

Anonymity in deceased donation: should donor families be permitted direct contact with transplant recipients?

Dr Dominique Martin, MBBS, PhD

Dominique.martin@deakin.edu.au

SATS & SATIBA Congress 2019
Sep 7, Krystal Beach Hotel



Deakin University CRICOS Provider Code: 00113B



The work presented here was originally funded by the Australian Organ and Tissue Authority, otherwise I have no conflicts of interest with regards to this presentation.

All opinions expressed in this presentation are my own and do not necessarily reflect those of any of the organizations with which I have been or am currently affiliated.

- What do we mean by anonymity in deceased donation?
- Emerging demand for facilitation of direct contact between donor families and transplant recipients
- Potential motivations, risks and benefits of direct contact – (independently *or* professionally facilitated)
- How should donation agencies approach the issue?

Issues paper: Direct contact between
deceased donor families and
transplant recipients

MARCH 2017

Anonymity in deceased donation



“Anonymity of the gift relationship is the prevailing legal, ethical and social norm in deceased donation programs worldwide; most countries do not permit the disclosure of identifying information which would enable the next of kin – “families” - of deceased donors to know the individuals who receive a transplant using their relative’s organs or tissues.”

(Martin and Then, manuscript in preparation)

Anonymity in deceased donation



Donation and transplantation involve medical procedures, and patients and families involved have legal rights to privacy and confidentiality.

The identities of both parties may not be disclosed by people working in the healthcare system – in some jurisdictions this is explicitly prohibited.

Families and recipients in Australia (and in many countries) may exchange written correspondence in which identifying details are removed.

Israel and the United States

- Direct contact (e.g. telephone, face-to-face meetings) facilitated by donation agencies, subject to consent of both parties to identity disclosure
- Despite facilitated option available, direct contact may be rare
 - 1% in the US (Post 2015)

Organ donor's family forms heart-to-heart friendship with transplant recipient

ABC Radio Perth By Emma Wynne

Posted 2 Aug 2016, 3:40pm



The emotional moment liver transplant recipient meets donor's mum

Digital Staff • Sunrise 🕒 Monday, 27 May 2019 2:12 am



PHOTO: Tatiana Neuser-Bostel and Scott Overstone. Tatiana received Scott's son's heart in 2007. (720 ABC Per



Emerging interest in the option of direct contact



- Donation promotion activities, and social media activities of donor families & recipients may increase
 - Risks of accidental identity/relationship disclosure
 - Opportunities for identification/"matching" of donor families or recipients
 - Desire for meetings between families and recipients
- Independently arranged meetings have occurred in Australia between families and recipients following accidental and intentional identifications
- Some community organizations have expressed the desire of some donor families and transplant recipients to have the option of meeting

Why might families and/or recipients want to meet?



Potential benefits and motivations

- families may be reassured about the donation decision
- recipients may be able to express their gratitude more effectively in person
- families and recipients may share and receive more information about the donor as a person
- both parties may achieve a sense of peace or closure
- publicity around reports of contact between families and recipients, may help to promote donation

Why might families and/or recipients prefer to avoid direct contact?



Potential risks

- disappointment with the other party
- exacerbation of grief on the part of the donor family or guilt on the part of the recipient
- potential for emotional or financial manipulation or exploitation
- difficulties managing a relationship when expectations are mismatched

Independently arranged contact



May occur through

- Private investigation or accidental exposure of identity through social media or news reports
- Use of social networking platforms to identify "matches" among those willing to disclose identity

Several positive media reports...

...but increased risks

- Families or recipients may not wish to have their identity discovered, or to meet
- Case reports of stalking, harassment, and attempted financial extortion
- Lack of informed consent, counselling and support in the event of a negative experience
- Errors in identification of "matches"

DIY/independent facilitation of direct contact in Australia



Step 1

To join the Register, you must first join as a Member.

To prevent duplication and reduce processing times, please ensure that you are not already a Donor Families Australia Member. If you aren't sure, please just contact us.

Step 2

Once your Donor Families Australia Membership is confirmed, complete the Donor-Recipient Contact Register Application (click on the **Donor Families** or **Recipient** Application button below).

Please ensure you have scanned documents of cards or letters (if received) before commencing with your application and do complete all box's with an asterisk.

You will be provided with the Contact Process and Conditions which you will need to read, acknowledge and accept before submitting your application.

Step 3

We will let you know when we find a match.



Donor Families Australia
Inc.

<https://www.donorfamiliesaustralia.org/contact-register>

Professionally facilitated contact



Always involves

- Informed consent to identity disclosure
- Sharing of contact details only when both family and recipient(s) choose to disclose identity and establish direct contact

May involve

- Mandatory or voluntary counselling
- Presence of a professional at the first face-to-face meeting
- Hosting of the first meeting at a hospital, transplant centre or donation agency office

Outcomes

- Mostly positive, but some reports of disappointment, difficulties arising from differences in sociocultural background of families and recipients, or increased grief or guilt

Key findings from an Australian stakeholder forum



- Empirical **research** in this field is **limited**; anecdotal experiences appear influential on public and professional understanding of the issues.
- Significant **diversity** in Australian stakeholder opinions & motivations
- If professionally facilitated contact option provided, independent contact may **persist**
- **Protection** of privacy and confidentiality of donor families and recipients requires **education** and support

- When considering whether to permit or provide the option of professionally facilitated contact, authorities should
 - learn from international experience
 - engage closely with a wide range of stakeholders to ensure that any changes are respectful of the diversity of community values and preferences.
- Every donor family and transplant recipient is unique: there is no 'one size fits all' approach to the issue of identity disclosure, communication and contact between families and recipients.

Thank you!

Dominique.martin@deakin.edu.au



References



- Martin DE and Then SN. (in preparation). Anonymity in the gift relationship.
- Post MA. (2015). What matters and what doesn't: Organ, eye and tissue donor families, grief support and recipient communication. *Grief Matters: The Australian Journal of Grief and Bereavement*, 18(1), 18.