how can donor families and recipients minimise risk of unwanted identity disclosure.

Discussions during the forum were frank, honest and at times raw. It was evident that there is a wide range of opinions and that organ donation and transplantation is a complex issue with many ethical points raised in regard to protecting anonymity of individuals, yet providing enough information about donors/recipients that humanises the donation process.

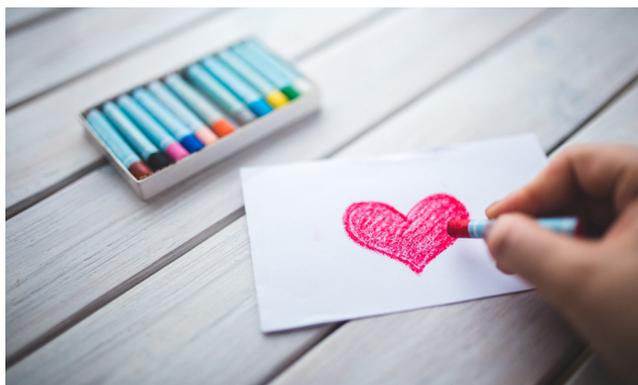
Many stories were shared and whilst it is only fair to note that not all experiences have been positive – there can be legal issues, complications from timing and emotional damage, for example – certainly in the case of feedback to Donor Families Australia, the overwhelming sentiment is one of gratitude, healing and humanisation.

Our own Kelli McDonald spoke of her personal experience with finding one of her mum's recipients via social media. Although there were some privacy issues, they were able to work through them together and come to a respectful agreement. It was a positive experience for them.

There was a very strong message to the Organ and Tissue Authority that there are failings within the current system regarding communication. There would be an expectation that following this forum, recommendations to review the communication process between recipients and donor families will occur. Some of the discussions covered considerations such as the need for counselling, establishing timeframes which were appropriate for both parties, buddy (peer support) systems, and protocols for what information is shared and how / appropriate protection of identity.

We believe that this forum will help with ongoing discussions and direction of organ and tissue donor and recipient interactions.

Donor Families Australia need to ensure that the voice of donor families continues to be heard and that any future discussions regarding this particular topic needs to include representatives from all the different stakeholders.



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>



SECOND CHANCE Liver Transplant Support & Social Group Pre & Post Transplant Recipients & Families

FUNDRAISING EVENT

8TH JULY 2017

Event ID -05366



FESTIVAL FUNCTION CENTRE

292 FINDON RD, FINDON SA

6pm -late

DINNER DANCE

3 COURSE MEAL

\$60.00 PER HEAD

ENTERTAINMENT

BY

NORTHERN HARVEST

GUEST SPEAKERS

FROM

DONATE LIFE



BOOKINGS ESSENTIAL
TICKETS AVAILABLE
PH: DI DAWSON
0402 105 833
ALL BOOKINGS MUST BE IN BY:
18TH JUNE, 2017

Proceeds to go to the Flinders Foundation

ON-SITE PARKING AVAILABLE

INTRODUCING BIOTHERAPEUTICS ASSOCIATION OF AUSTRALASIA

Kellie Hamilton, Councillor, Biotherapeutics Association of Australasia (BAA) and Senior Scientist, with the Donor Tissue Bank of Victoria has contributed to this edition with an article introducing BAA, how this peak body works and what it does in this important sector.

Thank you to Bruce McDowell for inviting the Biotherapeutics Association of Australasia to contribute to your newsletter. We are very fortunate to have Bruce recently join our Council as our Community Representative and we look forward to Bruce's continuing input into this sector which we are all passionate about improving.

The Biotherapeutics Association of Australasia (BAA) was born in 1998 originally as the Australasian Tissue Banking Forum (ATBF), then later retained the acronym but changed its name to Australasian Tissue & Biotherapeutics Forum. The Association hosted its inaugural scientific meeting in April 2000, an annual event providing an opportunity for people working in or interested in the areas of tissue banking and cellular therapy to meet, develop their scientific and technical knowledge, and

share knowledge to ultimately improve the outcomes for patients requiring clinical tissue or cell transplantation/therapies.

The Biotherapeutics Association of Australasia (BAA) is a peak body representing cellular therapy and tissue bankers in Australia and New Zealand. The BAA exists to facilitate the development of knowledge, promotion of knowledge sharing and professional interaction among its members, and to foster and promote best practice in the preparation of tissue grafts and cells for transplantation purposes.

'Tissue Banking' in the local context generally refers to musculoskeletal (bones, tendons, ligaments), skin, cardiac (heart valve, pericardium), amnion and corneal allografts which are retrieved, processed, and stored for up to five years awaiting transplantation. Storage conditions depend on the tissue type, but most tissue grafts are stored at -80°C or colder.

Across Australia and New Zealand there exist more than twenty organisations involved in the banking of one or more tissue types. Tissue grafts can be donated by deceased donors with the consent of their families, or by living donors – the most common living donations



being femoral head bone donation by patients undergoing primary hip replacement surgery.

Tissue donation not only saves lives (particularly the critical use of skin allografts for burns), but greatly enhances the lives of recipients, allowing them to live their lives with a quality that otherwise would have been restricted.

Bone grafts are used to replace bone loss in recipients, whether through degenerative processes or as a result of tumour removal. The allograft bone acts as a scaffold into which recipient cells can migrate, as well as providing mechanical stability.

Tendon and ligament grafts are used to replace irreparable tendons and ligaments in recipient joints, allowing a return to normal activities.

Heart valves are used to replace leaking or diseased recipient valves which may be the result of degenerative processes or congenital defects. Pericardium patches are used to surgically repair congenital defects predominantly in children. In many circumstances and indications, the use of allograft tissue is the best surgical option for the patient. Demand for allograft tissues frequently exceeds the local availability.

Cellular therapy is an emerging field of medicine where cells are administered to patients to combat a wide range of diseases. Stem cells can be haemopoietic stem cells which can be collected and stored for patients with haematological disease such as leukaemia or mesenchymal stromal cells a new cell therapy currently in clinical trial to treat a broad spectrum of immune mediated diseases and affect tissue repair.

Another exciting new therapy in development is a cell based therapy that recognises and destroys cancer cells. This therapy is a revolutionary approach to targeted immunotherapy to treat cancer and is known as chimeric antigen receptor (CAR)-T cell therapy. It is emerging worldwide as a potential new paradigm for the treatment of an array of cancers in the near future.

Tissue banks and translating cellular therapies laboratories in Australia are regulated by the Therapeutic Goods Administration (TGA).

At the time of writing, we have more than fifty individual members from more than twenty different organisations who are employed in the tissue banking or cellular therapies sector.

This coming November we will be hosting our 17th Scientific Meeting in Auckland, New Zealand. It will be the first time the event has been held outside of Australia. We are looking forward to gathering ‘across the ditch’ and enjoying the hospitality of our Kiwi members, and working with each other on ways to improve the donation outcomes for donors and donor families, and tissue/cell recipients alike.

We acknowledge and hold in the highest regard donors and their families, without whom these life-changing transplants would be possible. I am always heartened by the selfless, courageous spirit of families who make the decision to donate their loved ones tissues or organs at such a difficult time.

It encourages those of us working in this field to strive to make the best possible use of the donation, ensuring it helps as many recipients as possible and is as safe as possible.

Many BAA members have worked in this area for more than twenty years, a testament to the privilege we feel being a conduit between donors and recipients. We see the vast difference that donation makes to the lives of the many recipients – lives saved, mobility regained, vision restored, and pain reduced or eliminated. Many of our members also have the honour of forming bonds with the families of donors, and living donors in their roles as donor or transplant nurses. I have always felt it a privilege to be working in this field, and I know my colleagues feel the same.

We encourage you to have a look at our recently upgraded website for further information. Visit: www.bioaa.org.au

Thank you to all the Donor Families.

Kellie Hamilton

BAA Councillor

Senior Scientist, Donor Tissue Bank of Victoria

HEALTH PROFESSIONAL TRAINING TO SUPPORT FAMILIES IN DONATION CONVERSATIONS

The Family Donation Conversation (FDC) Workshops aim to ensure all families are cared for compassionately and communicated with in the best possible way as they come to understand the death of a loved one and as they consider making a decision about organ and tissue donation.

The FDC workshops are provided nationally by the Organ and Tissue Authority (OTA) through two sequential education modules that provide health care professionals with the necessary knowledge and skills to sensitively support grieving families and to empower them to make a proactive, informed and enduring decision about organ and tissue donation.

The first FDC workshop is a two-day core module which focuses initially on detailed information about grief and family reactions to catastrophic news. The workshop then focuses on providing and teaching skills for communicating with families when explaining death and donation. The second workshop is a one-day practical module which focuses on practical skills training to build on the core FDC workshop with opportunities provided to practice challenging scenarios in targeted role plays.

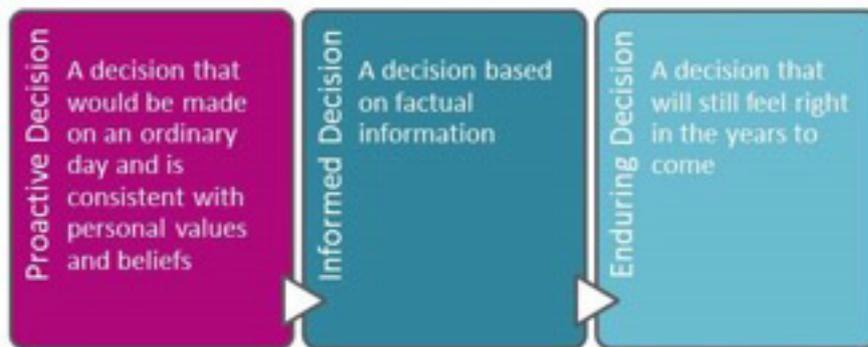
The FDC workshops were developed in 2012 in consultation with staff across the DonateLife Network, peak professional bodies, and the Gift of Life Institute (GoLI) in Philadelphia, United States. The workshops are based on international best practice and the available literature regarding grief, family care and donation including Australian and international research providing family perspectives on their

needs and their donation experience.

The attendees of the FDC workshops are primarily Intensive Care and Emergency Department doctors and senior nurses. Social and pastoral care workers may also attend these workshops if their work involves caring for families of patients who may have the potential to be organ and tissue donors.

The workshops aim to provide a meaningful learning experience so participants will feel

compelled to assimilate the core elements of the workshops into their routine practice. They are delivered nationally by a small and dedicated



group of specialist facilitators, including experienced donation specialists, intensive care specialists and grief counsellors, who have been specifically trained to deliver the workshops in a way that encourages the participants to be open to the learning opportunities as well as encouraging the sharing of ideas between participants and facilitators. This includes a mix of didactic presentations, group discussions and activities, and role play activities throughout the workshop to support teaching and learning. Participants discuss experiences and act out scenarios in role plays to demonstrate their understanding of the training and obtain feedback from the facilitators on their communication skills.

The FDC workshops have a set of guiding principles which underpin the teachings of the workshops. Importantly, the principles reinforce that family care and a family's loss should be the priority of the health care worker and the foundation of all that they do.

Participants are reassured that family care and donation are not competing values as families can be well cared for and at the same time, can be provided with information about donation. The principles reinforce that all families have a right to receive information about organ and tissue donation and this information should be provided to families in a sensitive and culturally appropriate way.

At the completion of the two-day workshop, all participants will have gained further knowledge about the range of reactions experienced by families who receive catastrophic news. Their communication skills will be enhanced and they will be better equipped to listen and to respond to the needs of the individuals and families. They will know how best to support families in end of life situations and subsequently the donation conversation. They will have greater understanding of the needs of grieving families and the importance of treating families as they wish to be treated.

They will be better skilled at exploring concerns raised by families and how to provide information about organ and tissue donation so families are better equipped and supported to make the decision about organ donation that is right for them and their family.

It is reinforced to the participants that their communication skills will significantly influence whether a family will be able to trust them and understand the information that is being provided.

Australian and international research is presented in the two-day workshop, informing participants about families' decision-making. The key elements of the research include: the need to meet the basic needs of families (including physical, spiritual and social needs), impact of sharing Australian Organ Donor Registration information, family motivations for agreeing to donation and reasons for declining donation.

The families that we have the privilege to work with continue to be our most important

teachers. Participants are encouraged to share experiences and discuss lessons provided to them from the families they've worked with. Discussing these experiences, together with the research, enables participants to understand and be guided by the variety of views and reactions that families may experience. The communication skills taught in the workshop supports participants to be attuned to a family's individual needs and to tailor their communication to best support that family.

The workshops are reviewed every two years to ensure the material continues to meet the training needs of the sector and responds to any practice developments including findings reported in the Australian Donor Family Study and feedback from families through other forums. Consistent with this timetable, the workshop is currently being updated for modification in 2017.



FDC workshops are recognised by OTA, the DonateLife network and the clinical community as our opportunity to ensure families will be provided the best possible care and will be empowered to make a fully informed donation decision.

***Bernie Dwyer, National Training Coordinator,
Organ and Tissue Authority***



Donor Families
AUSTRALIA

Donor Families Australia

is here to:

Care

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

your experience with similar people to support those making life changing decisions

Donor Families Australia is a place for Donor Families to go
We want to hear all our Donor Families' stories and experiences
We want to assist all Donor Families with what they are going through
We will always act as a voice for our membership

**Help us build a caring community
and shape the future**



www.donorfamiliesaustralia.com