



Australian Government
Organ and Tissue Authority



The National DonateLife Family Support Service

July 2020

The National DonateLife Family Support Service

The National DonateLife Family Support Service (NDFSS) refers to the support services and resources offered by DonateLife to families in Australia. Established in 2010, the NDFSS encompasses the support of doctors, nurses, social workers and bereavement support staff across DonateLife Agencies and hospitals in all Australian states and territories.

The support services offered through the NDFSS begin in the hospital setting, generally in the Intensive Care Unit (ICU) or the Emergency Department (ED), to support all families of potential organ and tissue donors with their practical, physical and emotional needs during end-of-life care, their decision-making about donation and through the donation process should it proceed.

The NDFSS offers support services and resources to those families who consented to organ and tissue donation as well as to the families of intended donors where donation did not go ahead, including where organ donation was not possible but tissue donation occurred. The NDFSS also includes follow up information regarding eye and tissue donation where donation occurred outside of the ICU or ED or outside of the hospital setting.

Principles and values

Delivered by a team of DonateLife staff, the NDFSS works to maintain a high standard of empathy and care in the provision of grief and bereavement support for families of actual and intended organ and tissue donors.

In providing the NDFSS, DonateLife uphold the following values:

- Deliver a person-centred service**

We offer specialised support that recognises uniqueness and individuality, and respects the choices, dignity and the rights of family members, including respecting an individual's decision to opt-out from contact with DonateLife support services at any time.

- Dedicated and professional continuity of care**

We have an established network of trained professionals who are focused on providing the best possible support to families throughout their donation experience and afterwards, including connecting families to appropriate professional support services in the community.

- Compassionate and thoughtful**

We recognise that the needs of families are unique and that support must be considerate and understanding with a focus on family well-being.

- Meaningful support**

We provide information and communicate with families in a way that is clear and easy to understand.

Family support

A team of DonateLife staff is required to provide the necessary care and support for donor families. It is important that the provision of family support remains flexible to meet the needs of the family, and the circumstances of the donation. Similarly, it is important that families can opt-out of receiving further contact from DonateLife at any time.

The NDFSS identifies a number of contact points for staff to offer support and information to donor families, as well as making provision for assessment of the need for families to access further support services, if necessary.

National DonateLife Family Support Service



1
Information and support provided in the ICU or ED



2
Donation outcomes phone call



3
Introduction letter and resource pack



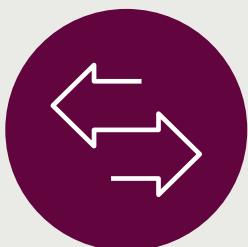
4
Follow up phone call



5
Further contact and support (as discussed and agreed with the family)



6
Invitation to the DonateLife Service of Remembrance (annually or on request)



Families are able to make contact or opt-out of contact with DonateLife at anytime.

Support provided in the hospital

Regardless of whether the donation proceeds, the NDFSS offers family support services to all families of potential donors to assist them with their immediate practical, physical and emotional needs during the time of end-of-life care. DonateLife staff can also provide families with information and answers to questions they may have about death, donation or other related matters.

DonateLife staff can refer families to existing hospital services such as social workers, or offer assistance to families who wish to speak with religious or cultural practitioners.

Outcomes of the donation

DonateLife staff contact the donor family after the donation surgery to provide information on the outcomes of donation. This may include the number of recipients and what organs and/or tissues were donated. This usually occurs 24-36 hours after donation. Families report that this initial phone call can provide some reassurance and solace¹.

DonateLife staff provide the same support service to the families of intended donors (i.e. those families who have consented to donation and the donation and subsequent transplantation did not proceed for medical and/or related reasons). In these circumstances, the DonateLife staff ascertain if the family requires any support and identifies whether the family wishes to receive further contact from DonateLife.

Correspondence and support resources

Approximately two to four weeks after donation occurs, DonateLife support staff provide the donor family with further written information on the donation surgery and the transplant outcomes, as well as outlining the support services offered through the NDFSS. Accompanying this letter is the NDFSS resource pack, which provides the donor family with additional information on organ and tissue donation, bereavement, and the range of professional support services available to them. Families of intended donors are also provided with the NDFSS resource pack.

Follow up contact and support

DonateLife staff telephone the family to confirm receipt of the letter and/or support resources. During this phone call, DonateLife staff can provide support and advice to families including making recommendations for professional counselling and grief support services. For families who do not live in the area where their loved one died, or are located in regional or remote areas, DonateLife will discuss bereavement support with the family, including the availability of local services.

As transplant recipients may still be recovering from their surgery at this time, the potential to provide an update on transplant outcomes to donor families may be limited. If the donor family requests to know more about the health progress of recipients, DonateLife staff can arrange a follow-up discussion.

DonateLife staff may continue to contact the donor family, including families of intended donors, to offer and provide additional support as indicated by the families. The family may like to have ongoing contact with DonateLife, in which case DonateLife will make the necessary arrangements to facilitate this.

Families can opt-out of receiving further contact from DonateLife staff, at any time.

Invitation to the DonateLife Service of Remembrance

DonateLife staff invite donor families and families of intended donors to attend the annual DonateLife Service of Remembrance in their area. The Service of Remembrance provides a forum for acknowledgement of and gratitude to donors and their families. It is also an opportunity for all those touched by organ and tissue donation to meet with others whose lives have been changed by this experience.

Attending the Service of Remembrance is a personal choice and families can request that DonateLife staff do not send them an invitation if that is their preference.

Recipient updates

Some donor families may wish to receive ongoing updates regarding the health progress of recipients. Donor families can contact DonateLife at any time to seek updates on recipient progress. DonateLife staff will liaise with transplant coordinators to obtain and provide anonymous information on the general health status of transplant recipients to donor families.

¹ Proof Research Pty Ltd, *National Study of Family Experiences of Organ and Tissue Donation: Wave 3, 2014 and 2015 research report*, Organ and Tissue Authority, Canberra, 2019, p. 76.

Support resources

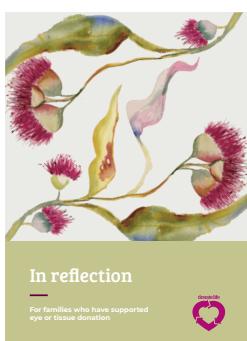
There are many resources available to support donor families. These resources are provided to families through the NDFSS and are also available on the DonateLife website or by contacting the DonateLife Agency in each state and territory.



The **Understanding Death and Donation** booklet contains information on brain death and circulatory death as well as organ and tissue donation. DonateLife staff provide this booklet to families in the hospital to support informed decision-making about donation. It is available in 11 languages from the DonateLife website.



The **In-Reflection** booklet support families who have participated in organ and tissue donation. DonateLife staff provide this booklet to donor families as part of the NDFSS resource pack. It includes information about grief, support services and the donation process. This booklet is available in 11 languages from the DonateLife website.



The **In-Reflection** booklet for families who have supported eye or tissue donation is for families who consented to eye and tissue donation. DonateLife provides this booklet to eye and tissue banks to use in their aftercare programs. It includes information about grief, support services and the donation process. This booklet is available in 11 languages from the DonateLife website.



The **Counselling Support Services** brochure provides contact details and information for professional support services in all Australian states and territories. DonateLife staff provide this booklet to donor families as part of the NDFSS resource pack.

Contacts

Families are able to contact DonateLife staff at any time. DonateLife also welcomes feedback from donor families and the community to improve the service and support offered to families in the future.

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Families who have made a decision about donation are invited to provide feedback on their experience in the National Donor Family Study which is conducted by the Organ and Tissue Authority (OTA) every two years. Findings from the National Donor Family Study provide valuable evidence for the ongoing review and enhancement of the care and support provided to families before, during and after donation. The final reports for the study are publically available on the DonateLife website (www.donatelife.gov.au/resources/donor-families/national-donor-family-study).