

REPORT OF COMMUNITY CONSULTATIVE FORUM

Contact between donor families and transplant recipients

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OVERVIEW

- Initial presentation was of the key points raised in the Issues Paper, which was made available prior to the forum.
- The survey results were presented by Donor Families Australia, Transplant Australia and LiverKids.
- Discussion of potential benefits – in the current Australian context.
- Discussion of potential risks – in current context (independently arranged and if option offered through DonateLife / Transplant units).
- In the current Australian context:
 1. What would TP candidates need to know about this before TP
 2. What would prospective deceased donors/donor families need to know about this issue
- In the current Australian context:
 1. What supports / advice might TP recipients and donor families need if decide to pursue contact or approached with request to meet
 2. How can donor families and TP recipients minimise risk of unwanted identity disclosure
- What do policy makers and governments need to know about this issue – when considering potential changes to current policy and practice
- Any additional key issues

ATTENDANCE

Donor families	9 Total present: 11
Recipients	10 Including 2 parents of children, and 2 partners – total: 12)
Organ and Tissue Authority Representatives	10 Mixture of medical staff (2), nurses / support co-ordinator (4), admin (4)
Independent / Department of Health policy advisors / professionals	4 Individuals
Attendance: 37 TOTAL	

All discussions involved keeping to the topic and allowing every person to contribute by passing microphone. The comments below are what was shared by everyone present.

1. Potential Benefits:

- To say “thank you”
- To see the impact donation has made on the recipient and their family
- Closure
- To find out more about the donor from the recipient – reveals mystery
- “Feel good” about the donation
- Positive impact in the community
- Humanise process
- Takes the intangible to tangible
- Story sharing – personalises the ‘donor’
- Healing
- Finding answers to new feelings felt by recipient
- Peace
- Boosts autonomy and respect
- See first hand the difference it has made and see health restored
- Satisfy wonder
- Show appreciation
- Provides motivation and feeling of worth from the recipient.

2. Potential Risks (current system):

- Compounds hurt
- How to manage (perceived) expectations
- Legal concerns – extortion, paying for treatment
- Conflict of belief structures/cultures
- Stalking
- Mystery revealed results in disappointment
- Misinformation (current system risks) – unsupported, assumptions
- “Too early” contact can be disappointing due to health set backs
- Uncertainty about the response from the other party
- The family unit needs to be considered
- Not everyone wants contact and may cause harm by contact
- Emotional damage – mental health concerns

3. Potential Risks (if facilitated by DonateLife / TP units):

- Time – working out an acceptable time frame: some recipients told of their prolonged and difficult recovery time and how the expectation to write or have contact in these

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early months may cause distress for both parties (donor families' expectation that health is restored earlier than it actually is; recipients feeling they may let their donor family down by not being better than 'should be').

- Rejection
- Some donor families may have multiple families that wish to be in contact – how will this impact on their mental health?
- Paediatric patients – how minors are managed/maintaining confidentiality for the children needs to be considered
- Policy making and resources – how would it be funded?
- Given overseas trends – minimal numbers likely to utilise service
- Drain on existing resources

Other issues raised at this time, included alternative ways to manage contact.

1. A supportive system similar to the adoption database – people who desire contact can leave their name. If two consenting parties wish to meet, this is facilitated in a mutual environment and has the ability to remain anonymous
2. Video contact/messages that could remain anonymous – if those who find writing letters too difficult and impersonal
3. Anonymous IT portal – filters could be in place to remove identifying features but where communication can be facilitated in 'real time'

EXPERIENCES SHARED

Those donor families, who had met some of their recipients, spoke of their experiences and how they were managed.

- One couple had been in contact with three recipients with three different relationships formed: one had phone contact only, one met each other once and has left it that if the recipient wishes to contact again he can and the last one catches up a couple of times a year and has a more open friendship/relationship. All three contacts have been well received by the donor family and each one has been a satisfying experience for them.
- Kelli McDonald spoke of her personal experience with finding one of her mum's recipients. It was via social media and how although there were some privacy issues they were able to work through them together and come to a respectful agreement. It was also a positive experience.
- Others spoke of cases where there were issues of 'stalking' to the point where a restraining order was required.
- Management of media was discussed in relation to printing stories from either recipients or donor families with regard to keeping information anonymous. DonateLife staff are unable to disclose information however if the general public speak to media they are not legislated to keep personal details private. One particular person felt strongly that media should be banned from publishing dates and names with particular concern for those

individuals who do not wish to know details about 'potential' matches. Members of LiverKids stated that only first names of children are only released to protect their own identity and that of their family as well. It was advised at this stage if people want to reduce the risk of unwanted disclosure that they refrain from discussing donor/recipient details on social media sites.

DOING THINGS DIFFERENTLY

What might transplant candidates generally need or want to know about this issue before receiving a transplant?

- A lung recipient strongly stated the impact transplantation has on your mental health and possible issues that may arise
- Other recipients spoke about the time differences in different units surrounding the transplant work-up education – for example a kidney recipient may be listed for years prior to their transplant. Conversely one recipient was an emergency transplant following a sporting injury and had no pre-transplant education.
- Another spoke of the current lack of support for correspondence and letter writing.
- Confidentiality in the current system and how to protect yourself if needed (ie: social media)

Rights of children and how to protect them

What might donor families need or want to know about this issue before donation?

- One donor family member was very passionate about sharing his feelings about at the time the shock and range of emotions that are present cannot really prepare you to 'consider' whether you would or would not like contact with your recipient in the future. At the time you are too focused on getting through the moment and dealing with the reality that is faced then and there. He went on to say that once the donation process is over, you are left with a very empty feeling and not cared for.
- It is currently not widely known about what contact is or is not allowed in the current DonateLife campaign
- Education about organ donation in schools important to improve the societal changes to how donation is perceived.
- Coordinator education was brought up as making more DonateLife co-ordinators aware of the feelings/emotions felt by donor families so can improve their approach.
- One of the medical staff highlighted the need for debriefing after a donation (with follow up of the families to how it could have been done differently) to improve the system in ICU.

What supports / advice might transplant recipients and donor families need if they decided to pursue direct contact or are approached with a request for contact by someone?

- Counselling
- Establish a time frame that is appropriate for both parties
- One lady suggested a 'buddy up' system where both recipients and donor families (not the specifically received and donated parties, but more as a support group scenario) are encouraged to support each other.
- Donor Families Australia highlighted the closed facebook site as offering this type of support to the community. Also discussed the support groups run by Donor Families Australia with informal get togethers that provides this type of support. Asked DonateLife / Organ and Tissue Authority to consider allowing Donor Families Australia access to information given and shared to donor families at time of donation.
- Who would provide the support? Government?

Minimising risk of unwanted disclosure in the current environment

- Not revealing year or time of year
- Social media – tighten privacy settings
- Not using surnames
- DonateLife do not reveal dates
- ? Legislate against media printing specific information

What do policy makers and government need to know?

- Fix the current communication system by ensuring there is acknowledgement of letters, that they have been forwarded to correct units, delivered and then communicate this information back to the author of the letter.
- Realise that there are positive benefits to meeting and that if both parties wish to meet then this should be supported.
- Establish better frameworks for support for families
- If the process is humanised there is better understanding and it 'makes it real'.
- Better or different options for communication
- Governmental policy changes:
 1. Accredited system
 2. Ethical considerations
 3. Legal risks
 4. Cost
 5. Balanced perspectives
 6. Choice
 7. Minority still need representation

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8. Proceed with caution, gradual process
9. Privacy protected for those who want to remain anonymous
10. Include stakeholders in decision making
11. De-identified information sharing

SUMMARY

The purpose of the day was to establish the perceptions from individuals about what lies behind the reasons for and against donor families and recipients meeting. We were reminded that discussions were not about *whether or not* contact between donor families and recipients should occur, but focused on the current system and if changes were to be made what considerations are needed.

There was a relatively equal number of donor family representatives, organ recipients and others, with positions within the organ and tissue sector.

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

There was a very strong message to the Organ and Tissue Authority that there are failings within the current system regarding communication. There would be an expectation that following this forum, recommendations to review the communication process between recipients and donor families will occur.

The report from this forum will help in ongoing discussions and the direction of organ and tissue donation and transplant recipient interactions.

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