



Guidance Document

Providing Service to Tissue Donor Families

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*American Association of Tissue Banks
8200 Greensboro Drive
Suite 320
McLean, Virginia 22102
(703) 827-9582 (703) 356-2198 Facsimile*

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American Association of Tissue Banks
8200 Greensboro Drive
Suite 320
McLean, Virginia 22102
www.aatb.org

For questions on the content of the document, please contact the AATB at:

(703) 827-9582 or (703) 356-2198 (Fax)

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Maggie Coolican (co-editor)
Robin Cowherd (co-editor)

Pam Albert
Mary Beth Aubry
Christine Belitz
Scott A. Brubaker (AATB liaison)
Jeff Cox
Sara Craig
Julie Crumbacker
Mary Beth Fisk
Catherine Hackett
Mary Ellen McGlynn
Victoria McNeel
Amy Moeder
Cynthia Reed
Rita Reik
Paula Symons
Candy Wells

Version 2 update:

Maggie Coolican (co-editor) – (retired)
Robin Cowherd (co-editor) – LifeNet Health

Pam Albert – New England Organ Bank
Michelle Andrews – Tissue Center of Central Texas
Mary Beth Aubry – Community Tissue Services
Maureen Balderston – Washington Regional Transplant Community & AOPO rep
Scott A. Brubaker – AATB liaison & document coordinator
Bethany Conkel – Purposeful Gift
Veronica Fernandez – New York Organ Donor Network
Myrna Garcia – Donor Alliance
Sarah Gray – AATB liaison
Catherine Hackett – Regional Tissue Bank (Halifax, NS, Canada)
Eleanor Haley – Living Legacy Foundation of Maryland
Mary Ellen McGlynn - New Jersey Sharing Network
Cynthia Reed – Iowa Lions Eye Bank
Candy Wells – LifeCenter Northwest

TABLE OF CONTENTS

I.	Introduction	5
	A. History and Purpose	5
	B. Definitions	6
II.	Bereavement Support Services	8
	A. Philosophy	8
	B. Family Needs	8
	C. Components of a Support Services Program	10
	D. Gifted Tissue for Research	12
	E. Evaluation of Services	12
	F. Resources for Donor Families	12
III.	Appendix I - Importance of Language when Supporting Families	12
IV.	Appendix II - Experience of Care Survey	14
V.	References	15

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PROVIDING SERVICE TO TISSUE DONOR FAMILIES

I. INTRODUCTION

A. History and Purpose

Each year approximately 30,000 individuals become tissue donors in the United States. Their family members follow previously known wishes of the donor or are asked to make a decision or authorization about tissue donation on behalf of the donor. Through these generous donation decisions, about two million tissue grafts are distributed annually and more than one million tissue transplants may occur every year.

There are many more tissue donors than organ donors. However, the standard of practice of providing services for *Tissue Donor Families* may be inconsistent, and for this reason, some families may not receive support services³. In recommendations provided by a subcommittee of the Association of Organ Procurement Organizations (AOPO), tissue donor families are entitled to the same level of follow-up care as are organ donor families².

The AATB's *Standards for Tissue Banking* at Standard D2.600 Services To Donor Families, and AATB's *Standards for Non-Transplant Anatomical Donation* at Standard NT-D2.600 describe *Services to Donor Families* or a referral to a support system must be offered to the *Authorizing Person*. The requirements additionally expect subsequent communications and periodic evaluation of services to be documented, maintained, and readily available, and a reference to AATB Guidance Document No. 4 is made. To meet the intent of these standards *Tissue Banks* and *Non-transplant Anatomical Donation Organizations* must consider this guidance document when providing *Services to Donor Families*.

The Bill of Rights for Donor Families³ also provides guidance for services that are, or should be, offered to Donor Families. By listing primary considerations in regard to specific aspects of bereavement, this document provides additional and more specific recommendations as guidance in providing a best practices standard of care for all families who authorize tissue donation.

This guidance document was originally issued in March 2007 and underwent extensive editing over a year-long period to create version 2. New sections include "evaluation of services," "gifted tissue for research," and "terms to avoid." Updates were made to expand sections such as "definitions," "family needs," and "components of a support services program."

¹AOPO Donor Family Services Council, Donor Family Follow-Up Survey, September 2003

²AOPO Donor Family Services Council, Tissue Subcommittee Position Statement on Level of Care for Tissue Donor Families, December 2005 (found at the Donor Family Council library, see Shared Files, of the AOPO portal)

³*Bill of Rights for Donor Families*, National Donor Family Council, National Kidney Foundation, 1994, 2004

B. Definitions

As used in this Guidance Document and/or in AATB *Standards*, the following definitions apply where indicated for deceased donation [Words that are defined in Standard A2.000 Definitions of Terms appear in italics and are capitalized (e.g., *Signed*)].

Authorizing Person: Upon the death of the *Donor*, the person, other than the *Donor*, authorized by law to make an anatomical gift.

Bill of Rights for Donor Families:

A document developed by the National Donor Family Council of the National Kidney Foundation, that provides guidance for the rights and legitimate expectations of families whose loved ones die and are considered or become potential organ and/or tissue donors.

Document of Authorization:

Legal record of the gift of tissue, permitting and defining the scope of the postmortem recovery and use of tissues for transplantation, therapy, research and/or education *Signed* or otherwise recorded by the Authorizing Person, pursuant to law.

Document of Gift: The *Donor's* legal record of the gift of tissue permitting and defining the scope of the postmortem recovery and use of tissues for transplantation, therapy, research and/or education. It must be *Signed* or otherwise recorded by the *Donor* or person authorized under law to make a gift during the *Donor's* lifetime.

Document of Gift/Authorization:

Term used when the standard refers to both a *Document of Gift* and a *Document of Authorization* as defined above.

Donation Coordinator:

A *Responsible Person* who seeks *Authorization* from an *Authorizing Person*, or who makes *Notification* concerning donation, recovery and use of the gift, or in the case of a *Living Donor* or *Client Depositor*, the *Responsible Person* who seeks *Informed Consent*. For *Authorization* purposes, this person may also be referred to as a “designated requestor.”

Donor Risk Assessment Interview (DRAI)⁴:

A documented dialogue in person or by telephone with an individual or individuals who would be knowledgeable of the donor's relevant medical history and social behavior. For example this may be: the donor, if living;

⁴ For use when communicating with a *Tissue Donor Family*, it's advised that other terms are used, such as Medical History Interview, Medical/Social History, Donor Family Questionnaire, etc., in place of “Donor Risk Assessment Interview.”

the next of kin; the nearest available relative; a member of the donor's household; other individual with an affinity relationship (e.g., caretaker, friend, significant life partner); and/or the primary treating physician. Alternatively, a living donor may complete a written questionnaire. The relevant social history is elicited by questions regarding certain activities or behaviors that are considered to place such an individual at increased risk for a relevant communicable disease agent or disease (RCDAD).

Experience of Care Survey:

A series of questions formulated to gather *Donor Families'* thoughts about services provided. Questions should confirm whether services have met their needs. Surveys may be conducted face to face, over the phone, via email or Internet, or on handwritten forms. Answers provided can be assessed to determine if modifications to services are needed. This survey can be titled to meet local needs.

Limited English Proficiency (LEP):

When used in respect to an individual, a person who does not speak English as their primary language and who has limited ability to read, speak, write, or understand English.

Recipient: A person into whom tissue is transplanted.

Services to Donor Families:

A defined policy or support program describing tissue donation follow-up offered to the *Authorizing Person* (or party). This may include written communications regarding: potential uses of tissue; recovery outcome information; bereavement information and support; provision of a copy of the *Document of Gift/Authorization*; and/or guidance describing how to contact the tissue bank if any questions arise regarding the donation. Frequency of follow-up and program maintenance is at the discretion of the tissue bank, however, periodic evaluation of services is required.

Tissue Bank: An entity that provides or engages in one or more services involving tissue from living or deceased individuals for transplantation purposes. These services include assessing donor suitability, recovery, (processing)⁵, storage, labeling, and distribution of tissue.

Tissue Donor Family (aka Donor Family, Donor Families):

Family members/persons who follow the tissue donation wishes of, or who provide the authorization decision for, a decedent.

⁵ For use when communicating with a *Tissue Donor Family*, it's advised that "preparation" or "making tissue ready for transplant" be substituted in place of "processing."

II. BEREAVEMENT SUPPORT SERVICES

A. Philosophy

Support *Services to Donor Families* may be characterized by:

- An appreciation that potential *Donor Family* members are the experts about their own bereavement.
- An understanding that bereavement services begin with the first contact the family has with a health care professional.
- A consideration that *Tissue Donor Families* should be expert resources in the planning, development, and review of a program developed to support them.
- Interaction between tissue bank staff members with specific skills and training and the *Donor Family* to effectively meet bereavement and donation needs.
- An understanding that organizations that recover and prepare tissue have a responsibility to address *Donor Family* questions and/or concerns regarding tissue donation in a timely, effective, and compassionate manner.

B. Family Needs

A comprehensive *Tissue Donor Family* support program provides the following:

- During the authorization/notification conversation, the *Donation Coordinator* will:
 - offer sympathy for the death of the donor and allow family members the time to express grief and tell their story before any donation discussion;
 - refrain from using medical, regulatory, or tissue banking jargon (See Appendix I Terms to Avoid, Terms to Use);
 - be present for the family through active listening in an ongoing and systematic way with continual empathetic assessment;
 - identify and respect family's, cultural, religious, and/or ethnic differences and/or requests;
 - provide an estimated time line for the discussion; and
 - offer non-judgmental respect for decision-making.
- Information should:

- be presented with a modulated tone of voice;
- be offered in smaller amounts (dosing) dependent on family needs;
- be complete to ensure family understanding of tissue donation and transplantation, research, and compliance with regulations;
- outline how family members may carry out the decedent's donor designation;
- provide an opportunity to make a donation decision;
- include the tissues that might be available for donation, transplantation, and/or research, and how they could benefit others;
- describe that tissues are recovered by specially trained technicians in a way that is similar to a surgical procedure;
- include the time elements involved in tissue preparation (recovery, preparation, distribution and transplantation/research);
- be about grief and mourning;
- be presented with sensitivity and compassion in language and terms that are easily understood by the family; and
- every reasonable effort should be made to ensure that the opportunity for donation is provided as needed when a Limited English Proficiency (LEP) scenario is encountered, such as:
 - utilizing interpreters when communicating with *Donor Families* identified with LEP;
 - employing bilingual support services personnel; and
 - translating the *Document of Gift/Authorization* into the *Donor Family's* or *Authorizing Person's* language of proficiency.
- Conversation will allow for:
 - family empowerment and control over whatever is within the ability of the family to influence or make decisions about;
 - time to answer or explain family questions;
 - probing to ensure complete answers to questions;

- echoing: repeating key words from what the person has just said;
- reflecting content: summarizing what the person has said;
- reflecting feelings: helping the person label the feeling;
- paraphrasing: a restatement giving the meaning in another form;
- exchange of contact information between tissue bank staff and the *Donor Family* after the discussion; and
- appreciation to the family regardless of the outcome of the discussion.

Throughout services provided after donation, the donation professional should:

- enhance their skills with an understanding of current issues and models in loss, grief and mourning;
- have a responsibility to understand what the family is experiencing and where they may be in their grief;
- respect the privacy of the family and adhere to confidentiality;
- be highly skilled in oral and written communication and able to define medical terminology in layman's terms;
- demonstrate compassion and empathy regarding information about their loved one's death;
- provide details on how the family may obtain an autopsy report, or learn the cause of death or reason the donation cannot be placed for transplantation and/or research; and
- refer the *Donor Family* to an appropriate agency (Medical Examiner, Coroner, Hospital) for information concerning the death.

C. **Components of a Support Services Program**

Services to Donor Families may include:

- Information concerning the donation outcome or support services shall be presented with sensitivity and in language and terms that are easily understood by the family. Every reasonable effort should be made to ensure that support services are provided to potential *Donor Families* with Limited English Proficiency (LEP).

- An initial letter expressing sympathy for the family's loss and gratitude for the donation with information on the outcome of the tissue donation recovery for transplant or research.
- Provision of a copy of the *Document of Gift/Authorization* if requested by the *Donor Family* or required by law or internal policy. These may be mailed, faxed or emailed.
- Information about the family support follow-up program.
- Grief materials, bereavement support information, and other resources.
- General information about tissue donation, transplantation and research.
- Affirmation of the value of their loved one's donation.
- An opportunity to have their questions and concerns addressed regarding their donation experience.
- Periodic contact through telephone calls, cards, or letters for at least one year, unless family chooses to opt out.
- Upon request, provision of updated information about how the tissue was used for transplant or research.
- A process that supports communication initiated by *Recipients* for *Donor Families* if agreeable, and, when possible, from *Donor Families* to *Recipients* (i.e., cornea donation, donation of the heart for valves).
 - As necessary, a process for communication from researchers with *Donor Families*, if agreeable, or for information about how tissues were used in research.
- An opportunity to honor and/or memorialize the donor.
- An opportunity to participate in community events promoting tissue donation.
- An opportunity to evaluate the donation and bereavement experience.
- A *Donor Family* group that assists with planning and review of the *Donor Family Services* program.
- Follow-up services may also be offered to those *Donor Families* who have authorized donation but:
 - the donor was determined to be ineligible and recovery did not occur; or
 - donated tissue was recovered but not able to be used for transplant/use.

D. Gifted Tissue for Research

When a family donates for research and/or medical education the entity that obtained authorization should:

- Provide the family with information regarding how patients will benefit from this research as well as the way(s) in which the gift will be used to facilitate advances in medical/surgical research and/or procedures;
- Develop a process that supports communication initiated by research organizations if agreeable, and, if possible, from *Donor Families* to research organizations; and
- Upon request, provide updated information about the gift.

E. Evaluation of Services

Services to Donor Families must be periodically evaluated for effectiveness. The evaluation should include contacting *Donor Families* about their experience regarding the support provided by the program. The evaluation schedule may vary but information collected should help guide changes/additions/deletions to the current program to meet ongoing bereavement/support needs of *Donor Families*. Use of an *Experience of Care Survey* has become common practice for evaluating services. See Appendix II Experience Of Care Survey.

F. Resources for Donor Families

Individual websites of OPOs and tissue banks provide useful information for *Donor Families*. The following website can be accessed for a comprehensive list of grief resources for *Donor Families*:

<http://www.aatb.org/Grief-Resources>

III. APPENDIX I

Importance of Language when Supporting Families

Terms to Avoid	Terms to Use Instead
<i>Approach</i>	Donation discussion, Discuss donation, Provide donation information to the family, Conversation about donation
<i>The Ask</i>	Offer donation information/opportunity to a family
<i>Body</i>	Name of patient
<i>Body Parts</i>	Donated organ and/or tissues, the gifts

Terms to Avoid	Terms to Use Instead
<i>Declare Brain Death</i>	Determine brain death
<i>Discarded tissue</i>	Tissue that cannot be used for transplantation or research; cannot be placed
<i>Cadaver</i>	Deceased donor
<i>Case or referral</i>	Donor, patient, working with a family using the patient's name
<i>Committed suicide</i>	Completed suicide, died by suicide
<i>Distributed tissue</i>	Tissue used for transplantation or research
<i>Donor Pool</i>	Patients who may be able to donate, maximize donation, expand the potential for donation, patients who provide the opportunity for donation
<i>DRAI</i>	Life review; Medical/social history or questionnaire, similar like when you give blood; medical and lifestyle questionnaire
<i>Eligible</i>	Able to donate
<i>Expired Goods</i>	Tissue that can no longer be transplanted
<i>Expired</i>	Died
<i>Fetal demise</i>	Cause of death <i>in utero</i> (in the womb) or shortly after birth
<i>Fetus</i>	Baby, or baby's name
<i>FPA</i>	First person authorization, patient made a personal donation decision
<i>Goods</i>	Tissue, specific name of tissue, tissue grafts, tissue forms
<i>Harvest</i>	Recover, surgical recovery, donate (i.e., we can recover bone, he can donate bone)
<i>Incinerate</i>	Cremate
<i>Incompatible with Life</i>	Life limiting diagnosis, terminal condition, non-survivable diagnosis
<i>Ineligible</i>	After further evaluation, we will not be able to move forward with donation
<i>Legal Death</i>	Death
<i>Life Support</i>	Artificial support, respirator support, ventilator support, mechanical support

Terms to Avoid	Terms to Use Instead
<i>Non-heart beating donation</i>	Donation after cardiac death
<i>Non-viable</i>	Life limiting diagnosis, terminal condition
<i>OA (osteoarticular), or OC (osteochondral)</i>	Tissue grafts used to repair a person's damaged joint
<i>Option</i>	Opportunity
<i>Processing tissue</i>	Preparing tissue
<i>Processor</i>	Company that prepares tissue for transplantation or research, Partner
<i>Product</i>	Tissue, organ, gift
<i>Recovered or heal from the death</i>	Learning to live with the death, finding a new normal, making sense of the death
<i>Rejected donor</i>	After further evaluation; not able to donate; Tissue cannot be used for transplantation
<i>Shelf Life</i>	Transplantable, viable, the amount of time that tissue can be used for transplantation after recovery
<i>Stillborn</i>	Delivery after your baby died
<i>Suitable</i>	Able to donate
<i>Unsuitable</i>	After further evaluation; not able to donate
<i>Used or Utilized</i>	Shared, helped, gifted, transplanted
<i>Vegetable</i>	Someone who is no longer able to communicate with others
<i>Will save lives</i>	Possibility of saving lives
<i>Yield</i>	Number of gifts that are able to be transplanted

IV. APPENDIX II

Experience Of Care Survey

If an *Experience of Care Survey* is used to evaluate effectiveness, it could:

- include all or a representative sample of willing participants;
- be sent approximately one year after the donation occurred, or at the conclusion of the *Donor Family Services*;

- include a list of all or specific materials provided as part of the program with a request for the *Donor Family* to evaluate the materials and/or services provided;
- solicit demographic information about the *Donor Family*;
- request additional comments regarding the program, the organization (tissue bank), or the *Donor Families'* overall donation experience. (Note: This survey is not intended to evaluate the *Donor Family's* experience with hospital personnel);
- provide results that influence budgetary decisions involving bereavement services, and
- include some or all of the following questions:
 - How has the opportunity for tissue donation affected your grieving?
 - Given your experience, would you be willing to donate again? If no, please explain.
 - On a scale of 1-5 with 1 being not satisfied and 5 being extremely satisfied, how would you rate *Donor Family Services* overall?
 - What services did our staff provide that was most helpful to you? Why were they helpful?
 - What services did our staff provide that was least helpful to you? Why do you believe they were not helpful?
 - Would you like to receive additional resources at this time? If so, what types of resources would be helpful?
 - Would you be willing to submit a story/poem/photo to our family support newsletter?
 - Would you like instructions on how to submit a quilt square to our quilt project/donor quilt program?
 - Are you interested in information about our volunteer program?
 - Sample surveys and sample letters are available on the AATB website:

<http://www.aatb.org/Donor-Family-Service>

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