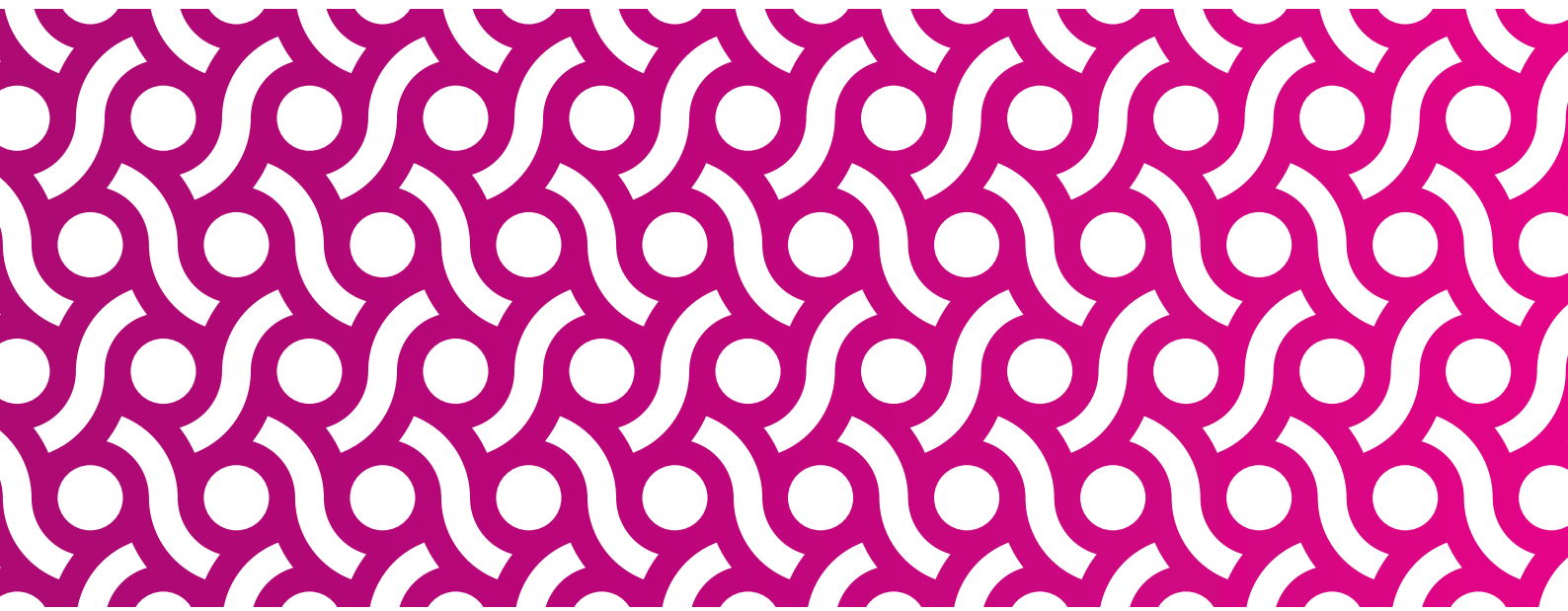


National Study of Family Experiences of Organ and Tissue Donation

Wave 5

Experiences in 2018 and 2019 – Research Report



Prepared by **Proof Research Pty Ltd** for the **Organ and Tissue Authority**

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Organ and Tissue Authority
PO Box 802, Canberra ACT 2601
T 02 5156 6662
E enquiries@donatelife.gov.au

Proof Research Pty Ltd
PO Box 6987
Upper Mount Gravatt QLD 4122
T 07 3392 4446

Executive summary

The Organ and Tissue Authority gathers feedback on the experiences of donor families in the National Study of Family Experiences of Organ and Tissue Donation (Donor Family Study). This report details the findings of Wave 5 of the study and represents the views and experiences of families who made a decision about donation in 2018 and 2019. The research includes families who consented to and those who declined donation. The research seeks to understand families' experiences before, during and after the decision about donation, to understand and monitor how the needs of families can best be met.

This wave's findings demonstrate that almost all families (96%) felt comfortable with the decision they made about donation.

Amongst the family members who consented to donation in 2018 and 2019, 491 family members opted to participate in the Wave 5 study, resulting in a 20.7% response rate. Families who declined donation were also approached, with 34 family members choosing to participate. This equates to a 7.2% response rate.

Of the 525 family members who participated in Wave 5 of the Donor Family Study, 197 volunteered to take part in an in-depth interview. This included 187 family members who consented to donation and 10 family members who declined donation. From this group, 31 family members were randomly selected to take part in an in-depth interview, including 25 who had consented to donation and six who had declined donation.

We wish to acknowledge and thank all family members who gave their time so generously to talk about their experiences. Feedback from families is integral to the study, providing insight and evidence that leads to improvements in the way donor families are cared for and supported.

Impact of prior knowledge

Findings from the Donor Family Study continue to highlight the importance of prior knowledge of a family member's donation wishes when it comes time to making a decision about donation in hospital.

Families who know what their family member wanted find it easier to make a decision about donation (88% of family members who discussed and knew their family member's wishes found the decision easier). When decisions align with a family member's wishes, families feel comfortable with their decision.

Conversely, the study shows that when the wishes of a family member are unknown, the decision about donation tends to be a more difficult one, with 16% of those who had not had a conversation with their family member being more uncertain of their decision. When wishes are unknown, family members can struggle to come to a unified decision, and this can result in conflict, discomfort, and sometimes regret over their decision.

Prior knowledge of a family member's donation wishes is important for families when making a decision about donation.

Motivations and barriers to donation

Consistent with previous waves, most donor families (78%) saw organ and tissue donation as a chance for something positive to come out of a personal tragedy. Seven in 10 (72%) family members were motivated to say yes to donation as they felt their loved one would have wanted to help others.

When looking at barriers to donation, the main reason most families declined donation was because they knew or felt that their family member would not want to donate (30%). The next highest reported reason for declining donation, at 27%, was the belief that their family member had been through enough. This is consistent with Wave 4 findings.

Interaction with hospital staff

The experience of those who are asked to consider donation usually begins in the Intensive Care Unit or Emergency Department of hospitals across Australia. The majority of families, irrespective of their decision about donation, felt hospital staff treated them with consideration and sensitivity (91% of families who consented to donation felt this occurred to a great extent, and 82% of families who declined donation felt this occurred to a great extent).

Families who made a decision about donation in 2018 and 2019 mostly experienced great kindness, compassion, empathy and sensitivity from hospital staff. Families were also especially appreciative of the respect shown to their family member by hospital staff. Families who stated they were treated with consideration only to some extent were more likely to have experienced inconsistencies in the level of care shown to them by hospital staff.

The majority of families approached about donation felt that hospital staff made it clear that their family member's condition was critical and that they would not survive (97% of families who consented and 94% of those who declined donation). These findings have been consistent since Wave 1.

Helping families to understand that their family member will not recover requires clear, concise and consistent communication and information from hospital staff, delivered with authenticity, compassion and empathy.

Brain death testing

During 2018 and 2019, 25% of family members surveyed, who experienced the neurological determination of death pathway, were asked if they would like to be present during the brain death testing of their family member. This is a significant decrease since Wave 4, where 36% of family members were given this opportunity.

Of the families who chose to be present, the majority (86%) of consenting families and all declining families, said that it helped them to understand that their family member had died. Some families will need the clarity that comes from brain death testing before they can take in new information about donation.

Witnessing brain death testing often helps families to understand that their family member has died. All family members should be given the opportunity to witness the brain death testing of their family member, as it can help to provide clarity of their family member's death. Family members who choose to attend should be supported by hospital staff during the testing.

The donation conversation

Consistent with previous waves, health professionals continue to be the primary initiator of the donation conversation. This occurred with 60% of families who consented to donation and 71% of families who declined donation. Families who raised donation themselves represent 27% of families who consented to donation and 9% of families who declined.

In 2018 and 2019, 46% of consenting family members were asked about donation by a health professional before (10%) or at the same time (36%) as being told of their family member's neurological death or expected death. Amongst families who declined donation, 80% were asked to consider donation at the same time or before being told of their family member's prognosis.

Wave 5 findings indicate that families are much more receptive to the donation conversation after they have had time to accept that their family member is not going to survive. Approximately three quarters (76%) of family members who consented to donation, and 65% of families who declined donation, felt that the timing of the approach by health professionals was appropriate. While timing is one factor; the way donation is approached must also be considered.

The donation conversation should only be raised by health professionals after neurological death or expected death has been confirmed with, and understood by, the family, and the family provided with time to digest the news.

The way families are approached about organ donation can influence not only their decision, but their view of donation. The overwhelming majority of family members in Wave 5 who consented to donation felt that discussions about donation were handled sensitively and with compassion (92% of family members strongly agreed). This is significantly less so amongst families who declined donation (56% strongly agreed that the conversation was handled sensitively).

With regards to making an informed decision about donation, 98% of family members who consented to donation agreed (88% strongly agreed) that they were given sufficient information to allow them to make an informed decision. Families who declined donation were significantly less likely to feel that they were given enough information to allow them to make an informed decision about donation (64% strongly agreed that they were).

Almost all family members (98%) who consented to donation in 2018 and 2019 agreed that their family was provided with enough opportunities to ask questions about donation (89% strongly agreed). Families who declined donation were significantly less likely to feel this way (60% strongly agreed).

Most families (97%) who consented to donation felt they were given enough time to discuss donation and to make their decision (88% strongly agreed). Families who declined donation were much less likely to feel they were given sufficient decision-making time (50% strongly agreed).

When asked how the way in which donation was discussed with them at the hospital could have been improved, 61% of family members felt that no improvements were necessary as the discussions were handled well and staff were compassionate and supportive. However, there is still scope for improvement, as 18% of families suggested better communication to keep families informed of the process and timelines. Families who declined donation suggested improvements in the timing, approach, and the tone of the donation conversation, as well as who is present in the room.

Families need clear and consistent communication, compassion, time, and privacy.

They should be provided with sufficient information to enable them to make an informed decision and hospital staff should ensure that families know that they can ask questions at any time. Key pieces of information required at this stage are around the donation process and timelines.

Donation process

Nine in ten (92%) donor families participating in Wave 5, recalled meeting or having a discussion with a DonateLife staff member. After this meeting 83% of donor family members felt well informed, whilst 15% still had unanswered questions, and 3% left the discussion with no clear understanding of the donation process. Significantly fewer families (48%) who went on to decline donation recalled meeting with a DonateLife staff member. Of the 15 families who did meet with a DonateLife staff member and subsequently declined donation, 80% felt they were well informed after this meeting.

In 2018 and 2019, 52% of consenting donor family members recalled being provided with written information explaining organ and tissue donation whilst in hospital. Of families who declined donation, just 6% recalled receiving written information.

Information delivered verbally should be tailored to the needs of individual family members – succinct and delivered in layman’s terms for ease of processing, or more detailed when requested. Donation Specialist have specific skills and training and it is important for a Donation Specialist to be involved in the conversation and process to aid in supporting and informing families when they are making a decision about donation. Written information, given to families whilst in hospital, is supplementary detail that may provide support and assist families to consolidate their understanding of donation.

Three quarters (76%) of donor family members in Wave 5 were offered the support of a social worker or chaplain at some time during their family member’s stay in hospital. Of families who declined donation, 70% report they were offered this type of support. Families noted that the support received helped them during this time.

In terms of the information provided to families about donation surgery, 85% of donor family members felt they were given the information they wanted and 88% felt that the amount of information they received was just right.

The research found that the following can reduce the distress of family members between the time of consenting to donation and donation surgery:

- **Being kept informed about timeframes**
- **Allowing private time with their family member**
- **Health professionals continuing to care for their family member with respect**
- **Being shielded from witnessing procedures that directly relate to donation surgery**

Donation surgery

Almost all families (96%) who consented to donation during 2018 and 2019 felt they were given enough time with their family member prior to donation surgery. The majority of donor families had positive experiences with ICU staff; 93% of donor family members felt that their family member was treated with respect by ICU staff in the lead up to the donation surgery.

A recurring theme present in the Donor Family Study is the support provided when a family member’s loved one is taken for donation surgery. This is a difficult time for families because of the finality of the situation and families often feel lost and alone at this point. There is an opportunity to strengthen the provision of support for family members at the time when their family member is leaving for donation surgery.

It is often helpful to prepare families and talk through options on how they might like to spend this time. Families may also benefit from having a social worker or suitable person available to support family members when their loved one leaves for the donation surgery.

Follow-up service and DonateLife resources

During 2018 and 2019, 95% of family members who consented to donation state they were offered support from either a hospital and/or DonateLife staff member. Of those families who were offered support from DonateLife, 90% accepted it. The support from a DonateLife staff member was reported to be helpful by the majority (97%) of family members. Of the families surveyed, 21% who declined donation said that a follow-up phone call from a DonateLife staff member would have been helpful.

Families can initially under-estimate the value of follow-up contact and resources from DonateLife. However, over time the support offered by DonateLife can provide families with reassurance and comfort. Some family members surveyed (18%) advised that ongoing contact with DonateLife helps them because it makes them feel less alone, and that they are valued and not forgotten.

In terms of DonateLife resources, donor families found the initial phone call informing them of the outcome of the donation to be helpful (99% of family members who received it). The content of the DonateLife letter and some basic information about the transplant recipients are also considered helpful by 99% and 100% respectively of donor families who received these.

Most donor family members (85%) felt the contact they have had with DonateLife has been at the right level. Conversely, 13% of donor family members felt they have not had enough contact with DonateLife since their family member died, a significant decrease since Wave 4 (20%).

Contact from DonateLife provides families with support. Family members need to feel that their loved one is not forgotten and that their donation is appreciated. One of the greatest comforts for family members was to know the progress of recipients.

Correspondence with recipients

More than half (56%) of donor families who participated in Wave 5 have received a letter from at least one transplant recipient, via DonateLife. All those who received correspondence from recipients were comforted by this (77% found the correspondence to be of great comfort; 22% of some comfort). For most donor families, hearing from recipients not only reaffirmed their decision to donate, but made them feel that their family member's death wasn't in vain. This correspondence from recipients often also filled donor families with pride for their family member, and most importantly, helped them to heal.

In Wave 5, 30% of donor families who had opted-in to receive correspondence from recipients, had not received any. These families reported feelings of disappointment and sadness by the lack of contact.

DonateLife will continue to work with transplant teams to convey the significance for many donor families of receiving correspondence from the recipient.

On reflection

For 96% of families who consented to donation, the decision about donation made in 2018 and 2019 still sits well with them today, 86% very much so. When reflecting, families not comfortable with their decision cite not knowing their family member's donation wishes and difficulty coming to terms with their death as the two predominant reasons.

One quarter (24%) of families who declined donation are not very comfortable with their decision about donation today; 6% are very uncomfortable with their decision. Some of these family members wanted to donate but there were other members of the family who didn't, and in the absence of knowledge of what their family member would have wanted, the family opted to decline. On reflection, some feel that they may have made a different decision if they had more time.

The majority of donor family members (96%) found comfort from their family member being able to donate. For these family members, donation provided comfort through knowing that their loved one has helped somebody (90%) and that they have honoured their loved one's wishes (53%).

Consistent with previous waves, 88% of family members surveyed who consented to donation would donate their own organs and/or tissues after death. Among families who declined donation in 2018 and 2019, 83% would make the same decision again, while 7% would make a different decision about donation, and 10% are undecided.

We are heartened to note the vast majority of families reported being treated with compassion and respect during their experience. It is important to recognise families who consented to donation reported finding something positive out of this very difficult time.

We thank all families who gave their time to contribute to this report by providing feedback. The sharing of your experiences will help guide further improvements in the way donor families are cared for and supported throughout the donation process in Australia.