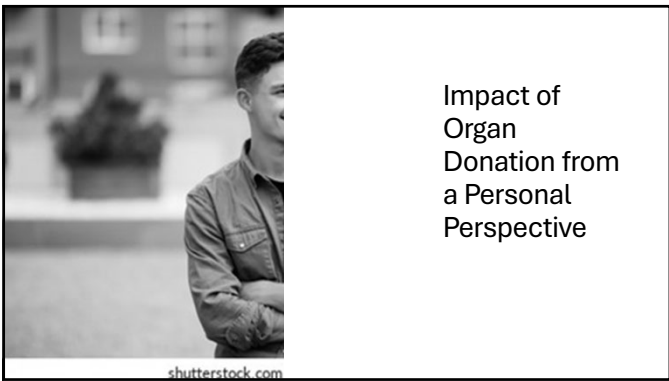


1



2



3

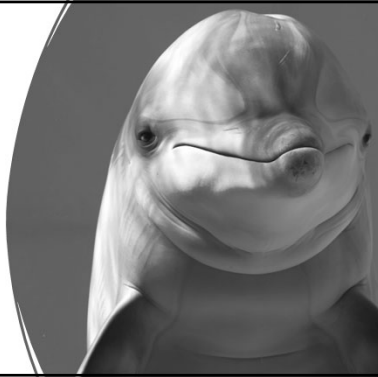
Value of Life, Reflected in Death

- Emotional, as the object of grief and remembrance
- Religious and Cultural-How we treat our dead both defines and reflects our culture, and respect for these beliefs unites us as humans. •
- Scientific and Medical uses, Ancient use may have reflected curiosity about “what’s under the hood”. But modern, non-transplant uses include medical education, product development, device manufacturing, biomechanics, safety testing, search and rescue, forensic research and exhibition.
- Therapeutic-Life Saving and Enhancing Transplant

4

Post-Mortem Attentive Behavior

- Birds Do It, Bees do It...
- Elephants and Dolphins, too.



5

Legal Status of the Deceased Body

- Ecclesiastic Property
- No Property Right in Individual or Family
- Quasi Property Right in Certain Survivors
- Disposition Right of Individual, if Exercised Pre-Mortem

6

Uniform Anatomical Gift Act

- Answers:
 - Who May Give
 - How
 - For What Purpose
 - To Whom

7

What is the Uniform Law Commission ?

- 125 Year Old Body of Commissioners appointed from each state, to draft laws where uniformity across states is desirable
- Among the Laws they've drafted are - Uniform Anatomical Gift Act, Uniform Commercial code, and the Uniform Determination of Death Act (UDDA)
- UDDA in early 1980s, has been adopted in whole or in part in 40 states. UAGA , in 1968, adopted in one form or another in all fifty states, Puerto Rico and U.S. Virgin Islands.

8

8

UAGA: Who may make a gift PRIOR to death (Section 4)

- Anyone 18 years or older
 - Or an emancipated minor
 - Authorized by state law to apply for a license
- An agent of the donor (unless prohibited by power of attorney)
- Parent
- Guardian

9

UAGA: Manner of Making the Gift PRIOR(Section 5)

- Statement or symbol on license/ID card, donor card
- Will/Advanced Directive
- During terminal illness, communication to two individuals (one disinterested)
- Process for those physically unable to sign
- Revocation, suspension, expiration or cancellation of license or ID does not cancel document of gift

10

UAGA Preclusive Effect (Section 8)

- Complete bar to changing donor's wishes, unless donor does it expressly, himself.
- **Revocation** is not **Refusal**
- Gift of One Part is not Refusal of Others
- Parent May Revoke Gift or Refusal of Minor decedent.

11

Health Care Decisions Act Donor Form

You may mark or initial one item.
() I donate my organs, tissues, and other body parts after I die, even if it requires maintaining treatments that conflict with other instructions I have put in this form, EXCEPT for those I list below (list any body parts you do NOT want to donate):

12

UAGA: Who may make gift AFTER death (Section 9)

- Agent
- Spouse
- Adult Children
- Parents
- Siblings
- Grandchildren
- Adult who exhibited special care and concern
- Acting Guardian
- Authority to Dispose

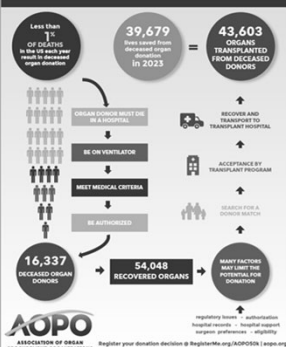
13

UAGA: Rights/Duties of Procurement Organizations

- Includes examination of all medical records
- Must search for parents of an unemancipated minor
- Search the statutory hierarchy
- Advise any and all parties of a document of gift, amended document or revocation

14

HOW THE ORGAN DONATION PROCESS WORKS



15

Donation Process

- All deceased or imminently deceased patients in a hospital referred to OPO for initial assessment
- If found initially suitable they are a "Prospective Donor"
- Prospective Donors are assessed for authorization, either as registered donors, or through statutorily authorized persons
- All Prospective Organ Donors are maintained on ventilation to perfuse organs
- If the patient appears to be deceased, they will be assessed for neurological death. If 'brain dead' organs may be recovered.
- If the patient is given a grave prognosis, family may opt to remove ventilation; if the patient then passes, their organs may be recovered

16

UAGA: Immunity

(Section 18)

- "Good Faith" immunity
- Who is not liable, including donor's estate
- Rely on representation

17

How Death is Declared: Uniform Declaration of Death Act (UDDA)

- A product of the ULC- Circa 1980s
- Recently revisited without conclusion

18

Existing UDDA language and Hot Spots

...An individual who has sustained **either*** (1) **irreversible*** cessation of circulatory and respiratory functions, or (2) **irreversible** cessation of all functions of the entire brain, including the **brain stem***, is dead. A determination of death must be made in accordance with **accepted medical standards***...

19

Findings of UDDA Study Committee

Portions of the UDDA do not align with current medical practice.

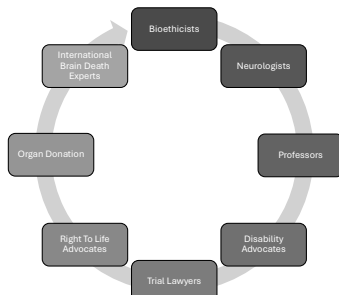
General consensus that clinical practice for diagnosing brain death did not always directly square with the "entire brain, including the brain stem" as used in the UDDA.

Similar concerns were expressed that the "irreversible cessation of circulatory and respiratory functions" criteria may not reflect current medical practice.

The clinical process of diagnosing death is established and undertaken by the medical profession. The declaration of death, by contrast, is a legal process defined by the law. These two processes should align.

20

Who was around the table?



21

Result

- Sufficient Consensus was not reached on:
 - Need for Change
 - Nature of Change

22

The Legal Importance of Death

- Estate Disposition, Estate Planning Civil Litigation, Criminal Liability,... death is a *sine qua non*—the jumping-off point for all that comes next.
- Without a death, there's no gift of a transplantable heart; no estate to haggle over; and no wrongful death, homicide, or manslaughter to pay for or prosecute.
- Getting death right is almost as important to our system of laws as it is to our health care system. And at present, the importance of the topic seems to be the only thing doctors, lawyers, judges, bioethicists, and patient advocates can agree on.

23

Considerations for the Trustee

- From the onset of service, the trustee is considering the life and eventual death of the beneficiary.
 - Budgeting
 - How a person's diagnosis may impact their life
 - A disbursement's potential impact on remainder beneficiaries (including Medicaid in first party trusts)

24

End of Life Plans

- Why it's important to ask early about End of life plans
- Importance of religious, cultural and individual considerations for each beneficiary
- Treatment of the decedent's body (and the costs that come with it) is deeply rooted in religious and family tradition
- Exploration of various different service providers for End of Life that serve different cultures, religions, disciplines
- Consider an irrevocable, pre-paid plan that is not tied to any particular service (Ex: Special Considerations)

25

Disbursements near end of life

- Hospice Care
- Additional Caregiving or Medical support
- Comforts such as massage, music therapy, flowers, visits from family/friends ([POMS: SI 01120.201.F.3.b](#))
- Medical Aid in Dying (See Discretionary Distributions in Today's Political Climate, Stetson10/2023, Brand and Tedford-Coles)

26

Transactional trust considerations at time of death

For First Party Trusts [POMS SI 01120.203.E](#) states as follows:

- E. Allowable and prohibited expenses for special needs and pooled trusts established under section 1917(d)(4)(A) and (C) of the Act

The following instructions about trust expenses and payments apply to Medicaid special needs trusts and to Medicaid pooled trusts.

1. Allowable administrative expenses

Upon the death of the trust beneficiary, **the trust may pay** the following types of administrative expenses from the trust prior to reimbursement to the State(s) for medical assistance:

- Taxes due from the trust to the State(s) or Federal government because of the death of the beneficiary;
- Reasonable fees for administration of the trust estate, such as an accounting of the trust to a court, completion and filing of documents, or other required actions associated with termination and wrapping up of the trust.

27

Transactional trust considerations at time of death, cont.

2. Prohibited expenses and payments

Upon the death of the trust beneficiary, the following are examples of some of the types of expenses and payments **not permitted** prior to reimbursement to the State(s) for medical assistance:

- Taxes due from the estate of the beneficiary other than those arising from inclusion of the trust in the estate;
- Inheritance taxes due for residual beneficiaries;
- Payment of debts owed to third parties;
- Funeral expenses; and
- Payments to residual beneficiaries.

28

Final considerations in trust administration following death

- Some States may be even more restrictive than the POMS
 - In Colorado, not even taxes or fees may be paid
- Some third party trust documents do not allow for burial or other expenses post death or are silent on the issue
 - Consider gaining permission from remainder beneficiaries in these circumstances
- Pre-need end of life plans are recommended
- Consider a close-out fee to pay for final expenses (such as services incurred prior to death, final taxes, trustee fees, etc.)

Note: There are multiple other considerations re: notification to Medicaid, remainder beneficiaries, final taxes, releases, etc.

29

Contact Us:

Megan Brand
Executive Director
CFPD - Colorado Fund for People with Disabilities
mbrand@cfpdtrust.org
www.cfpdtrust.org



CHRISTINA STRONG | DILWORTH PAXSON LLP
2 Research Way Princeton, NJ 08540
Tel: (908) 217-1053 | Fax: (215) 893-8537
cstrong@dilworthlaw.com |
www.dilworthlaw.com



30
