



Donor Families
AUSTRALIA

2016 Strategic Planning

A report of the National Strategic Planning Meeting held at the Quest Apartments, Mascot, Sydney: 22nd- 23rd October 2016

This report describes the first face to face meeting held by Donor Families Australia since the organisation's inception. The report briefly reports on the organisation's achievements to date as a 'grass roots expansive' organisation. The report presents the key outcomes from this meeting; identifies the work priorities for the organisation, and presents a 5 year strategic plan to achieve its key objectives.



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Introduction

It is with great pride that I introduce the report covering our inaugural Strategic Planning weekend of October 2016 in Sydney.

The weekend brought together the committee of DFA for their first face to face meeting. After almost four years of Skype meetings it was nice to be able to put a face to the voice. It was like meeting an old friend for the first time.

This group of people, representing all states and territories, had generously given up their weekend and their free time normally spent with family and friends to tackle the important issues concerning Donor Families.

In amongst the following pages, so tirelessly put together by our resident expert, Holly Northam, you will read the fruits of those two days.

When I think of the beginnings of this group and how we started with a handful of Donor Families and Holly we can see how much has been achieved over a relatively short period of time. When we started there was no avenue for Donor Families to express themselves within the system. Donor Families were not listened to or represented in any numbers of consequence with the best example of this being the 2008 National Reform Programme that gave us the twin objectives and the nine key elements. This exercise was compiled by approximately 70 people around the table with only 1 individual having the experience of being a Donor Family. To this day these twin objectives and nine elements still are the basis of how Australian Organ and Tissue Donation policy decisions are directed.

Now Donor Families have successfully found strength in numbers and I am very pleased to say these numbers are growing at a fast rate. DFA provides the only place where Donor Families can get support from each other, communicate openly with Recipients and are provided with advocacy.

Please read this document of what DFA has achieved and more importantly what it intends to achieve in the future.

Bruce McDowell
Chairman



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Acknowledgement

Thank you to donors and donor families

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

Thank you to the founding donor families and especially Bruce, Karen, Leanne, Rick, Philippa, Graham and Elayne for the honour of allowing me to contribute to Donor Families Australia and to all the subsequent members. I wish the warmth of friendship, the strength of wisdom, and the rewards of generosity to all those who are touched by this organisation. The benefits gained by our society from your decisions are incalculable, but include leadership, selflessness and charity in caring for those in need.

Holly Reflection-From 2013 (First DFA newsletter) to 2016



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Board of Directors

Bruce McDowell, Western Australia



Bruce and his wife Karen became a Donor Family in 2008, when their nineteen year old daughter Alysha died in a car accident and they said “yes” to Alysha being a Donor.

Bruce has previously been a WA DonateLife Advisory Committee member and formed part of an initiative to build the Donor Awareness Fountain in Geraldton, WA.

In addition to his own accounting practice, Bruce is inaugural Chair of the Donor Families Australia Board of Directors.

Graham Harrison, New South Wales



The death of Graham and Elayne’s ten year old son Ben following surgical complications in 1993, resulted in their decision to donate his organs and as an outcome, Graham became heavily involved in the promotion and improvement of the organ donation and transplantation systems.

Over the years he has been involved with ACCORD, Australians Donate, Transplant Australia and more recently, ShareLife Australia.

However, it is through Donor Families Australia that he sees donor families’ voices grow collectively, to the point where they will be involved in all aspects of improving Australia’s organ donation and transplant systems. He is particularly interested in donor family support at the time of donation and the years that follow.



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Holly Northam, Australian Capital Territory



Dr Holly Northam is a Senior Lecturer at the University of Canberra. She is a Registered Nurse, Midwife, and Churchill Fellow. Holly's work centres on giving voice to the vulnerable and identifying health care strategies to enable people to flourish. Holly's PhD study explored the decision-making experience of bereaved families who had to make organ donation decisions on behalf of a loved one, and identified factors that influenced the families to agree or decline donation.

With over 30 years of clinical experience, amongst her previous clinical roles Holly was an organ donor co-ordinator and manager of the ACT Organ and Tissue Donation Service. Holly is also a Director on the Board of ShareLife Australia. Holly has fought hard to ensure Donor families have a voice and are heard. Holly has a passion for equity and social justice in health care.

Leanne Campbell, Victoria



In 2009, Leanne and Rick's twenty-one year old son Brett was tragically killed in a freak accident whilst holidaying with friends. Brett had made his wishes known in regards to organ donation and so his parents consented; his gift saved three people's lives.

Leanne is passionate about supporting donor families. She is a volunteer with DonateLife, the Donor Family Representative for Transplant Australia (Victoria) and a support group leader with The Compassionate Friends Victoria.



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Philippa Waldron, Western Australia



In February 2009, Philippa's life was forever changed; her beautiful, kind, wonderful husband Peter died suddenly and without warning.

Married for 37 happy years, they were looking forward to retirement and travelling, especially to Spain to see their Spanish grandchildren. It was not to be... life can change in an instant.

Philippa retired from the newspaper industry after twenty-five years and was invited to join Donor Families Australia where she finds involvement very rewarding. She notes how she feels part of a very caring, loving Australia-wide family, who are there to help and listen to everyone.

Kevin Green, Victoria-



In 2007, after eight years on dialysis, Kevin became recipient of a donor kidney.

Kevin is a painter by trade, and now able to do a full day of work without feeling his previous exhaustion. To demonstrate his new found fitness Kevin has so far competed in three Australian Transplant Games; one being in Melbourne which he chaired as Transplant Australia Representative. There have also been three Games in Great Britain and one World Transplant Games in Sweden. He is also Victorian Captain of the Transplant Cricket Team.

In 2012, Kevin established the *Donor and Recipient* Facebook page which he continues to administer. The page now has around 1100 members and hosts continued conversation between Recipients and Donor Families.



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Kelli McDonald, Queensland



In 2013, Kelli's Mum, Maree suffered a brain aneurysm. Upon realising their Mum's brain death was imminent, Kelli and her two brothers approached medical staff advising of their Mum's wish to become an organ and tissue donor. Maree gifted three people a second chance at life; donating her lungs, liver and a kidney.

Kelli says that she and her family received exceptional care from the Townsville General Hospital's ICU Doctor, Nurse and DonateLife Co-ordinator, however, she feels that current support systems could be improved for donor families post -donation.

Since her Mum's gift, Kelli has become passionate about DonateLife's *Have the chat that saves lives!* campaign and through her position on the Donor Families Australia Committee, hopes to improve post donation support for other Queensland donor families.

Helen Day, Northern Territory



Helen Day lives in Darwin and is the mother of three sons and a daughter, aged between 22 and 30. She also has two grandchildren.

On 29 April 2012, Helen's second eldest boy, Stewart was killed in a freak motorbike accident. He was four days short of his 24th birthday. Stewart devoted his life to helping people in need, volunteering in Uganda for six weeks at age nineteen, and another six months when he was twenty-one. On both occasions, he worked long hours to save for these trips.

In his life, he always put others first and it was a blessing that he could save and improve six lives through his organ donation.



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Helen has devoted her life to continuing her son's legacy by helping people in need. She volunteered in Uganda at the end of 2012 and has been a spokesperson for DonateLife NT, sharing Stewart's story to inspire families to talk about organ donation, educate families and encourage more people to enrol as organ donors. Helen has experience with donor *and* recipient families, having a great understanding of the emotion and turmoil they experience.

Helen would like to see more support given to donor families and is keen to support families living in the Northern Territory. An accountant by trade, after her son's death, she changed her career to be able to help people in need. Helen is currently undertaking a Diploma in Counselling and Certificate IV in Child, Youth and Family Intervention which she expects to complete by June 2016.

Lizzie Mazur, South Australia



In June 2011, Lizzie's sister Jennet died after a 5 month battle with acute liver failure. Prior to her death, the medical staff discussed the possibility of her becoming a donor. Having waited for a lifesaving liver transplant that never came, the chance of helping others seemed the obvious choice. Jennet's gift changed the life of three others and their families.

Following her sister's death, Lizzie became active in volunteering for DonateLife in South Australia where she has formed a very strong relationship with the staff members there. Becoming a member of Donor Families Australia in 2016, Lizzie has become passionate about advocating for donor families and has the desire to offer greater support after donation. Her personal experience with travelling interstate and with a young family, Lizzie would like to see greater support for the children of donor/recipient families.

Sorana Walker Healy, Queensland

Sorana lives in Far North Queensland and is married with two grown up daughters and three amazing grandchildren. Sorana works as a Practice Manager with IPN Medical Centres.

In 2013 Sorana's sister, Deidre suffered a fatal cardiac event. Sorana and her family honoured Deidre's wish to be an Organ and Tissue Donor and Deidre went on to enhance the lives of 4 recipients and restore sight to 2 recipients. Deidre's recipients have kept in communication with the family since their transplant and the family have found this a very important part of the healing process.

Sorana has become involved as a volunteer with Donate Life and became a member of Donor Families Australia. Sorana together with her family honour Deidre's memory by opening and honestly discussing their journey through



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organ and tissue donation by speaking at events and community engagements. Sorana looks forward to meeting many Donor Families and Recipients to share stories or to simply listen.

Rebecca Free, Tasmania

Jann Easterly (NSW Hunter Valley Region- New Board Member: November 2016)



Jann described her reasons for joining the committee of DFA this year: “I joined Donate life this year. I lost my brother in March 2016 unexpectedly due to complication from a boat accident. My brother donated his organs and has helped save the lives of three people.

I am passionate in promoting organ donation and supporting other Donor families, as well supporting recipients”.

Donor Families Australia Logo

Designed by Kiri Northam for Donor Families Australia, December 2012.

Logo design Copyright © Donor Families Australia 2013



About The Design

The heart shape was chosen as being the most recognisable and emotive organ. Following the concept of two lives connecting, I experimented with the placement and connection of two hearts. I settled on the rippling hearts to signify the impact organ donation can have on families and the community; the butterfly effect that one good deed can achieve. The angle of lean helps to emphasise vulnerability and creates a more accessible visual.

The gold and green colour scheme was chosen to underline the organisation as a national body. The gold hearts are used as a metaphor for generosity and to be completely abstracted from the actual organ, to avoid any negative connotations. The green was chosen as a calming complementary colour to be used to help identify the brand.



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Executive Responsibilities: 2016- 2017

Position	Name
Chair	Bruce McDowell
Deputy Chair	Leanne Campbell
Secretary	Graham Harrison
Treasurer	Helen Day
Donor Family Personal Contact Coordinator	Philippa Waldron
Communications Coordinator	Lizzie Mazur
• Technical Support	Sam Hawkins
Outreach Coordinator	Kevin Green
Policy Coordinator	Kelli McDonald
Newsletter Editor	Bruce McDowell
Evidence & Advocacy Coordinator	Holly Northam
Funding: Identifying sponsors & support	All



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DFA Achievements (2013- 2016)

DFA is a national independent grass roots organisation comprising families who have donated their loved ones' organs and tissues- Increasingly live donors and recipients are also reaching out to this new organisation for support and voice. Established in 2013, there was a need for an organisation in Australia specifically dedicated to organ and tissue donors and their families. DFA was established to address this need and specifically seeks to give voice to this vulnerable group of people who have often been hidden by regulatory practices.

Reflection of the achievements of the past 3 years since DFA launched as an organisation. Tremendous progress has been made. DFA is a recognised identity- its logo is recognised and its work is evident. DFA have expanded from the initial four people who knew that there was a need for an organisation to give voice to Donor Families; to the current situation where DFA is an organisation who offer a voice and support to over 150 donor family members, and over 1100 Donor –Recipient members on the Facebook donor- recipient site.

DFA were initially dismissed and suppressed as an entity by donation organisations; but with a positive approach, professionalism and persistence the organisation has progressed to its current level of leadership and support to represent a credible and trustworthy national voice for Donor Families. DFA offer inclusive membership by supporting disenfranchised families as well as those satisfied with their donation experience.

There have been more than 7000 organ donors and an unknown number of tissue donors since 1989, but the people who agreed to donation and their courage and generosity are often invisible. Evidence that bereaved family decision-makers and the community perceive donor families as invisible and unrecognised is a barrier to donation. DFA seeks to address this and other barriers to donation arguing that grieving families should not be blamed if they choose not to donate, especially if information and communication are insensitive to the patient and their family's needs. Over the coming two years we will roll out a number of strategies to ensure that donation becomes a respected and normal part of end-of-life-care in Australia; and donors and their families are visible, heard and honoured. It must be remembered that providing an organ or tissue donation is a decision that impacts on the lives for those involved forever.

Some achievements to date:

1. A logo and a national organisation.
2. Donor memorials and sites of reflection to raise awareness of donation around Australia.
3. A credible voice for, and representative of, donor families.
4. Ministerial and high level recognition in government and by NGO's.
5. Major contributor to the Ernst and Young (EY) Review (Appendix 5).
6. Influential in holding the OTA to account for service delivery to donor families.
7. Influential in changing health professional and community attitudes towards organ donation.
8. Providing donor families a place to support each other, and donor families and recipients a place to converse and get to understand more of each other's journey.

Examples:

- Geraldton Donor Awareness Fountain
- Sydney Town Hall Media panel 'Don't blame families, fix the system' collaboration with ShareLife.

Representations to the EY review included issues

- Including the possibility of donation; 'urban myths' around the idea that organ donation or less likely in Australia because of our road rules (Research has debunked this view).



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- Discussion about the Register and ‘first person’ consent, with one delegate indicating this was preferred by Australians over the Spanish opt-out system which was understood to mean organs were taken regardless of the family view– another ‘urban myth’.
- The need for transparent information about the process of organ and tissue donation for the community and health professionals, and appropriate education of staff.
- Care for organ and tissue donor families- Family’s experience of ‘cold calling’ to request donation.
- Examples of why some families say no.
- The need for mutual trust so that the community know what to expect when agreeing to donation and don’t find out everything at the worst possible time.
- A donor/ donor family-centred approach towards all activities .
- Engaging donor families at every organisational level.
- More appropriate and continuing contact with the donation organisation.
- Care and sensitivity in terminology: for example, not using ‘harvest’; and provision of proper counselling; not as expressed by some families who stated they were counselled by staff who were “falling asleep” or who “Hung up on them”.
- Letters (wrong name used).
- The problem of insensitive use of images-the DonateLife logo.
- Governance issues/ paternalism in approach by authority.
- Issues of families who have experienced poor medical practice.
- The different types of donation (DCD, DBD, tissue) and confused understandings of terms.
- Lack of proper follow up.
- Families paying for donor memorials.
- Authority failed to engage in public recognition of donor and family.
- Donor recipient correspondence.
- **No complaints process.**
- DFA advocated for a 24 hour hot-line for information and support; for DonateLife to be overtly transparent in their practices and engagement with donation because it is such a controversial area (especially in light of the cultures/ religions/organ trade and China). DFA suggested building trusting and informed relationships with spiritual advisors caring for the dying and their families.
- DFA asked why money couldn’t be directed to public recognition of donors rather than awareness campaigns that were simplistic and set the community up for distress, when the needs of families and potential donors are not met.
- DFA pushed the need for family engagement at every point including potential to be involved to support families.

Recent progress:

- Changing culture: previously donors not seen as ‘hero’s’ by OTA; and Donor Families were effectively dismissed as irrelevant, “I have never been so disrespected’ (Member of DFA Executive recounting experience of speaking to Advisory Council, 2016).
- Recently there is evidence of a new more inclusive approach being used by OTA leaders and workers.
- National ‘DonateLife Thank You Day’ followed the EY review.
- DFA representatives contribution to education sessions for health professionals, remembrance day events and other organ donation awareness activities that help normalise organ and tissue donation.



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Reflecting on the original 2013 DFA Action plan:

- Key objectives have been met: Donor families now have a voice, a method of communication and DFA are experiencing a significant growth in membership and engagement.
- The executive interpret the growth in the organisation -and its positive communication of the gift of donation as having the potential to benefit the community more broadly- by having the DFA message of donor family's and recipients voices of healing and hope going *viral* in the social media domain. These positive messages are likely to improve organ donation outcomes whilst also enabling support and recognition for bereaved families.

Examples of Achievement:

- Personal support for families: individual acknowledgement, letters on anniversaries and support. Information at times of Christmas and other times when families face a greater emotional burden of grief and seek out someone who understands similar experiences.
- National Newsletter: a voice for donors and their families.
- Awareness raising events and Donor Family support events.
- Transformative education of health professionals by representative of Donor Families Australia.
- Lobbying of health leaders to understand and recognise the gift and possible sacrifice of Donor Families.

Recognising the Gift of Donation

Bruce McDowell (Chair DFA) and Hon. Fiona Nash (Parliamentary Secretary) at the Geraldton, WA Donor Memorial Fountain: June 14, 2015, (below).





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DFA National Strategic Planning Meeting (Oct 2016). Members of the DFA committee with OTA CEO (acting) Felicity McNeill, (below).



Aunty Agnes Shea OAM, Ngunnawal Elder and Chair of the Ngunnawal Council of Elders (below) was invited by DFA to Welcome The Honourable Minister Ken Wyatt and Mrs Wyatt, Ms Felicity McNeill – Dr Frank Van Haren, Donors, Donor families, recipients and all attendees to Country in Canberra (2016) for ‘Thank you day’. Her words convey the meaning that DFA seeks to voice.

“Welcome and thank you for supporting this important day. It is wonderful to acknowledge our most vulnerable people- of all cultures and faiths who are asked to make life saving decisions to give of themselves or their loved ones to others. This is a most sacred time- and must be respected. By thinking deeply about how we can all respond to the needs of others -we have the opportunity to bring our community together and help humanity flourish. Thank you to all donors, donor families and those who wished to donate but could not- your gifts heal not only suffering patients- but our society”.





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Meeting Key Outcomes

Executive Summary: Key Conclusions from Meeting

Vision:

1. Maintain independence.
2. Continue to provide support, voice and advocacy for donor families.
3. Gain full support and ensure represented throughout all OTA activities, policies and outcomes.
4. Attain financial independence.

For DFA

Urgent:

1. Make representations to the Commonwealth Department of Health & Minister re the new Board makeup
2. Become a registered Charity Organisation
3. Update Website

For DFA Advocacy and voice:

Priorities:

ACTION: Challenge policy makers to address the donor- recipient desire to meet in an ethically and legally approved and psychosocially supported manner.

ACTION: Challenge key stakeholders to address perceived deficiencies in National DF/Recipient letter exchange

1. DFA Vision

Care, Support, Advocate & Educate

DFA seeks to continue the gift of donors to save the lives of suffering people in our community and to care for those who have donated. The organisation does this through its aims which are to provide **care and support** to families who have donated their loved one's organs and /or tissues; to **advocate and give donor families a voice**; to **educate the community about the benefits of donation**, whilst **respecting, acknowledging and supporting** those touched by donation decisions.

Group consensus:

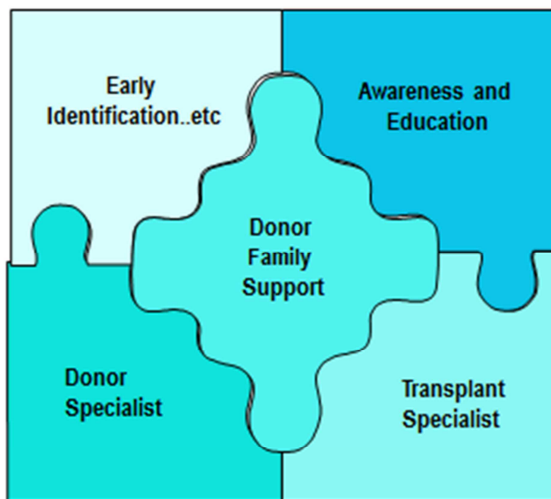
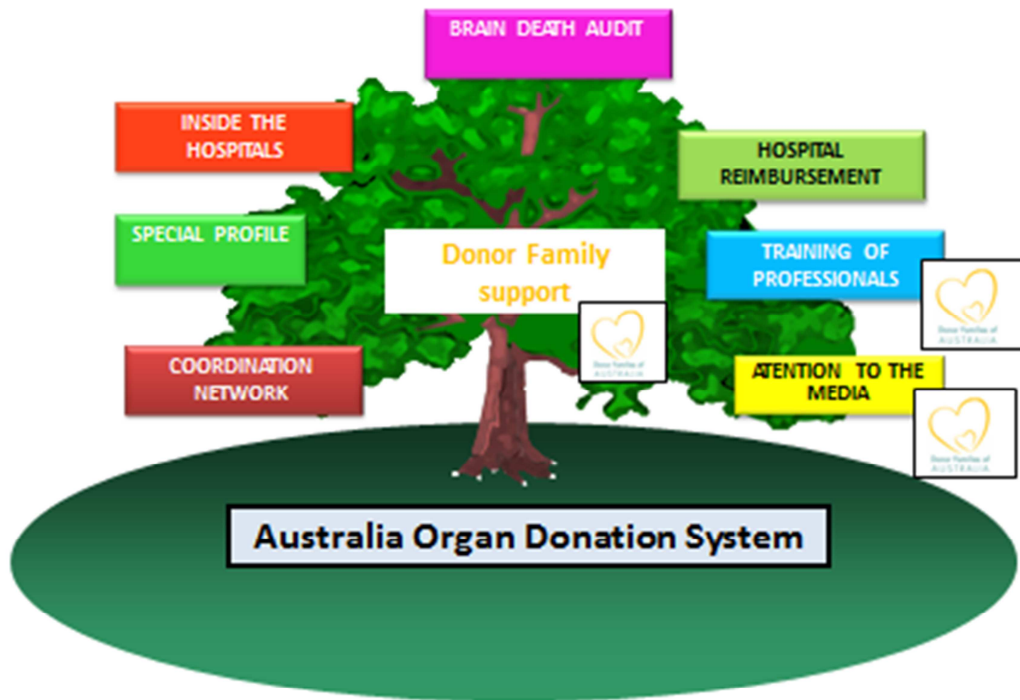
Previously suppressed: progress: DFA are now perceived to have a voice

The vision is unchanged from the initial 2013 vision; however, it is important to make it explicit that live donors as also key stakeholders.



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Figure 1 and 2: A shared vision by collaborator ShareLife of DFA providing the strength and support to allow a flourishing donation and transplantation organisation



Australia Organ Donation System



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2. Communication and Engagement:

Discussion:

- **Communication:**

- 1. Families: member communication:**

- Method:**

- 1. Personal contact, (anniversaries, important dates and personal support)
 - 2. Newsletter: interactive: invite: 'letters to editor'; provide real stories about real people- including sensitive areas such as death of recipients.
 - 3. Facebook
 - 4. Website
 - 5. Independent voice re complaints
 - 6. Volunteering education and support
 - 7. Advocacy and voice re recommendations/ issues
 - 8. Lobbying and advisory: DFA Official position statements: for example: DFA position on Opt-in/ opt-out.
 - 9. Education: patients, families, healthcare professionals, community, governance and regulatory stakeholders. For example: documentary, school and university education, health professionals

- Advocacy for community respect and reciprocity for donor families:**

- Advocacy for organisational acknowledgement and accountability:**

- 1. for donation decisions and related experience of consumers
 - 2. for the sensitive use of appropriate language
 - 3. for formal evidence of the donation outcome: example death certificates
 - 4. for public recognition of benefit of the donation: correspondence re outcomes, 'Thank you day', memorials, media voice
 - 5. for transparent, credible and accountable feedback complaints process

- Group consensus:**

- DFA Goal: Authentic and credible representation of donors and their families.**

ACTION 1: DFA maintain and strengthen this goal to reach and support those affected by donation decisions.

Group consensus: that with voice there has been a shift in power dynamics whereby the leadership group feel empowered by having an independent voice.

- DFA Facebook site and website powerful communication tools:**

ACTION 2: Keep sites and update- ensure consistency and messaging aligned with core values;

ACTION 3. Continue to support Kevin Greens' donor-recipient Facebook site.



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Group consensus:

a. DFA Stakeholders

1. DFA members:

DFA seeks to provide an individual and compassionate approach to DFA Members who include live donors and family members of deceased organ and tissue donors

- 2. Associate members:** Organ and tissue recipients, their families, health care professionals and others interested in supporting donors and their families.

b. DFA Collaborators and potential collaborators

1. Government

Politicians; The Organ and Tissue Authority; State and Territory DonateLife Network; Tissue Banks, The Commonwealth Department of Health and Aged Care, State and Territory Health regulators and organisations.

2. NGO's:

ShareLife Australia/ Outcomes Australia; Transplant Australia

Potential collaborators: Kidney Health Australia; Heart Foundation; Consumer Health Forum and others.

3. Health Organisations:

PlusLife WA;

Potential collaborators: Transplantation Society of Australia and New Zealand (TSANZ); Australian College of Critical Care Nurses (ACCCN), Australasian Transplant Coordinators (ATCA); Transplant Nurses Association (TNA); Australian and New Zealand Intensive Care Society ANZICS), and others.

c. Language and imagery used in communication that impacts Donor Families:

- 1. Problem: Insensitive use of language and imagery:** in official and unofficial communications regarding organ and tissue donation and transplantation. When language and imagery is used without empathy and compassion for those involved harm may occur. For example, the DonateLife Logo remains offensive to some families because it is visually reflective of a recycle symbol and causes distress to some. Insensitive terminology that is frequently used to describe organ donation surgery such as 'harvest' may lead to donation refusals and preventable patient deaths.
- 2. Reflections on language used by health care professionals and leaders from the OTA when discussing and describing donation, family relationships with the governing organisation and family decisions are represented below.** Discussion revolved around the idea that some donor families (Service Users) have been labelled as 'angry'- and the negative consequences of that label on the formation of trusting relationships between consumers and service providers.



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Table 1.
Examples of words that reflected positive or harmful communication experienced within the group.

Positive	Harmful
hero	quota
hope	recycle
relationship	harvest
Trust, collaboration	ridicule
healing	silenced
support	disrespected
voice	selfish
listening	frustration
leadership	distress
transparency	'angry'

ACTION 4: Given the reassurance provided by the acting CEO that the EY recommendation that the DonateLife Logo should be reviewed was being actioned: DFA will maintain a watching brief. This issue will be included in ongoing discussions with key leaders.

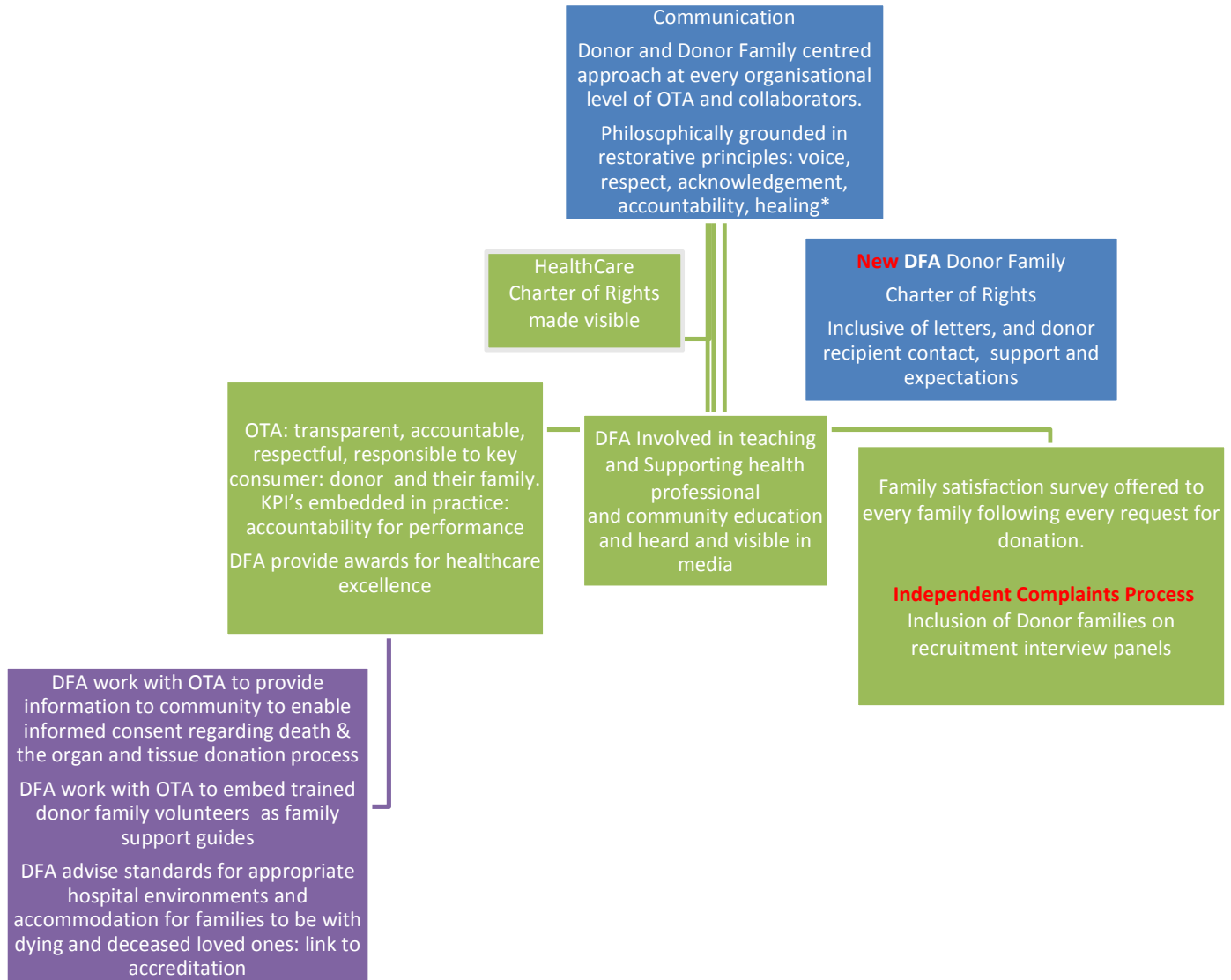
ACTION 5: DFA to bring issues relating to the insensitive use of language to the attention of OTA and other collaborators, and offer advice on appropriate use of terminology to enable respectful and compassionate communication that meets community expectations.

ACTION 6: DFA to include information about what families should expect regarding the appropriate use of language and communication in a proposed new **DFA Donor Family Charter of Rights.**

ACTION 7: DFA to offer the OTA, media and other organisations support and advice regarding the representation of organ and tissue donation and donors and their families in the media.



Figure 3: Summary of DFA Communication goals



*"Restorative Practice is a philosophy, in action, that places respectful relationships at the heart of every interaction. This relational approach is grounded in beliefs about the equality, dignity and potential of all people and about the just structures and systems that enable people to thrive and succeed together" (2014, Towards a Restorative City: Honoa ki a Rongo ki Whanganui, WORKPLACES, p.3).



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d. Policy and Practice

Donor and Donor family acknowledgement:

Priority Review

- 1. Problem:** Donor families report that official communication regarding the outcomes of organ donation to the donor family is not standardised or reliable. Some Donor families are reporting that it is not timely, sensitive or accurate. Donor families report that there appears to be no accountability for the quality, accuracy and timeliness of the correspondence to donor families from DonateLife across Australia.
- 2. Problem:** The quality of written communication between the DonatLife and Tissue Banks and donor families does not meet many consumer expectations.

ACTION 8: DFA approach the OTA to offer to work in consultation with OTA to ensure the expectations and needs of donor families are properly addressed in written communications.

ACTION 9: DFA approach the OTA and offer to collaborate in supporting OTA to structure and implement a transparent national communication process about the outcomes of donation for all families and health care professionals involved in organ and tissue donations.

- 3. Problem:** Concerns regarding de-identified Donor to Recipient, and Recipient to Donor communication are frequently expressed.

ACTION 10: DFA seek that the OTA conduct an urgent review of Donor Family and Recipient communication in collaboration with DFA.

4. Donor family and recipient meetings and relationships:

Problem: This is a key policy and practice area that needs to be addressed at the individual, transplant unit and hospital level and in national organisations and law.

ACTION 11: DFA seek the OTA to collaborate with DFA to conduct an urgent review of barriers and enablers of meetings between organ and tissue donor families and recipients to develop a transparent and accountable national legislative, policy and practice strategy to support and address the relational needs of these consumers and the community.

e. Evidence

DFA have collated a range of evidence to inform policy makers and practice. DFA see that as an ongoing priority to enhance organ and tissue donation decision outcomes.

Examples include:

- DFA member committee representation to provide a credible and trustworthy representation regarding the experience of organ and tissue donation
- Support for a research projects including the survey regarding donor family views of the logo
- Identification of donor recipient relationship research projects that need to be undertaken to improve donation outcomes



National Strategic Planning Meeting: 22nd - 23rd October, 2016.

3. Funding

DFA has entirely been reliant on volunteer efforts and donations and contributions by members until recently, when DFA was successful in a grant application to support DFA 'Thank you day activities'. Meetings are arranged using Skype at no cost to the organisation. The committee agreed that care must be exercised to maintain DFA's integrity and independence in all funding considerations. The group agreed to progress efforts to attain status as a charitable institution to enable DFA to receive tax deductible donations. Funding applications to the Packer Foundation are being pursued. A range of other funding organisations and possible sponsors are being pursued by the group.

4. Governance (see Appendix (2) - Minutes).

An AGM was conducted to discuss and agree on changes required for the constitution Committee positions were agreed on and a date was set for the 2017 AGM.

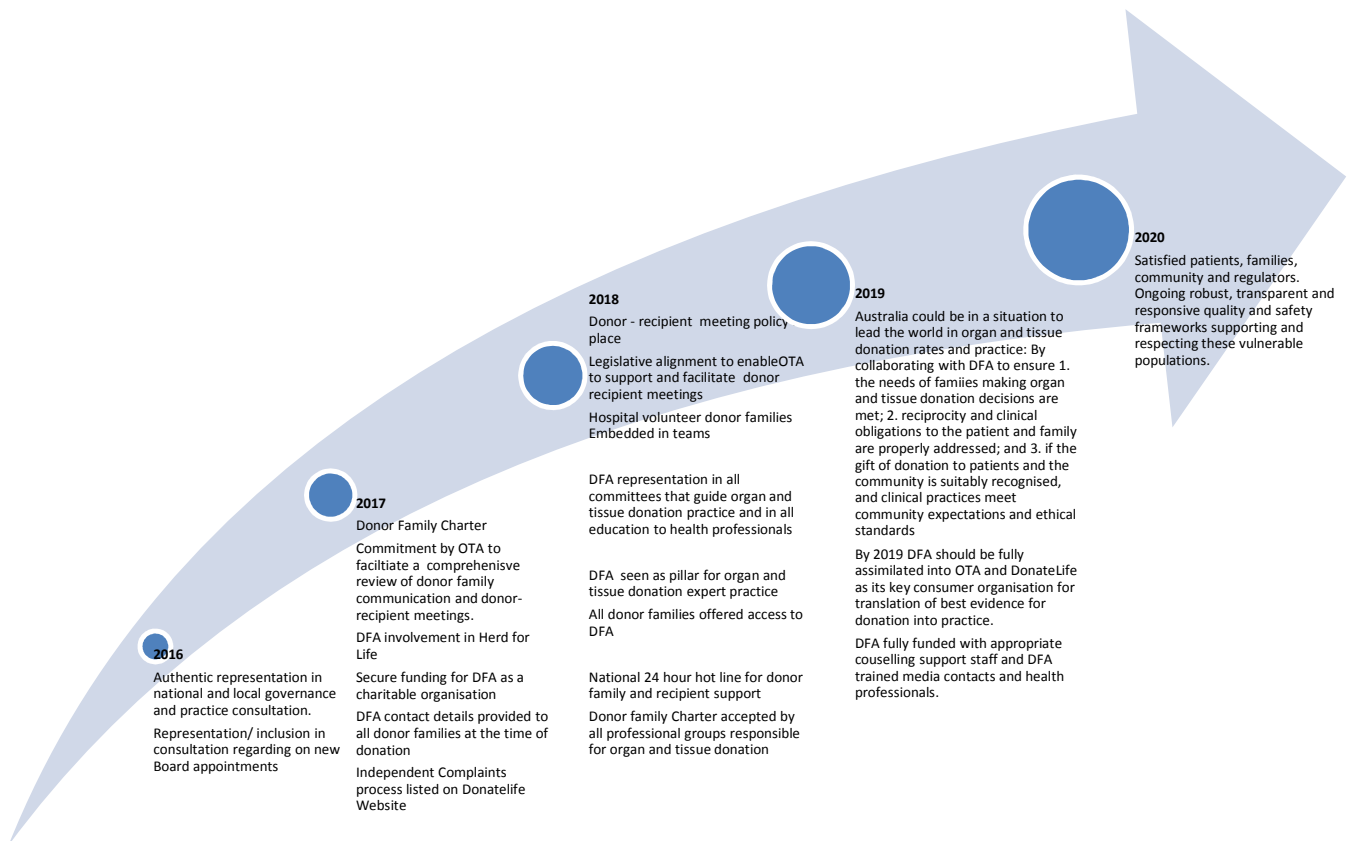


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Strategic Plan Time-Line

Group Consensus: Reveal our vision to others and support them to make our vision real.

5 Year Strategic Plan Time-Line





National Strategic Planning Meeting: 22nd- 23rd October, 2016.

Appendix (1)

Agenda

Session Times	Topic	Saturday 22 nd October
9am	WELCOME	<ul style="list-style-type: none"> • Bruce to open our Executive Weekend Workshop with a Minutes Silence. • Bruce to Welcome All • Holly - a welcome from the Chair of the Two Day workshop and an overview of how it will be conducted. • Each member will be invited to briefly introduce self and what has led them to DFA
9.15am	DFA Review	<ul style="list-style-type: none"> • Holly to review our responses as to what we each hope achieve out of the weekend workshop. • Bruce to review DFA's past 3 ½ years with reference to our original 2013 Action Plan. • Opportunity for members to reflect issues/points that have been raised. • Holly and Bruce: Summary of key points prior to morning tea
10.10	Morning Tea	
10.30	SHARELIFE AUSTRALIA	<ul style="list-style-type: none"> • Holly – to welcome Guest Speakers: Maria Gomez (CEO) and Brian Myerson (Recipient Director). Brief background as to ShareLife Australia and its current activities and objectives for the immediate future. Maria to share with use issues/challenges she see before DFA in the coming years. • Brian and Maria to reflect on their personal experience and insights regarding Donor/Recipient contact. • Post-it Notes will be provided for members to scribe items they wish to raise to generate further discussion and Feedback. • Holly and Bruce: Summary of key points and thanks to speakers prior to lunch
12.00pm	LUNCH	
12.45pm	CARE and SUPPORT	<p>Who and How do we support?</p> <ul style="list-style-type: none"> • Donor Families • Live donors? • Recipients? <p>How do we offer Peer Support?</p> <ol style="list-style-type: none"> Facebook <ul style="list-style-type: none"> ▪ Donor Families Australia - Bruce ▪ Donor & Recipients Australia – Kevin & Leanne ▪ DFA – NT - Helen ▪ DFA – SA - Lizzie ▪ DFA - Qld – Kelli & Sorana ▪ DFA new Facebook sites – WA/VIC/NSW/TAS??? DFA Website – open to all Future opportunities <ol style="list-style-type: none"> www.peersupportvoc.org DFA Workshops DFA one on one counselling Other <p>Holly and Bruce: Summary of key points prior to morning tea</p>
2.10pm	Afternoon Tea	



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Agenda

Session Times	Topic	Saturday 22 nd October - Continued
2.30pm	ORGAN and TISSUE AUTHORITY DonateLife	<p>Holly to welcome Guest Speaker: Felicity McNeill (CEO) Suggested topics that should be covered:</p> <ul style="list-style-type: none"> • Brief background on OTA/DonateLife and its relationship with State/Territory Branches. • Future OTA/DonatLife Objectives. • Challengers before the CEO. • What is planned to better support and embrace Donor Families in general and DFA in particular. • From the Chair – Holly highlighting current road blocks being encountered for open discussion as to how they can be overcome
3.30pm	Donor/Recipient contact with input from Felicity	<p>Discussion regarding the pros and cons of Donor/ Recipient contact. Graham - to lead the discussion commencing with a Sixty Minutes (8min) recording Graham will also provide a brief overview of the Contact Registry that was established within Transplant Australia that operated for 3 years, which brought 12 Donor/Recipient couples together.</p> <ul style="list-style-type: none"> • Post-it Notes will be provided for members to scribe items they wish to raise to generate further discussion and Feedback. • Holly and Bruce: Summary of key points and thanks to speaker
4.00pm	DFA ADVOCACY CHALLENGERS Enablers?	<p>Stakeholders Local/Regional/International</p> <ul style="list-style-type: none"> • Organ Transplantation Authority/DonateLife, • DonateLife State and Territory Branches, • Department of Health, • Assistant Minister for Health, • Transplant Australia • TSANZ, ANZICS, ATCA, ACCCN, Others <p>DFA Challengers and enablers?</p> <ul style="list-style-type: none"> • DonateLife Logo, • Access to an independent complaints advocate, • National and State memorial's, • Opt in Vs Opt out & first person consent, • Greater community visibility for Donor Families, • National management of DF/Recipient letter exchange, • Death Certificates inclusion of donation status, • Donor/Recipient first person contact, • National Online Donor Registration Campaign • Donor Family involvement in management protocol at the bedside • Other issues • Holly and Bruce: Summary of key points prior to dinner
6pm	DINNER	
7.30pm	ORGANISATIONAL STRUCTURE	<p>Bruce - - Rules of Association & AGM requirements NATIONAL Executive Committee - Position to be nominate & endorsed</p> <ul style="list-style-type: none"> • Chair - • Deputy Chair – • Secretary – • Treasurer –



National Strategic Planning Meeting: 22nd- 23rd October, 2016.

Session Times	Topic	Saturday 22 nd October - Continued
	ORGANISATIONAL STRUCTURE (continued)	<ul style="list-style-type: none"> • Branch Representatives <ul style="list-style-type: none"> ○ NSW – ○ ACT – ○ QLD – Mackey ○ QLD – Townsville ○ WA – ○ VIC – ○ SA – ○ TAS – • Funding Sub-committee chair - • Media Sub-committee chair – • Newsletter – Editor, Compositor, Distributor • How/When and Where for the next 5 years • Other??
9.00pm	HOLLY's REFLECTION	Holly – from her recent attendance at the University of California San Francisco Transplantation Symposium. Supported by photos and video of what relationships can be achieved between Donor Families, Health Authorities and Donor Families within the USA
10pm	Close	

Session Times	Topic	Sunday 23 rd October
8am	DFA 5 Year STRATEGIC Roadmap and Plan	<ul style="list-style-type: none"> • Bruce and Holly to lead brain storming discussion to whiteboard a strategic roadmap based on identified directions and information • 2017 • 2018 • 2019 • 2020 • 2021
9.30am	EDUCATE the Community	<p>Positioning DFA and education: identifying who are our targets? Community? Health professionals? Policy officers? Educational institutions? Media?</p> <ul style="list-style-type: none"> • Media policy • Media campaign, Non Profits: Rotary, Lions, Probus etc. • Volunteer recognition, education and support • Guest speakers at functions as required <ul style="list-style-type: none"> ○ Cultivate Media contacts in TV, Radio, Newspapers, Internet. • Information management and policies <ul style="list-style-type: none"> ○ DFA Media Library (website)
10am	FUNDING OPTIONS	<ul style="list-style-type: none"> • Go Fund Me www.gofundme.com • MY Cause www.mycause.com.au • Every Day Hero www.everydayhero.com • Fundraising Function • Community & Interest Group Funding • Corporate Sponsorship • Grants – Government/Corporate
Session Times	Topic	Sunday 23 rd October - Continued



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10.30am	Morning Tea	
10.45am	ISSUES MISSED	An opportunity for anyone to raise other items while we are still all together
11.30am	Chair Summary of the Weekend Achievements	Review by Chair (Holly) of weekend workshop. Time allocated to conclude or at least gain clarity and direction for further action of those issues that remain unfinished business. Bruce to Review action items identified
12 noon	LUNCH	
1pm	Meeting Closed	Those not leaving immediately onto farewell drinks at the Bar



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Appendix (2) Minutes

Saturday 22nd October

Attendees: Bruce McDowell, Leanne Campbell, Graham Harrison, Helen Day, Kelli McDonald, Lizzie Mazur, Philippa Waldron, Kevin Green, Holly Northam (Facilitator).

Apologies: Sorana Walker Heely, Rebecca Free.

Introduction

Bruce Welcome All. Acknowledged attendees had travelled over-night or had little sleep in an effort to attend.

Bruce opened the meeting with a Minutes Silence- to honour Donors.

The image used for the reflection was a picture of the US Gift of Life Medal given to families of organ, eye and tissue donors.



Holly Introduced the planned structure for the 2 day meeting and provided a brief overview of how the philosophy that underpins of restorative practice- respect, voice, acknowledgement, accountability and healing relationships is evident in the structure, relationships and successes of DFA to date. Holly explained that she would use these principles as a framework to facilitate the weekend.

Attendees briefly introduced themselves self and described what led them to join DFA. For many in the room this was the first face to face meeting with other members.

DFA Review

Holly Reviewed the responses to the pre-meeting needs analysis (Appendix 3)

The most important priorities for DFA identified by attendees prior to the meeting were:

- **National management of DF/Recipient letter exchange**
- **Donor/Recipient meetings in first person – based on Adoption and IVF models to be address as part of the OTA/DonateLife presentation or other**
- **Secure funding for DFA**
-

Attendees rating of priorities of the issues listed below	Rating: 1: most important – 10 least important)
1. Memorials/ recognition of donors and families	4, 6, 9, 3, 1
2. Complaints process	5, 1, 4, 5, 5
3. Logo	7, 3, 7, 7, 7
4. Legislative approaches to organ donation: Opt in Vs Opt out & first person consent	3, 8, 5, 9, 8



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5. National Online Donor Registration Campaign	8, 9, 8, 8, 9
6. Involvement of Donor Family management protocol at the bedside	6, 5, 3, 4, 4
7. National management of DF/Recipient letter exchange	1, 4, 2, 2, 3
8. Death Certificates inclusion of donation status	9, 7, 6, 6, 6
9. Donor/Recipient meetings in first person – based on Adoption and IVF models to be address as part of the OTA/DonatLife presentation or other	2, 2, 1, 1, 1, 2
10. Other	<p>*Become a recognised Charity Organisation Government, OTA and DonatLife to fully emb Please note: We also need to look at what is re “Low Hanging Fruit” and thus easiest to achiev Given enough motivation those with an * could achieved within 12 months *Become a recognised Charity Organisation an support from the Government, OTA and Donat</p>

Bruce

- Previously suppressed: progress: DFA are now perceived to have a voice
- Inclusive membership: supporting disenfranchised as well as those satisfied with their donation experience.
- **Achievements:**
- **1. Ministerial recognition (Fiona Nash)**
- **2. Major contributor to the EY Review (Appendix)**
- 3. Influential in lobbying for a change in CEO- holding to account for service delivery to donor families
- 4. Influential in changing health professional and community attitudes: for example:
- OTA representative recent presentation to Transplant Nurses Association re importance of letter writing by recipients to donor families.
- National DonatLife ‘Thank you day’ followed the EY review.
- DFA representatives contribution to education sessions for health professionals, remembrance day events and other organ donation awareness activities that help normalise organ and tissue donation
- **Recent progress:**
- 1. Changing culture: previously donors not seen as ‘hero’s’; and Donor Families were effectively dismissed as irrelevant, “I have never been so disrespected’ (Member of DFA Executive recounting experience of speaking to Advisory Council. Recently there is evidence of a new more inclusive approach being used by OTA leaders.
- **Reflecting on the original 2013 DFA Action plan:**
- Key objectives have been met: Donor families now have a voice, a method of communication and a significant growth in membership and engagement.
- Potential to ‘benefit others by going’ viral’ in the giving of voice’

SHARELIFE AUSTRALIA

Saturday morning session 2.

Collaborating with ShareLife: Presentation on Leading Practice by Dr Maria Gomez and Brian Myerson (Appendix 8)



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International organ donation expert presented that she has learnt the importance of caring for families prior, during and after the donation in Australia after hearing Donor Family voices- and this learning will be taken overseas to inform future international practice.

• **Four Areas of the donation transplantation continuum addressed:**

- 1. Current situation
- 2. Leading Practice
- 3. Donor Family
- 4. Hospital Certification

Why is donation important?

- 1. Survival rate after 5 years on dialysis is less than 50%
- 2. With a kidney transplant: 95% survival rate
- 3. Cardiac survival rate: Year 5 waiting: 80% will die
- 4. With transplant: 80% survival at 8 years
- Discussion about the benefits of Donation after Brain death compared with donation after cardiac death for potential recipients and the current statistical anomalies between Australia and international practice regarding Australian donation practices and their impact on recipients.
- Maria described the hospital donor identification process and discussion ensued about the need for staff education about brain death and care of the donor potential family- some of whom volunteer.
- Questions were raised about continuity of care so that the family members are not exposed to multiple personnel-Maria advised that it was important to have skilled experts to lead the family through the experience. Further questions and discussion about decisions made without proper support for family members who feel fearful that machines are turned off 'for the organs'.

Why measurement of each potential donation step is important:

International organ donation leading practice: Measure each step:

- 85% of families agree to donate
- 15% decline
- Family have rights to decide. Measuring using leading practice parameters: 2.8% of all hospital
- Brain Deaths potential for organ donation in ICU: 14- 15% of deaths are Brain deaths.

Donation Specialist medical officers: specialist doctors and nurses across the hospital using a whole of hospital approach.

Hospital services need to ensure rights for families to have an organ donation service to enable the donation doctor or nurse to work together with the treating clinician before the donation.

What is different?

1. Interaction from the point of admission to the hospital onwards

2. Framework of emotional support and help for families

The doctor must offer emotional support

A relationship based on respect, empathy and congruence.

In 2015 The Spanish had a 15% refusal rate. They use a classical approach (Matesanz)

They found that survey data on the willingness to donate had no correlation between the populations expressed views and the in hospital final donation rate. Public acceptance had diminished from 74% approval to donate to 61% and yet donation acceptance at death continues to improve.

This points to the impact of the staff in the hospital on the donation outcome. A further point is that the health professionals work hand in hand with the media around messaging regarding organ donation; there is no register.

A video of a donor mother directed to doctors was shown, 'I would like to encourage doctors to support families making organ donation decision'.

Donor family experience is a tool to educate.

- Why did families decline?
- Donor family testimonials help encourage others to donate.



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- Brian Myerson (Founder of ShareLife and transplant recipient) then shared the media report by ABC 7.30 Report that covered his experience of meeting a member of his donor family for the first time. This was a deeply emotional but positive experience for those present; especially Graham who had also met his sons' recipient and who expressed his frustration that 20 years ago he was fighting for the donor recipient relationship and the barriers still exist. Discussion ensued by those present who had met recipients or had sought to connect- and many expressed their frustrations regarding the barriers to positive healing donor family- recipient relationships that they knew were forged from experience.
- Further discussion about the way in which donors and recipients found ways to meet and the potential for harm if not managed appropriately.
- The agreed view was that the OTA need to engage with this issue and address misinformation and offer a structured process and support
- Brian expressed that the experience was 'wonderful' and discussion about protecting those involved by setting expectations appropriately and providing the support to enable a 'forum for healing'.
- The idea that with bereavement follow-up: regular communication, being flexible to peoples needs and 'keeping the door open' to changing needs.
- This was seen as a role that DFA could play in assisting and welcoming in families.
- The example of Scottish nurses who do home visits after donation was used as an exemplar in offering therapeutic relationships for bereaved families.
- The importance of having appropriate organisational support in enabling donor recipient communications both by letter and if desired, face to face, was seen as paramount.
- Subsequent discussion with those present ranged over issues of governance in Australia and included the proposed new Board structural arrangements and accountabilities. There was general discussion about the recognition that things were not working at present- that more skills were required. Discussion about accountability moved to idea of Hospital Certification and the NSW Plan and how to manage the process in Australia with consistency. The requirement that the approach should be unified- using the same language was touched on along the idea of leading practice in the organ donation process in the hospitals being measured and accountable using Hospital Certification and by changing culture to embed donor families throughout the organisation.

Strong committee support was expressed for Maria Gomez and Brian Myerson and their argument re Hospital Certification. In addition, Marias recommendation that to enhance Leading Practice: she wishes to take over-seas the role and impact of DFA: 'How to care for families before, during and after decision that she has learnt here was strongly endorsed.

CARE and SUPPORT

Who and how do we support?

Donor families: most vulnerable, without voice

Recipients: also vulnerable and many indicate they have no voice

Question of Identity:

Issue of scope of work and traction. Question and discussion about the role of Transplant Australia and the Transplant Games, general view that the personal support for recipients and donor families outside of the games was extremely limited.

At present DFA is totally reliant on the energy of the volunteer individuals who support the organisation.

Discussion regarding what defines DFA? Representation of donors and their families and increasingly the donor recipient relationships and shared support.

Proposal: DFA should consider setting up a first contact register for donor families and recipients wishing to meet.

Similar to that set up previously by Graham Harrison and covered by the ABC program '4 Corners'.

Continued discussion pointed to the assumption that the Donor Recipient site is very active and seems fuelled by donor families who want to meet the recipients of their loved ones organs or tissue. Resolution that this is a vital issue to DFA and needs to be progressed through continued lobbying to the OTA, research to collate evidence to inform the debate



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and potentially legislative change to enable the OTA to properly manage the potential relationships which it is thought would lead to enhanced donation outcomes. Action: Ongoing lobbying and research activity to define the problem and present possible solutions.

Question of Membership:

Discussion about the level of membership for Donor families and live donors compared to recipients. The view was expressed and supported by the group that DFA's first priority is to donor families, recognising however that recipients are reaching out for support too with similar and shared issues- and concern not to alienate recipient-s but that at this stage in the organisation it is best to maintain focus on the reason the organisation came into existence- to support donor families. Because of the complexity of the donor recipient relationship and to control the exposure of donor families to recipients related to the competing interests involved, it was agreed that the primary goal was to support donor families- especially when some donor family members struggle with insensitivity sometimes revealed by recipients.

Proposal: Donors (live) and Donor families entitled to full membership and full rights of representation on committees and voting.

Associate Membership should be offered to recipients and interested supporters.

Discussion regarding: DFA Facebook site and website:

Actions:

1. Keep sites and update- ensure consistency and messaging aligned with core values;
2. Continue to support Kevin's donor-recipient Facebook site.
3. Need FB page of each State and Territory for credibility
4. The Website Form needs information added about siblings

Action: Lizzie: Follow-up contact to see if able to support development and changes to site. :

ACTION all: Reach out with support through workshops, counselling other support services. Reach out to all counselling services, GPs and other service providers to alert to our presence.

Action:

DFA to explore counselling support options: recommendation- Sean Dicks (UC, ACT DonateLife).

At present there is inconsistent representation of DFA on the DonateLife webpages

Problem: There is also no complaints process or link on website

Useful resource: Compassionate Friends support groups: listening, training, phone skills,.

To train families as volunteers- needs to be done properly.

ORGAN and TISSUE AUTHORITY

DonateLife

Saturday afternoon, session 4: 13.30- 1600

Collaboration: Felicity McNeill, CEO, OTA.

Felicity introduced her approach by reflecting on her previous experience with the PBS and stating that she sought to ensure that "All the voices could be heard and none should be left behind", and that "You have to listen when no-one else would".

Discussion re donor recipient letter exchange :

Message directed was that you should never under-estimate' the power of one person to change the world' and that Donor Families were on an equal status with day to day business in the OTA. Discussion re the Transplant Australia Games and the COAG priority of organ and tissue donation. In her role the emphasis on people in hospitals- the necessity to recognise implications of part funding some positions. Looking at creating a conversation between health professionals and family members that is the best that it can be, to normalise organ donation by teaching health care workers, the public and schools and to train staff to address culturally diverse peoples needs.

As acting CEO working to meet the governance requirements but still awaiting the passage of the legislation and is



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aware of the potential for conflict of interest. Very protective of the sector- but working with transplanters to increase competence and ethical positioning re the approach to donation and transplantation, 'extended criteria donors' and messaging regarding these issues.

Working on the new strategic plan to increase live donation, and the paired kidney exchange program. Trying to bring a compartmentalised sector together and pushing to change culture. Funding is confirmed for 2018 and the target of 25 dpmp has been set.

The question re what happens about community engagement- and the idea that the community needs to lead this was put to DFA by Felicity.

Discussion about the new Board structure ensued; with the powers legislated; and timeframes involved. A question regarding the Advisory Council with positions due to expire on January 1st; the proposition that the legislation would have bipartisan support was acknowledged and wide ranging discussion then continued fro across the group highlighting issue such as lack of consistency in communications and practice across the country; eg. Breakdown in communication following donation in Victoria; a desire for continuity of care – in keeping with the process described by Dr Gomez; No consistent point of contact for follow up or contact.

Proposition: Graham:

Donor families have a great and ongoing contribution

- 'We can help each other out'
- We can help the system
- We can educate about the experience

Response: small population; need to articulate a clear vision; have a formalised system. Focus on a strong first hand message: communicate 3 or 4 priorities.

Discussion about disrespectful miscommunication at Advisory council meeting attended by Bruce and Sorana. Kelli expressed that DFA are seeking support of the DonateLife Network Communication with OTA: Language is an issue and as informed advocates it is necessary to advise.

ACTION:

DFA to focus on Voice and strategies to provide avenues for Donor families voices to be heard. Recommendation: Present 4-5 pages of DFA objectives to Felicity.

Donor/Recipient contact

Discussion regarding the pros and cons of Donor/ Recipient contact.

Graham - led the discussion commencing with a Sixty Minutes (8min) recording Graham provided a brief overview of the Contact Registry that was established within Transplant Australia that operated for 3 years, which brought 12 Donor/Recipient couples together. Group discussion reinforced the view that it was a priority of DFA to have donor-recipient relationships supported and properly regulated through the OTA.

DFA ADVOCACY CHALLENGERS

Enablers?

Stakeholders Local/Regional/International

- Organ Transplantation Authority/DonateLife,
- DonateLife State and Territory Branches,
- Department of Health,
- Assistant Minister for Health,
- Transplant Australia
- TSANZ, ANZICS, ATCA, ACCCN, Others

DFA Challengers and enablers?

- DonateLife Logo,
- Access to an independent complaints advocate,
- National and State memorial's,



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- Opt in Vs Opt out & first person consent,
- Greater community visibility for Donor Families,
- National management of DF/Recipient letter exchange,
- Death Certificates inclusion of donation status,
- Donor/Recipient first person contact,
- National Online Donor Registration Campaign
- Donor Family involvement in management protocol at the bedside
- Other issues
- **Holly and Bruce: Summary of key points prior to dinner**

ORGANISATIONAL STRUCTURE

Bruce - – Rules of Association & AGM requirements

NATIONAL Executive Committee -

Positions confirmed

Position	Name
Chair	Bruce McDowell
Deputy Chair	Leanne Campbell
Secretary	Graham Harrison
Treasurer	Helen Day
Donor Family Personal Contact Coordinator	Philippa Waldron
Communications Coordinator • Technical Support	Lizzie Mazur Sam Hawkins
Outreach Coordinator	Kevin Green
Policy Coordinator	Kelli McDonald
Newsletter Editor	Bruce McDowell
Evidence & Advocacy Coordinator	Holly Northam
Funding sponsors & support	All

Saturday evening session 7

Constitutional Matters

Proposal to change the commonly used name of 'Donor Families Australia' which is written in the constitution as 'Donor Families of



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Australia' to 'Donor families Australia' which is commonly used and preferred by Members.

Proposed: Bruce; **Seconded** Graham, all agreed. **Passed.**

Objects of Association:

Article 5: Discussion: qualification for membership of the Association

Proposed: Bruce: Voting power given to:

- a. Donor Families
- b. Living donors and their families
- c. Those supporting donor families, living donors and their families are Associate members and have no voting powers.

Seconded: Graham, all in agreement: **Passed.**

Next AGM: Tuesday 10th October 2017.

- a. Online AGM format

Article 13. Treasurer: Helen appointed: A second signature is required: Bruce and Helen to action.

Article 15. **Proposal:** Bruce: To progress DFA to attain a 'Deductible Gift Recipient' status asap. **Seconded:** Helen, All in support:

Passed

Holly Reflection: Learnings from recent attendance at the University of California San Francisco Transplantation Symposium.

Supported by photos and video of relationships that can be achieved between Donor Families, Health Authorities and Donor Families within the USA

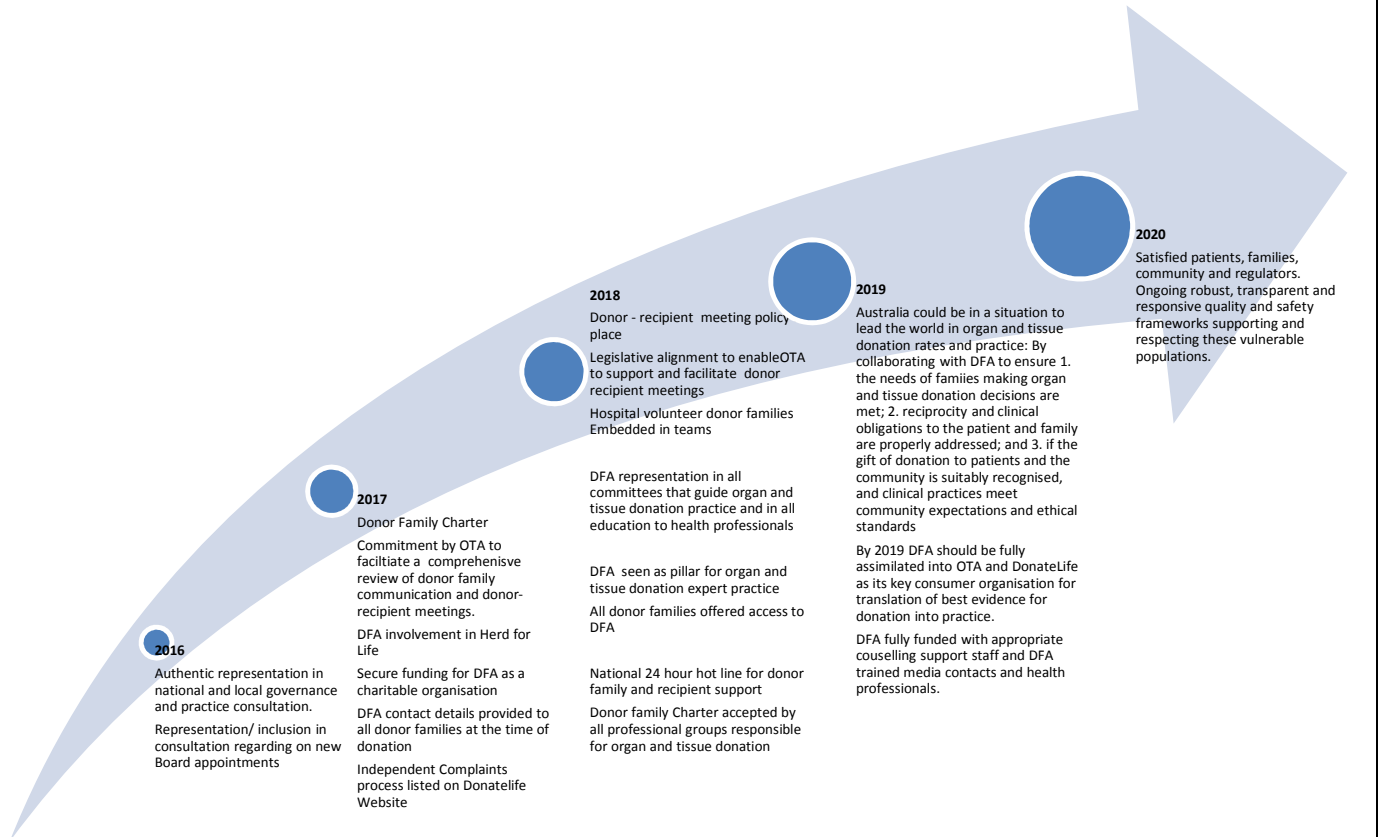


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Minutes

Sunday 23rd October

DFA 5 Year STRATEGIC Roadmap and Plan Group discussion



EDUCATE the Community

Positioning DFA and education: identifying our targets:

Community? Health professionals? Policy officers? Educational institutions? Media?

- Media policy: Position appointed for key contact: Lizzie Mazur
- Media campaign, Non Profits: Rotary, Lions, Probus etc as collaborators to work with education strategies.
- Volunteer recognition, education and support needs to be addressed as the organisation grows and DFA support and training needs to be focused on helping DFA to be seen as an organisation that provides expert Guest speakers for functions as required and the media.
 - Cultivate Media contacts in TV, Radio, Newspapers, Internet but these need to be coordinated and a database needs to be set up and maintained
- Information management and policies need to be addressed.



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- **ACTION:** Kelli volunteered to be policy coordinator so that DFA are able to proactively release DFA approved statements as required regarding key issues facing donation in the media and in policy.
 - DFA Media Library (website) or drop box to collate all resources for members

Discussion regarding funding options: The group decided that seeking money from other donor families was not desirable and most felt that it would not be appropriate to use programs such as:

- Go Fund Me www.gofundme.com
- MY Cause www.mycause.com.au
- Every Day Hero www.everydayhero.com
- **Community & Interest Group Funding:** The idea of corporate Sponsorship and community special interest group funding was seen as appropriate, as was the idea of applying for Grants – Government/Corporate: so long as DFA integrity and independent voice was maintained.
- It was reinforced that DFA need to acquire charity status to successfully continue and this had already been identified and was being pursued.
- ACTION: Leanne: Grant application to Packer Foundation

Untabled Business:

- Kevin introduced recipient Megan O’Loughlan and her amazing ideas for awareness and funding through the ‘Herd of Hope’ and the crossing of the Sydney Harbour Bridge in 2017. The group thanks Kevin for his introduction: endorsed this collaboration and look forward to pursuing the opportunities as they arise.

Facilitator Summary of the Weekend Achievements

Holly, Bruce, Graham:

Outcomes:

Actions:

Vision:

1. Maintain independence.
2. Continue to provide support, voice and advocacy for donor families.
3. Gain full support and ensure represented throughout all OTA activities, policies and outcomes.
4. Attain financial independence.

For DFA

Urgent:

1. Make representations to the Commonwealth Department of Health & Minister re the new Board makeup
2. Become a registered Charity Organisation
3. Update Website

For DFA Advocacy and voice

Priorities:

- 1: Challenge policy makers to address the donor- recipient desire to meet in an ethically and legally approved and psychosocially supported manner.
- 2: Challenge key stakeholders to address perceived deficiencies in National DF/Recipient letter exchange

New business

Introduction by Kevin to recipient, Megan O’Loughlan- ‘Herd of Hope’- Opportunities for sharing and collaboration



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Appendix (3)

Pre-meeting survey

Attendee Needs Analysis Survey

Thank you for taking the time to complete this brief survey. The de-identified information will be used to inform the preparation for the national strategic planning meeting of Donor Families Australia and help evaluate the outcomes.

1. Why do you think this meeting is important?
2. What would you like to see achieved by the end of this meeting?
3. Do you feel you have sufficient opportunity to voice your views regarding the direction DFA takes and to contribute?
4. What do you believe is the most important outcome that you would like to see from this meeting?
5. What do you believe if the most important role of DFA?
6. What are the key issues that DFA need to address?
7. What do you believe are barriers or enablers to achieving these outcomes?
8. What timeframes do you believe are appropriate given these targets?

Please rate from **1** Most important) to-**10** (least important) some of the questions and challenges DFA must address:

- Memorials/ recognition of donors and families
- Complaints process
- Logo
- Legislative approaches to organ donation: Opt in Vs Opt out & first person consent,
- National Online Donor Registration Campaign
- Involvement of Donor Family management protocol at the bedside
- National management of DF/Recipient letter exchange,
- Death Certificates inclusion of donation status,
- Donor/Recipient meetings in first person – based on Adoption and IVF models to be address as part of the OTA/DonateLife presentation or other
- Other: Please describe



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Appendix (4)

Australian Charter of HealthCare Rights



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AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high quality health system. A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.

Guiding Principles

These three principles describe how this Charter applies in the Australian health system.

1 Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.

2 The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.

3 Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.



For further information please visit www.safetyandquality.gov.au

AUSTRALIAN COMMISSION
SAFETY AND QUALITY IN HEALTHCARE

What can I expect from the Australian health system?

MY RIGHTS	WHAT THIS MEANS
Access _____ I have a right to health care.	I can access services to address my health care needs.
Safety _____ I have a right to receive safe and high quality care.	I receive safe and high quality health services, provided with professional care, skill and competence.
Respect _____ I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
Communication _____ I have a right to be informed about services, treatment, options and costs in a clear and open way.	I receive open, timely and appropriate communication about my health care in a way I can understand.
Participation _____ I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
Privacy _____ I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
Comment _____ I have a right to comment on my care and to have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

Appendix (5)



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DFA Response to a request to respond to the 2015 Ernst & Young 'Review of the implementation of the national reform agenda on organ and tissue donation and transplantation'.

Thank you for the opportunity to present Donor Families Australia three most preferred listed recommendations arising from the EY (2015) 'Review of the implementation of the national reform agenda on organ and tissue donation and transplantation'. In addition to listing our priority recommendations, we have provided advice regarding their interpretation and implementation.

This advice is provided with the caveat that:

- Donor Families Australia strongly recommends that the policy and practice of organ and tissue donation for transplantation in Australia must be extensively reviewed to ensure it is underpinned at a national, regional and local level by transparent evidence of an ethic of care that frames all relationships within the organisation and with the community.

This can be achieved by:

1. Embedding a 'donor centred' philosophy that makes it explicit and transparent that donors and donor families are intrinsic to the success of the organisation and should be visible in every part of the organ donation for transplantation process: to represent and provide recommendations relating to this sensitive area of practice.
2. Ensuring all communication, information and expectations of the donor- recipient relationship are represented and honoured in a transparent, compassionate and therapeutic manner that meets the needs of those involved and society.
3. Embedding donor family representatives in all education and evaluation programs to provide guidance to enhance clinical practice, and to ensure sensitive and appropriate care that meets community expectations.

Given that this will require a complete realignment of the OTA and AODR focus from being organisation centred to patient and family centred practice, these are the three preferred 3 recommendations:

1. Recommendation 18: To be effective in achieving international best practice, the national organisation must honour, and be seen to honour, the donors who enable the practice. It must be clear to the families and the wider community that donors and their families are heroes who are respected, honoured and acknowledged at every level of our society, this must be institutionalised. The symbols used to represent donors and their families must be sensitive and appropriate to those most affected.

0. Recommendation 17: It is vital that communications around organ and tissue donation for transplantation is supported by a nationally consistent evidence based approach to communications in multiple levels: at an organisational level, between staff and the organisation, between families and health care workers, between the community and the organisation, between donor and recipients and recipients and donors. Barriers to communication must be removed and the donor recipient relationship must be transparently recognised, supported and honoured. Education and policy must be based on contemporary and relevant evidence, and must be consistently delivered to all health care workers and the community and not promote unrealistic expectations.

From the experience of DFA: the organ and/ or tissue donor family/ recipient relationship is valued, honoured and much sought after. In practice there are significant barriers at National institutional and regulatory levels to these relationships. Since its inception DA has learnt that:

1. There are many stories of distress and potential harm that have been recounted by individuals and family members from both donor and recipient sides of the donor transplantation 'equation'. These have been



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brought about by real and/ or perceived institutional and regulatory barriers to meeting and communicating.

2. This may have contributed to 'complicated grief' and prolonged suffering for those involved. Further, some donor families have regretted their decision to donate because of the sense that the meaning of the donation was lost because they were unable to contact/ communicate with the recipient. This 'yearning to meet' is also spoken of by recipients.
3. Many donor families and recipients who are caught up in these experiences wish to communicate in a meaningful way with those on the other side of the experience whose lives were changed by the same dramatic event.
4. The shared experiences of those within the DFA 'family' who have communicated with recipients and their families suggests that most find meeting or communicating an overwhelmingly positive experience.
5. The story of the relationships and the connections between donor families and recipients is a positive message in the media which may underpin some decisions to donate or to sign the organ donor register.
6. In the DFA 'family,' the lack of transparency about donor and recipient communication has generated a level of mistrust regarding the organisational processes involved in organ and tissue donation in Australia. This is potentially damaging for organ transplantation outcomes.

1. **Recommendation 3:** The proportion of ICU specialists, staff and trainees who participate in the FDC Workshops should be monitored by the DonateLife Network by hospital- whilst concurrently evaluating the quality and effectiveness of these workshops in the experience of families. The question regarding monitoring must be centred on:
 1. Is the education appropriate to the task and its meaning?
 2. Is this education helpful to the families experiencing the request? I.e. Does it help families agree to donation without regret?
 3. Is the education provided to all the people who need it?
 4. Is the performance of the professional who underwent the education assessed?



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Appendix (6)



Donor Family Network

Donor Family Charter

Families have the right:

1. To a full and careful explanation about what has happened to their loved one, his or her current status, and his or her prognosis.
2. To be full partners with the health care team in the decision-making process about the care and support given to their loved one and to themselves.
3. To a full, clear and careful explanation about how the (impending) death of their loved one was or will be determined with appropriate reference to the concepts of cardiac and/or brain stem death.
4. To be given opportunities to be alone with their loved one during his or her care and after his or her death occurs. This should include offering the family an opportunity to see, touch, hold or participate in the care of their loved one, as appropriate.
5. To be cared for in a manner that is sensitive to the family's needs and capacities by specially-trained individuals.
6. To be informed if their loved one had previously indicated an intent to donate organs and/or tissues and their family's responsibility to honour that decision.
7. To be given the opportunity to make organ and tissue donation decisions on behalf of their loved one, where appropriate and in accordance with applicable laws. This opportunity should be included in the normal continuum of care by the health care provider after death has been determined and the family has had sufficient time to acknowledge that death has occurred.
8. To receive information in a manner that is suited to the family's needs and capacities about the need for organ and tissue donation, the conditions and processes of organ and tissue donation and the implications of organ and tissue donation for later events, such as funeral arrangements, viewing of the body and related practices.

Donor Family Network Donor Family Charter updated 2012



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Appendix (7)

Donor and Recipient Australian Facebook Group (G. Harrison)

Donor and Recipient Australian Facebook Group

The question asked: I'd like your feedback and comments into the way things are handled by the OTA and DonateLife so we can gather this information for this coming weekend to discuss it with the committee.

Those that responded: 5

6 donor family members: 3 male; 3 female	7 Recipients 4 male; 3 female
---	----------------------------------

Request to Facebook users by site administrator:

Hi to everyone in this amazing Group.

This weekend in Sydney the Committee of Donor families Australia are holding their first ever conference to set out some pathways for the group.

I'd like your feedback and comments into the way things are handled by the OTA and DonateLife so we can gather this information for this coming weekend to discuss it with the committee.

1. Things like Donor families and recipients writing letters and not knowing if they have been sent or received
2. Donor families not receiving correspondents about loved one's gift of life to others.
3. And Much needed Support.

So please take the time to post up your feedback to help us going forward
 And also your feedback on the things you like about the OTA and DonateLife.
 Feel free to message me your feedback as well.
 Regards Kevin

Discussion thread: Letter Communication

1. Would like correspondence to maybe receive a text to say correspondence received and when correspondence sent send a text
2. And if our letters aren't forwarded on why?
3. It took 6 years for DonateLife to tell me my donor was a female, they won't even give an approx age, I have written to my donor family every year but have not heard back.
4. That's just not acceptable at all. Not even to get a letter back saying they couldn't contact your donor family.
5. I just rang them, they checked to make sure I was who I said I was then asked when and where I had my transplant, looked it up and told me that they had sent the letter on. If I receive a reply that will be awesome but I really respect my donor family's right to not reply if that is what they choose although I would love to know more So I guess it's easy to find out if it has been forwarded, I'll give it another



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month and then ring to see if they have heard anything from my donor family - I guess they may say they don't want contact.

6. If you are a recipient & your coordinator has passed them on to the Donor Family coordinator have them check out whether the Donor Family coordinator has heard if they (family / families) want to hear from you & have received your mail. I have been told that if family move they don't always tell the DonateLife their new address. This can make hard for passing on mail.
7. My husband is celebrating 1 year post transplant on Sunday & we still have no idea if the donor family received our initial letter, so I am hesitant in writing anything further without confirmation that the family are receiving the correspondence we have sent.
8. I don't know what everyone else's thoughts are but as a donor mum the paperwork we went through with DonateLife once we realised our beautiful boy was leaving us, I would have liked to see a question asking if you are happy to be contacted by your recipient and visa versa. I feel this way people won't be wasting their time writing and yet not receiving a response as I found not getting a response hurtful.
9. I want DonateLife to confirm with anyone that sends a letter, be it donor family or recipient, that the letters have been received so that if we hear nothing we know that they do not want contact.
10. I also agree that confirmation of receipt of a letter that is months in the making should be able to happen, I haven't heard back after 3 months and am starting to wonder, even though I'm probably impatient. The doubts start to creep in after reading some of the stories.
11. I want the OTA & DonatLife to stop sending out generic letters that are often incorrect.

Discussion thread: Knowing more of the Donor/Recipient

1. I would really like to know my donors first name. I am fortunate that I have had correspondence so I know a bit about her. But saying my donor is sooo impersonal.
2. The reality is that you are allowed to use first names in correspondence. I have been communicating since 1994 using first names.
3. I want the recipients to at least know the first name of their donor or at the very least the initial. When I write a letter I would like to refer to xxxx by name.

Discussion thread: Donor/Recipient "First Person" contact

1. Meeting my donor family was extremely fulfilling for both parties, and both our extended families. To facilitate this for consenting parties would no doubt enhance positive activity around the organ donor issue.
2. I would like to see a survey done by the OTA between recipients and donor families about the likelihood of meeting. I originally thought it was a possibility, but it didn't restrict me from saying yes when I was told I would never know who, what or where. From the time I signed over xxx organs, I always hoped there meet his recipients, as are the wishes of many donor families & recipients within this group. Meeting if both parties agree!!!!!!
3. Yes - definitely this should be the case we were led to believe this was the case.



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4. I will never forget how difficult it was that night filling out all the paperwork and coming to the painful realisation that I was going to have to say goodbye to my beautiful boy. The only comfort was knowing that he would help 6 lives. I would really love to meet all of his recipients if they want to meet me! 😊
5. Some time ago on this page I think, a father who had lost his son some time ago, said that he had lobbied the government & DonatLife at the time about having contact with the recipients. He was told that for this to occur the Donor would have to be the one who gave permission for that to happen. A bit of an oxymoron! So how about when we register to become Donors we sign off saying if our families want to be in contact with the recipients they have permission.
6. That's a great idea xxx
7. I would like to see it set up the same as adoption. We the donor family should be able to sign a document that DonatLife have which indicates that if the recipient wants to contact us they can.

Discussion thread: OTA/DonatLife the organisation

1. I would also like to know if any of these OTA members are from a donor family or an actual recipient. If not how could they possibly really know the emotions of people that do, but still have control and no heart in the communication between recipient and donor families.
2. Exactly what I have been saying all along - they can't possibly know what is best for donor families unless they have walked in our shoes!
3. Totally agree
4. I could go on & on, I want them to show us some consideration and most of all to do their jobs, show some compassion.

Discussion thread: Counselling

1. I want more counselling offered to both parties, it seems to me that once the families give permission for donation to occur we are forgotten. I have read here that not all recipients get much counselling either.
2. You're never forgotten by the recipient -xxx & I never received or were offered counselling & really feel I needed it.



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DONOR FAMILIES AND LEADING PRACTICES IN ORGAN DONATION

Dr. Maria Gomez

Outcomes Australia CEO

Transplant Procurement Management- TPM Senior Expert. Barcelona University
Medical Coordinator International Registry in Organ Donation- IRODaT

Donor Families Australia Meeting
Sydney, 22th October 2016



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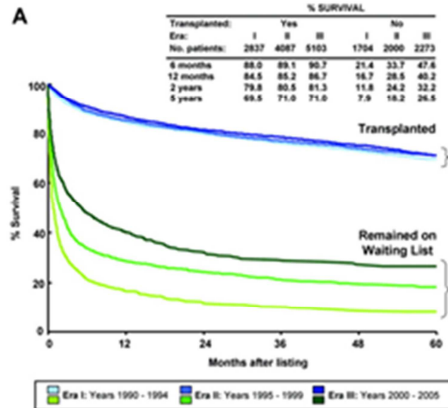


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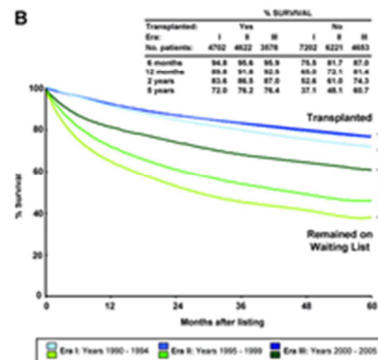
Organ donation save lives!



Patient Survival - 90 days after HD start Censored for Transplant 2001 - 2012 % [95% Confidence Interval]					
	No. of Patients	Survival			
		6 months	1 year	3 years	5 years
Australia					
2001-2003	3467	96 [95, 97]	90 [88, 91]	68 [66, 70]	50 [48, 52]
2004-2006	4222	96 [95, 97]	89 [88, 90]	68 [67, 70]	50 [48, 51]
2007-2009	4697	96 [95, 96]	90 [89, 91]	70 [69, 72]	53 [51, 55]
2010-2012	4450	96 [96, 97]	91 [90, 92]	-	-
New Zealand					
2001-2003	653	97 [95, 98]	92 [90, 94]	72 [68, 76]	54 [50, 59]
2004-2006	704	97 [95, 98]	91 [89, 93]	71 [67, 75]	51 [47, 55]
2007-2009	793	96 [94, 97]	91 [89, 93]	71 [68, 75]	53 [47, 58]
2010-2012	735	98 [96, 99]	94 [91, 95]	-	-



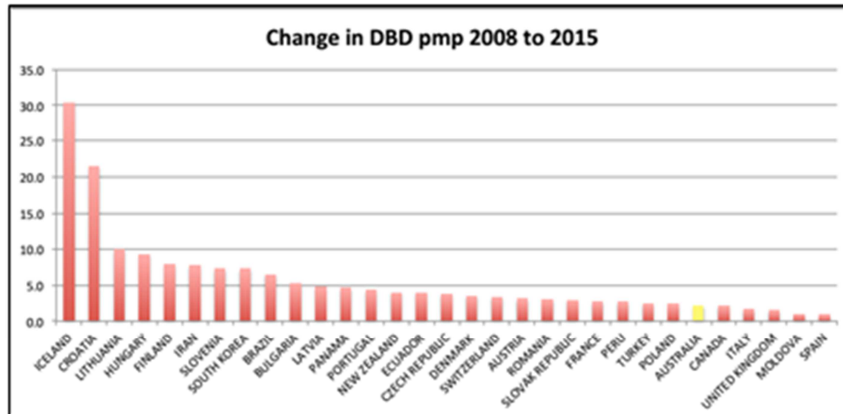
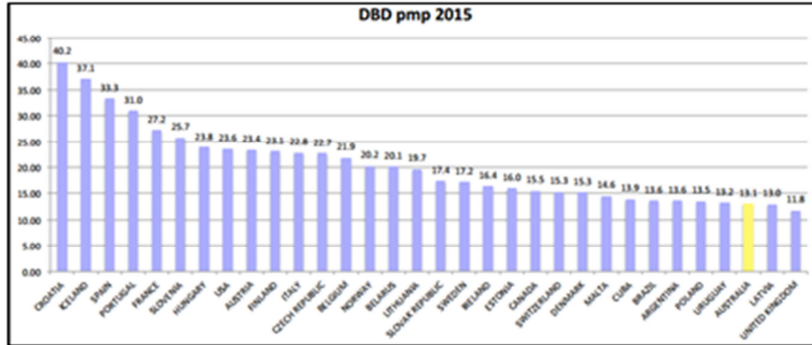
Cardiac transplant recipients Survival Rate USA 1990 - 2005





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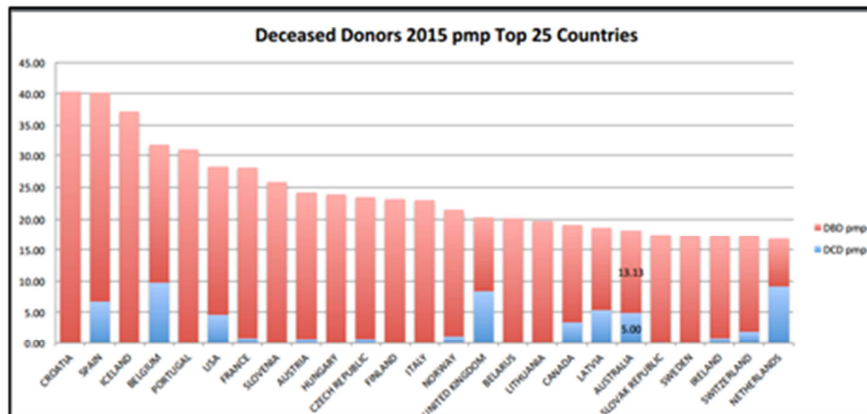
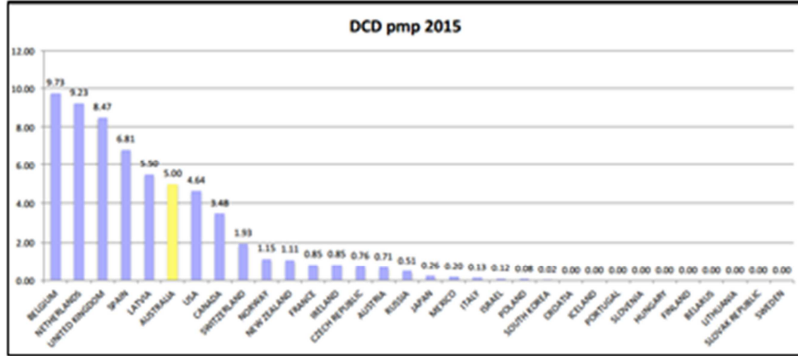
Top 30 countries Brain Death Donors PMP 2015





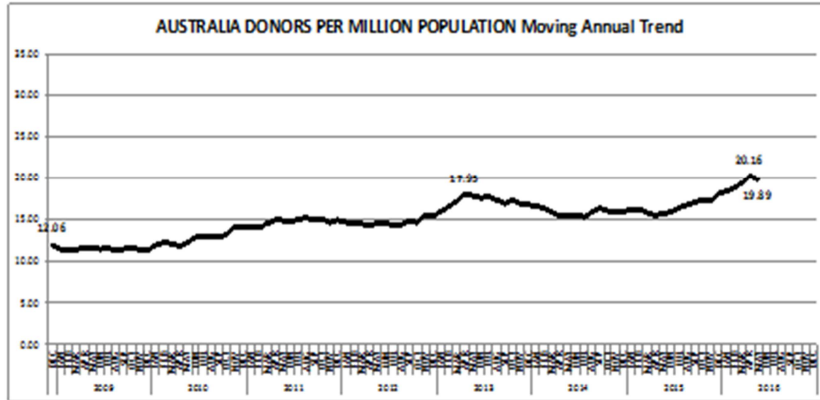
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Worldwide After Circulatory Death Donor PMP 2015

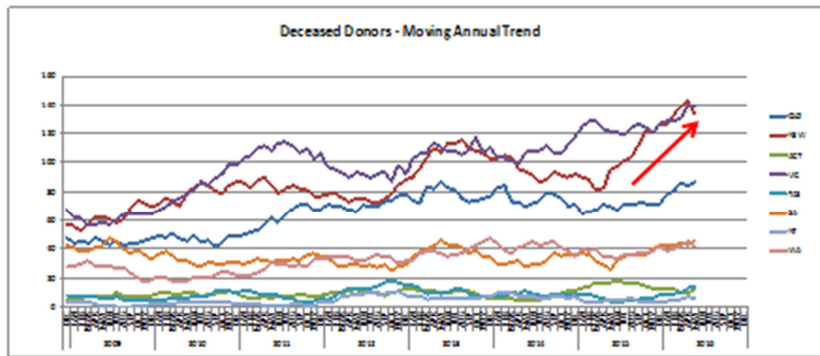




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Comparison of State Performance





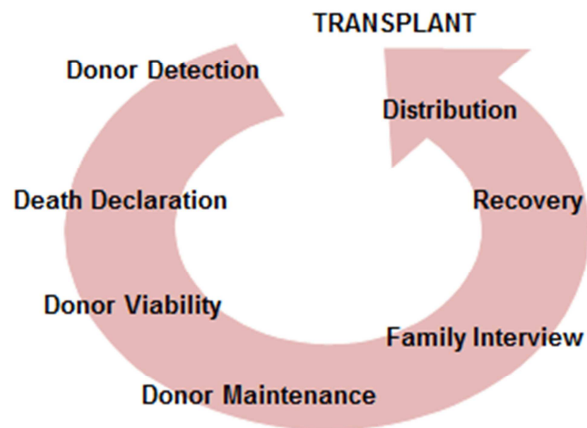
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Deceased Organ Donation is a Hospital Process



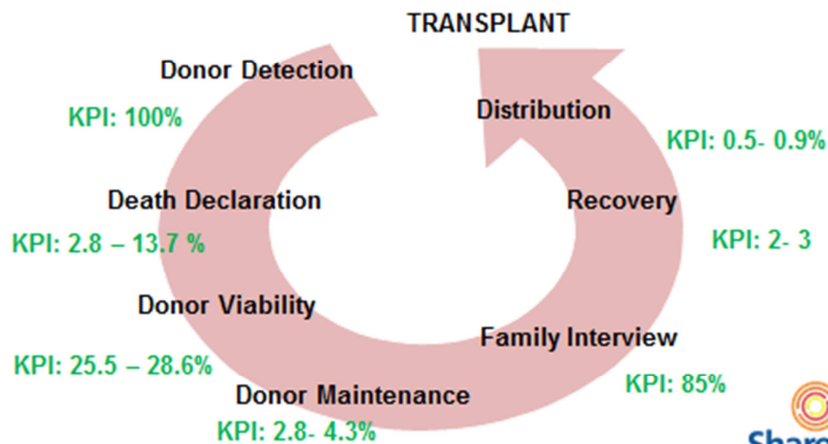


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Specialists who interact across the hospital



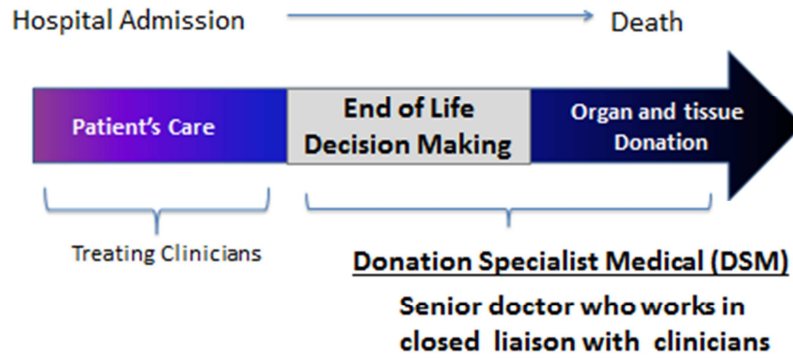
Deceased Organ Donation Process Key Performance Indicators (KPI)



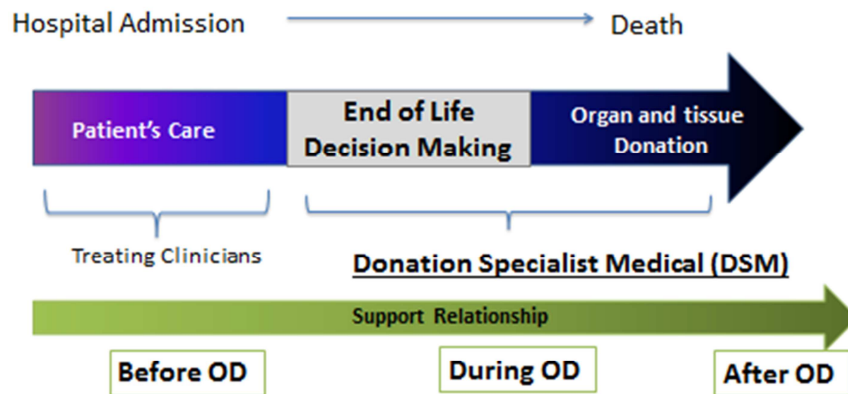


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Organ Donation is a Hospital Service



Donor Family Support





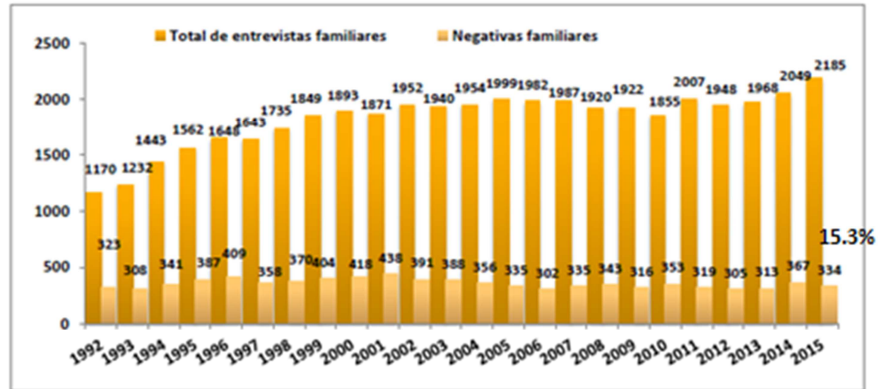
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Leading Practice Rules for family approach



- ✓ Interaction with families from admission to hospital and special attention regarding the families' perception about the treatment and communication.
- ✓ Family interaction in a framework of emotional support and help
- ✓ The doctor role is not only to cure or treat the patient but also to offer emotional support to relatives.
- ✓ Relationship based on respect, empathy and congruence

Family interviews Vs. Family Refusals in Spain 1992 to 2015





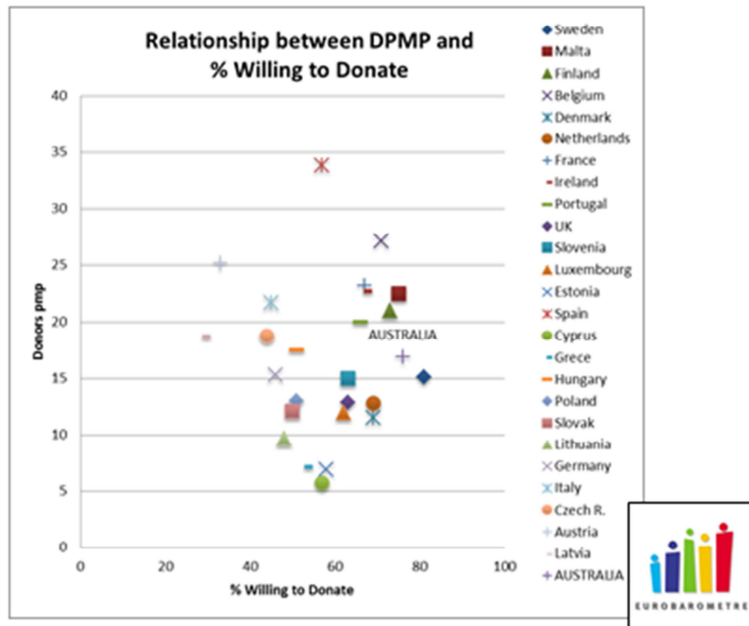
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“CLASSIC APPROACHES” TO IMPROVE ORGAN DONATION

- Changes of Legislation
- Publicity Campaigns
- Donor Registries
- Donor Cards / Driving Licenses
- Other ways of promotion...

NO SINGLE PROOF OF IMPROVEMENT OF REAL DONORS

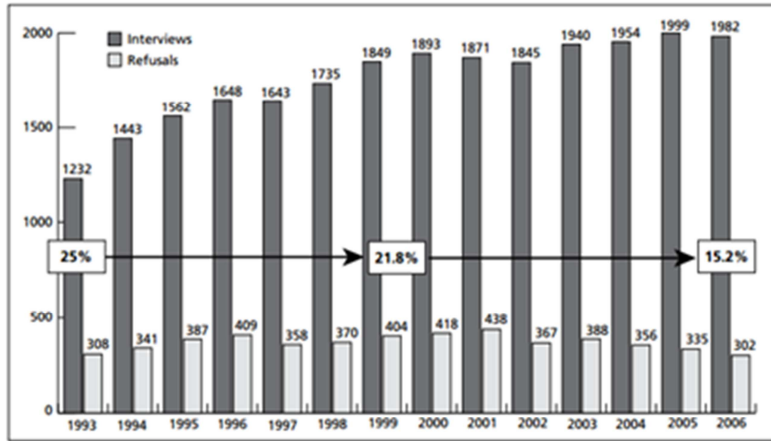
Rafael Matesanz Presentation. Sydney 2015





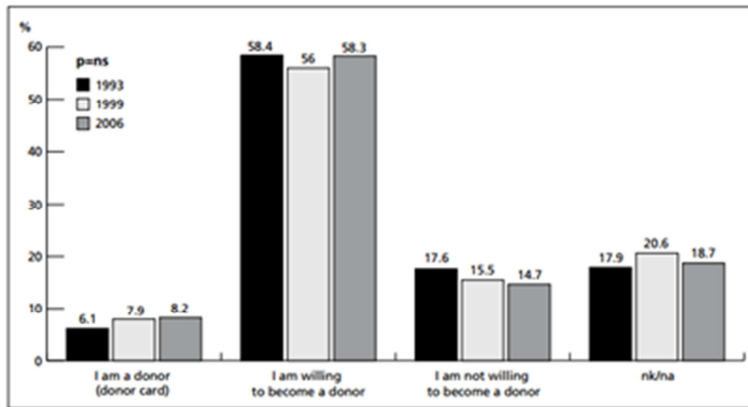
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% Family Refusal 1993 – 2006



DECREASE IN REFUSALS TO DONATE IN SPAIN DESPITE NO SUBSTANTIAL CHANGE IN THE POPULATION'S ATTITUDE TOWARDS DONATION. *ORGANS, TISSUES & CELLS*, (23), 27-24, 2010

Attitude towards donation of own organs in the 1993, 1999 and 2006 survey. Spain



DECREASE IN REFUSALS TO DONATE IN SPAIN DESPITE NO SUBSTANTIAL CHANGE IN THE POPULATION'S ATTITUDE TOWARDS DONATION. *ORGANS, TISSUES & CELLS*, (23), 27-24, 2010



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Madorell Family message



The Madorell family lost their son, Jordi, when he was 19 in a traffic accident

<https://www.youtube.com/watch?v=28va9gEGiuo>



Message from the donor family to health professionals

"I would like to encourage the doctors and nurses from Intensive Care Unit, after fighting to recover the life of a patient that is unfortunately not possible, please stop to think about the death and think about the possibility to save the life of others from that moment".

Reflexión que hace a los profesionales de la salud: "Me gustaría alentar a los médicos y enfermeras de las Unidades de Cuidados Intensivos, que cuando se ha luchado duro por la vida de un paciente, y ya no se puede hacer más, dejen de pensar en ello y piensen que pueden salvar vidas a partir de ese momento".



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EDHEP- European Donor Hospital Education Program

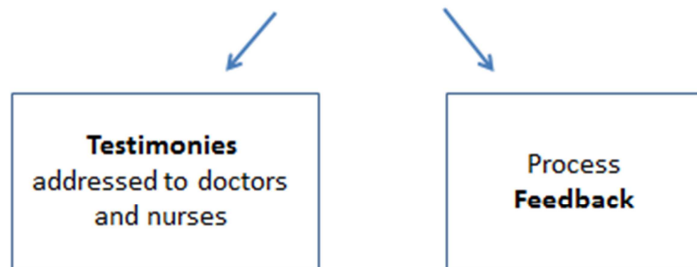
It was designed to meet the training needs of critical care staff in breaking bad news, caring for the bereaved, and requesting donation in Europe.

*Doctors and nurses often **feel uncomfortable approaching relatives about donation** and attribute this to a lack of training*

*Bereaved relatives express **dissatisfaction with inappropriate communication and support** when brain death is announced and thereafter when a request for donation is made*



Donor Families' experiences as a tool to educate healthcare professionals about breaking bad news and organ donation communication.





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FN also lost her son and describes the process:

"They told me the bad news standing next to my son. I couldn't keep standing, I felt I'll fall.. It was like a heart shot"

It is possible to conclude that FN and her husband denied organ donation...

F/N, también perdió a su hijo y recuerda el proceso: "Me lo dijeron de pie, donde tenían a mi hijo, no podía mantenerme en pie, me desplomaba, fue un impacto de bala directo al corazón". Se puede deducir fácilmente que F/N y su marido se negaron a donar.

Donor Families Studies Regional Hospital Carlos Haya from Málaga



- ✓ 86% of the donor families expressed organ donation as something positive within the painful death process.
- ✓ 100 % expressed their wishes to donate again if they are in the same situation

From families who denied organ donation,

- ✓ 30 % would change their decision regarding organ donation.
- ✓ They didn't understand brain death concept and they had dissatisfaction with the process.



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Donor families' testimonies for public awareness regarding organ donation

- News format not mass media campaign
- Focus on the hospital process to give the audience an insight into what actually happens

<http://www.abc.net.au/7.30/content/2015/s4377381.htm>

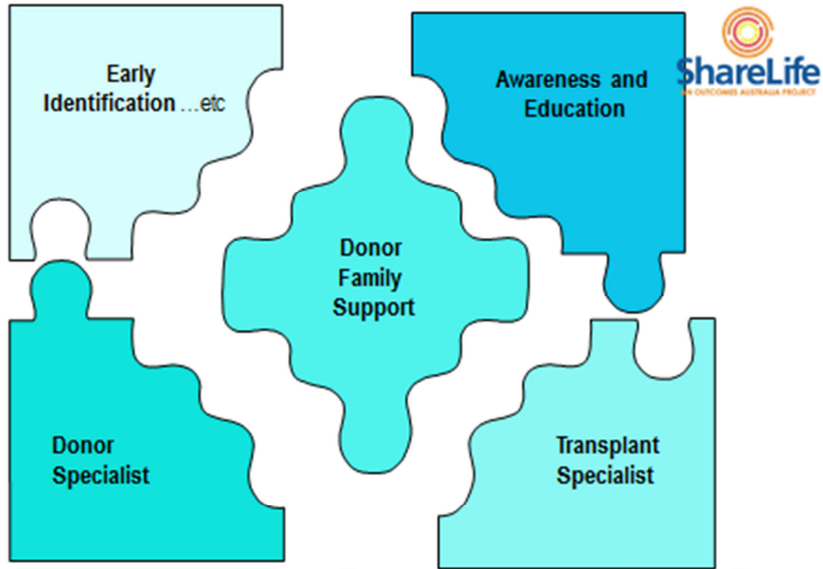


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Hospital certification on organ donation



Sydney Local Health District
Leading Practice
Implementation
2014 - 2017



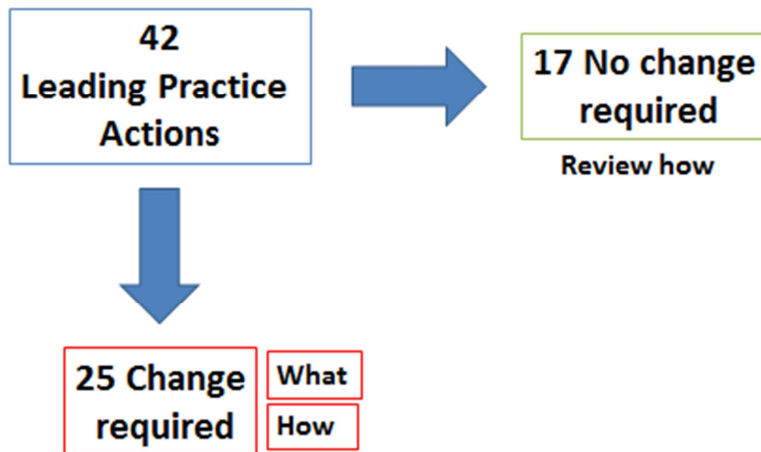


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Organ Donation for Transplantation Process	Leading Practice	Current Status at RPA	Actions required
System governance and infrastructure	The hospital has a dedicated Organ Donation for Transplantation Unit reporting to the Chief Executive	RPA has Organ donation staff who report to the clinical teams director and General Manager	Change the reporting structure of the Organ Donation for Transplantation Unit to the Chief Executive through Executive Clinical Director
	Staffing within the Organ Donation for Transplantation Unit includes dedicated medical and nursing staff	RPA has dedicated 2 organ donation nursing staff and 3 part time temporary medical officers due to the nature of the funding source. They are on the ICU roster for the other part of their positions. 6 designated respiratory.	Appointment of a permanent FTE Clinical Academic in Organ Donation for Transplantation, Appointment of Staff Specialist, 0.5 FTE Administration Officer - to include Data Collection, SOP developed for each position.
	Staff within the Organ and Transplantation team have ICU backgrounds	The medical organ donation specialists all have ICU backgrounds	No change required
	Members of the donor team are available 24/7	Currently members of the donor team are on call 24/7	Review of the clinical academic roster and staffing to ensure availability of members of the organ and transplantation team are available 24/7
	The hospital has specialised units in neurosurgery, neurology, cardiology	RPA is a quaternary and tertiary hospital with level 6 neurosurgery, neurology, cardiovascular services	No change required
	A Trans-cranial Doppler is available for blood flow tests as required	Available in hours OPD at RPA and OPD at CRGH	Protocols to be developed
	A tertiary pathology laboratory is available 24 hours a day, 365 days per year	RPA is a quaternary and tertiary hospital with level 6 pathology available 24 hours per day	No change required
	The hospital has a dedicated quiet family room to allow private conversation and grief responses	RPA has two dedicated consultation family rooms and a third room which contains lounge	Minor renovations in consultation with community to make the room more supportive and welcoming - tea & coffee facilities, TV, lounge

http://www.shd.nsw.gov.au/planning/pdf/OrganDonationPlan2014_2017.pdf

Donation and Transplantation Process	Leading Practice	Current Status at RPA	Actions required	Responsible	Time Frame	Cost	KPIs
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Hospital certification on organ donation

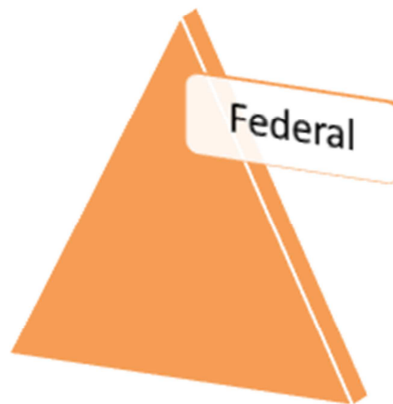
80% of the donors comes from 30 hospitals across Australia.

2014	Donors	Percent donors
Total (72 hospitals)	378	
• Top 30	301	80%
• Remaining 42	77	20%

30 hospitals be certified according leading practice



Accountability



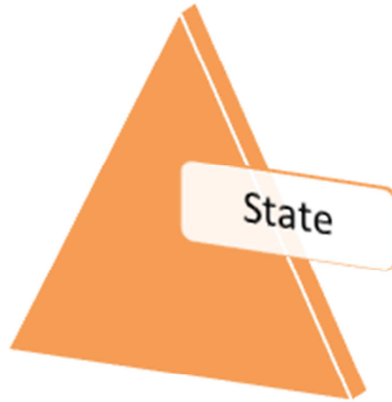
- Budget
- Certification standards
- Scorecard
- Annual Independent audit (Based on Relevant and defined KPIs)





National Strategic Planning Meeting: 22nd - 23rd October, 2016.

Accountability



Implement, lead and monitor hospitals certification



Accountability

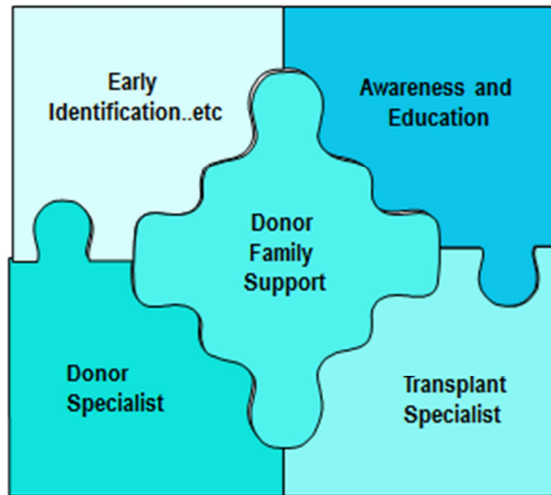


- Establish a functioning Organ Donation Unit
- Integrate with other relevant hospital units
- Maintain certification
- Achieve defined KPI's and outcomes

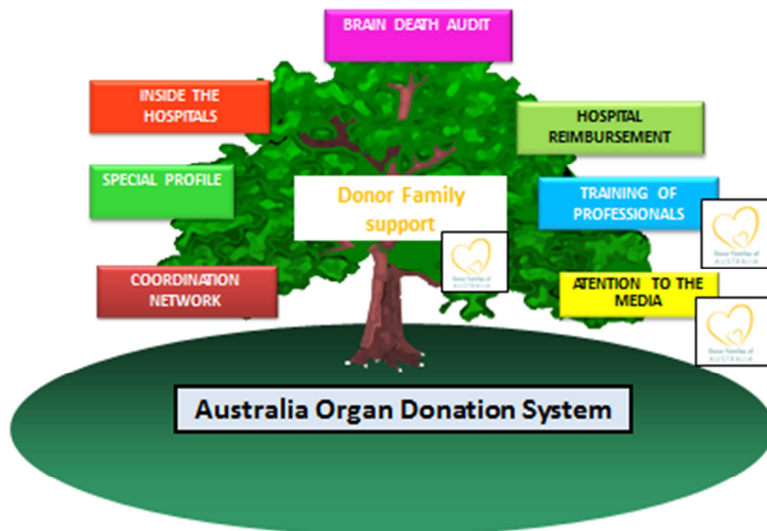




National Strategic Planning Meeting: 22nd - 23rd October, 2016.

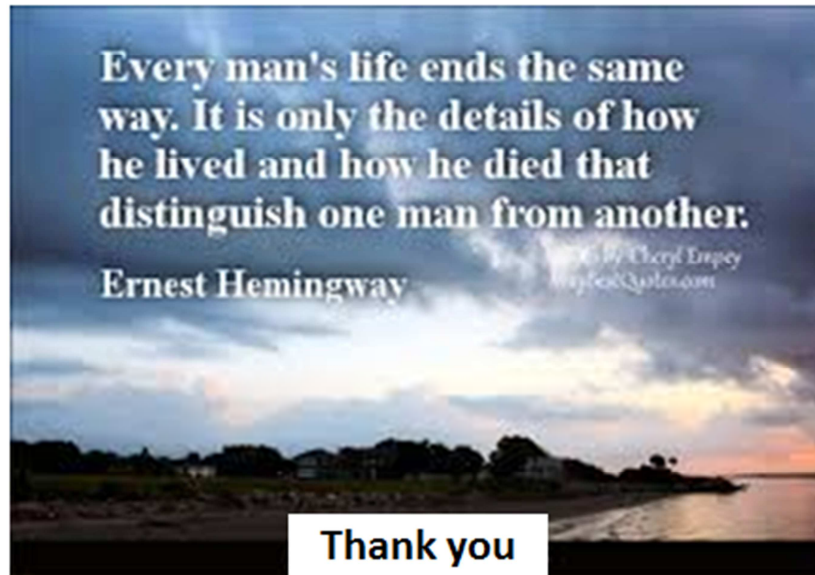


Australia Organ Donation System





National Strategic Planning Meeting: 22nd - 23rd October, 2016.



Deporte & Trasplante España

Trasplante + Deporte = VIDA



<p>alRe Asociació Catalana de Pacients amb Malaltia Respiratòria Avançada i Trasplantament Pulmonar</p>	<p>ALCER Barcelona Asociación para la Lucha Contra las Enfermedades del Riñón</p>	<p>AMFES Asociació mou-te i fes salut.</p>	<p>ANINATH Asociació de Nens i Nenes amb Trasplantament Hepàtic</p>
<p>ATH.cat Asociació de Trasplantats Hepàtics de Catalunya</p>	<p>ABEA Asociación Balear de Enfermos de Andrade</p>	<p>ADER Asociació de Malalts del Ronyó de Catalunya</p>	<p>ARLA Asociació de Malalts del Ronyó de Lleida-Aragó</p>
<p>AMARG Asociació de Malalts Renals de Girona</p>	<p>corsnous Asociació de Trasplantats Cardíacs i Pacients amb Insuficiència Cardíaca</p>	<p>Asociació Catalana de Fibrosi Quística Asociació Catalana de Fibrosi Quística</p>	