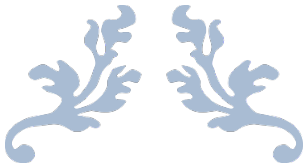

BEYOND GOODBYE

Trust Considerations in Death and Dying

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Impact of Organ Donation from a Personal Perspective:
(written from the perspective of Megan Brand)

From a very young age, I learned what organ donation was and its impact on the recipients. My mother's father (already deceased by the time I was born) and four of her eight siblings had inherited polycystic kidney disease. The only way it could be treated was through dialysis in the short-term and through kidney transplantation in the longer-term. I remember many excited moments when my aunt received calls to rush to the hospital and the times the kidney was not a match or not viable for some other reason. I also experienced two of aunts being live kidney donors for their siblings—the ultimate gift.

Fast forward to just four years ago when I was a mom to four and an aunt to many nieces and nephews-both biological and through marriage. In the summer of 2020, we received the call that no one wants to get. Our 19 year old nephew (my husband's sister's child) had been shot point blank while serving as a bouncer for a bar after denying entrance to the shooter. His parents share the following;

> *A noble and honorable sacrifice. The star on the driver's license. The conversations with family. This all sounds wonderful, and it is; You are giving a stranger (most likely) the gift of continuing their life....at least for a little while longer. Your loved one, who again, most likely, died unexpectedly, is "living on" still. Our family has gone through this process. We are in our fourth year, going into our fifth, without our son. With a piece of our family missing.*
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> *This process starts immediately when you get to the hospital. Within minutes, the doctors, surgeons, trauma staff have not only the task of telling you about the trauma your loved one has endured and the regret that there is nothing more they can do, but without delay, there is the other question that they have to ask, will your loved one donate his/her organs? And there begins the rapid fire decision making that will have to take place over the next few days.*
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> *Understand, that the surgeons/doctors/medical staff need the answer yes or no immediately in order to preserve the organs properly so that a recipient, anxiously awaiting for their phone call can rush to their hospital and prepare for their own life-saving surgery. Again, this is just the beginning of the multitude of phone calls between the Organ Donation center and yourself.*
>
> *Making decisions that will attempt to save someone's life, or at least prolong it a little while longer. Within the first few hours, as you are trying to wrap your head around the tragic death of your loved one, you are called multiple times by the procurement team. There is a deep dive into the patient's lifestyle....drugs, sexual history, health history, surgeries, lifestyle, and at the time...Covid. Positive covid test would have automatically negated our son from being an organ donor. A rule that changed multiple times over within the following year. Given his age, wherehe worked, he was tested multiple times.*

This actually extended his time hooked up to monitors and extended our agony of seeing him in this state. Were there blessings in this as well, hard to see at that time, but perhaps now, yes....our family from across the country were all able to arrive in time for the day of the procurement.

As the procurement team is working behind the scenes to find recipients and work out the logistics, another phone call takes place and you are asked, "are there any organs you do not want donated, and why?" This is not just your usual, heart, lungs, kidneys, this also extends to tissues, bone, eyes...this is another surgery after the procurement of the organs. Our one request was his one remaining eye . His eyes were beautiful, expressive, and deep brown highlighted by his long eye lashes. They held his joy, his sorrow. The answer of course is as much or as little as we want. There is no right or wrong answer. Were we selfish to withhold?

A question that enters your mind. How could it not?

Once those questions are answered, the logistics are in place, all of the testing is done, and the surgeon/doctor has declared your loved one 'dead', then another phone call comes and you have to schedule the actual procurement. For us, a lot of leeway was given. Not sure if this is the case for everyone, but we chose 5 am. For myself, it was a send off, a brightness of the day to give hope to a sad day. But then the ICU staff starts calling, and now you are deciding on prayers and playlists for the procurement surgery. Secondly, the honor walk. It is Covid era, so very few family were allowed to even enter the hospital, let alone be apart of the "walk". This is a humbling experience, and a way for those who have been taking care of your loved one to honor them. But again, the pressure to have something meaningful and put it together while planning a funeral....what is decided in those moments and how to hold a gathering outside while the surgery begins, where family and friends can gather....there is not a checklist, or a guide. What we had were well-meaning nurses and medical staff trying to get a decision from us and we were simply just trying to catch our breath.

The organs that were donated, were his heart (IL), lungs (WI), kidneys (NY, KY), pancreas (OH),liver (KY). We have heard from two of the recipients. We have reached out to all of them, but as this is a highly sensitive, private, special gift, what does a recipient and a donor say? What we have realized as time goes on, is that we don't get to choose. Just as the recipient does not get to choose who their donor is. This is a very difficult thought and realization to have. To begin with, one of the recipients, while well meaning, contacted us long before the initial first year anniversary. While this person wanted to know that their donor was a good person, and the same for us, it also was insensitive and put us in a position we were not ready to deal with.

You hope and pray that the recipients are of the same faith, ideology, good citizens, good people, but again, you don't get to choose. You don't get to choose when you meet them in person and find out that this incredible gift they have received and are thankful for, yet do not treat it as such and continue poor lifestyle habits. You don't get to choose.

In the end, in hindsight, knowing what we know now, would our decisions be the same? I believe so. Our son was a very empathetic, generous young man. We consider it a blessing that a part of him still lives on, someone else, still lives on because of him. We

continue to pray and thankful for the blessings of our son and the gifts he gave the recipient for a continued life.

The experience of each donor family is unique, and the circumstances surrounding each death and gift are, of course, unique. In the United States, about half of adults have registered their wish to be a donor, alleviating the need for their families to make decisions at a difficult time. The lessons we take from this beautiful story, generously shared with us is the lesson that more knowledge, more planning prior to the time of death and donation can provide solace at a time of loss.

The value of life, reflected by death

Mankind has placed value on the deceased human body since the dawn of human curiosity. The value arises in many aspects:

- Emotional, as the object of grief and remembrance- The Iliad (Homer) recounts that Hektor's father requested a truce during which the Trojans can bury their dead. Both armies collected their dead in peace, and this tradition carries on in modern wartime.

- Religious and Cultural-How we treat our dead both defines and reflects our culture, and respect for these beliefs unites us a humans. And perhaps it also defines and reflects intelligence more broadly, as "post – mortem attentive behavior" is shared by elephants, primates, and possibly even dolphins. See e.g. Wakes in the waves – why do dolphins and whales attend to their dead? | Yale Environment Review. Last accessed 9/26/24.

- Scientific and Medical uses, commenced millennia ago (Bay NSY, Bay BH. Greek anatomist Herophilus: the father of anatomy. Anat Cell Bio. 2010;43:280–3. doi: 10.5115/acb.2010.43.4.280). 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, as the source of life saving and enhancing organs and tissues for transplant.

The legal status of the dead body both demonstrates and responds to changes in its value. Neither this paper nor the talk we will be delivering will delve deeply into whether the human body or its composite parts are deemed property, quasi-property, priceless or worthless under American law. For excellent discussions of these issues see Newman v. Sathyavaglswaran, 287

F.3d 786 (9th Cir. 2002); and an interesting discussion in podcast Head Number 7, Episode 7, September 17, 2024, Head Number 7 | Wondery | Premium Podcasts. That having been said the legal concepts of the status of deceased bodies have included:

- Dead bodies seen as objects under the control of the king/priest, see e.g. "The law of burial places in England at the time of the American Revolution was therefore largely contained in ecclesiastical law. The Church's authority over human remains, particularly after interment, was justified based both on theology (the Church was the spiritual guardian of human remains until the Second Coming of Jesus Christ and the resurrection of the dead) and practical considerations (the Church owned the consecrated real property in which the remains were interred or entombed and therefore had physical control over them When Dirt and Death Collide: Legal and Property Interests in Burial Places (americanbar.org) accessed 9/26/2024

- English common law holding that there was no property right in a dead body, and, therefore, it could not be disposed of by will. See, e.g., Williams v. Williams, 20 Ch.D. 659, 665 (1882).

- Deceased bodies as objects under the control of the "head of the estate", see e.g. Brotherton v. Cleveland, 923 F.2d 477 (6th Cir. 1991);

- Deceased bodies as objects under the control of the "legally close", see original Anatomical Gift Act, 1987; and finally

- An object largely under the control of the individual whose directives pre-mortem direct post-mortem disposition. When that individual, during their lifetime, effectuates that control, it cuts off the ability of survivors or the state to alter or revoke the gift. Revised Uniform Anatomical Gift Act (2006) - Uniform Law Commission (uniformlaws.org)accessed 9/26/2024.

The ability to gift one's body post-mortem existed at E, nglish and American common law , and was exercised as a testamentary gift. (See, e.g. The Anatomy Act (1832) , which permitted a person to donate the corpse of family member in exchange for burial at the expense of the anatomy school.

The Uniform Anatomical Gift Act:

In 1968 in response to the growing viability of organ transplant as a therapy that was more than experimental, the reality of a market in deceased, and living human organs began to loom; hence, the Uniform Anatomical Gift Act was drafted, merging concepts on health law and estate law in a way which also reflected the need to determine whether or not a person is a donor within a time frame that permits the recovery of organs for transplant from a body while it is still on mechanical ventilation. In other words, no probate. This 1968 version was revamped in 1987 and 2006.

Like all Acts promulgated by the Uniform Law Commission, the Uniform Anatomical Gift Act is not a law until it is adopted by an individual state. Not surprisingly, states add their own special concerns and priorities within the general frame work of uniformity. Thus, for the specifics of who may make a gift, to whom, and when one must refer to the state where the donor died.

The adoption and enactment of the UAGA

The UAGA is the sole means of conveying organs and tissues from decedents for permissible uses. It defines the respective roles of participants in testamentary gift of the body, including;

1. The Donor (Testator)
    a. "Donor" means an individual whose body or part is the subject of an anatomical gift.
2. The "Agent (health care representative)
    a. "Agent" means an individual:(A) authorized to make health-care decisions on the principal's behalf by a power of attorney for health care; or(B) expressly authorized to make an anatomical gift on the principal's behalf by any other record signed by the principal. Agents may make a pre-mortem gift of the principal's body.
3. The "Guardian"
    a. The Guardian is a person appointed by a court to make decisions regarding the support, care, education, health, or welfare of an individual. The term does not include a guardian ad litem. A Guardian may make a pre-mortem gift of the principal's body as well.
4. The family and others who are "legally close":

a. an agent of the decedent at the time of death who could have made an anatomical gift under Section 4(2) immediately before the decedent's death;
b. the spouse of the decedent;
c. adult children of the decedent;
d. parents of the decedent;
e. adult siblings of the decedent;
f. adult grandchildren of the decedent;
g. grandparents of the decedent;
h. an adult who exhibited special care and concern for the decedent;
i. the persons who were acting as the [guardians] of the person of the decedent at the time of death; and
j. any other person having the authority to dispose of the decedent's body.

5. The "persons authorized to dispose of the body".

What the UAGA has to say about how the gift is documented?

"Document of gift" means a donor card or other record used to make an anatomical gift. The term includes a statement or symbol on a driver's license, identification card, or donor registry.

Donation in Estate planning:

A donor may make an anatomical gift:

(1) by authorizing a statement or symbol indicating that the donor has made an anatomical gift to be imprinted on the donor's driver's license or identification card;

(2) in a will;

(3) during a terminal illness or injury of the donor, by any form of communication addressed to at least two adults, at least one of whom is a disinterested witness; or

A donor or other person authorized to make an anatomical gift under Section 4 may make a gift by a donor card or other record signed by the donor or other person making the gift or by authorizing that a statement or symbol indicating that the donor has made an anatomical gift be included on a donor registry.

A minor within certain age brackets (generally the age of drivers license) may document a gift, which may be revoked by the parent if the minor dies while under the age of majority

The process of donation (see attached AOPO infographic, used with permission of the Association of Organ procurement Organizations.)

When does the anatomical gift take effect?

1. The "dead donor rule" requires that organs can only be recovered after death has been declared, and that organ recovery never causes the death.

2. Donation After Circulatory Death ("DCD")-When a patient, by means of an advance directive, or the patient's surrogate has determined that based on dire prognosis, the patient would wish life-sustaining treatment to be withdrawn, organs may be recovered if that withdrawal causes death within a short time period.

How is death determined?

The Uniform Determination of Death Act was drafted by the ULC in 1980. It was revisited in 2020 by the ULC, which after three years determined that insufficient consensus was reached on whether and how to amend the Act. To understand existing law:

1. [Determination of Death]. 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.

Part (1) codifies the existing common law basis for determining death—total failure of the cardiorespiratory system. Part (2) extends the common law to include newer procedures for determination of death based upon irreversible loss of all brain functions. Part 2, the cessation of brain function, occurs even while breathing is being artificially maintained. In other words, when artificial means of support preclude a determination under part (1), the Act recognizes that death can be determined by diagnosing loss of brain function.

Under part (2), the entire brain must cease to function, irreversibly. The concept of "entire brain" distinguishes determination of death under the Act from "persistent vegetative state." There is

considerable debate as to whether "the entire brain" death contemplated by the act includes the hypothalamus.

Considerations for the Trustee re: death and trust closure

The trustee has many different and varying considerations when it comes to death of the beneficiary. From the onset of administering the trust, the trustee is considering the life and eventual death of the beneficiary. It is included in budgeting and projections of life expectancy, how a person's disability may impact that life expectancy and planning, the impact of trust distributions and the impact not only on the beneficiary, but the potential for how the disbursement may affect the remainder beneficiary. When trustees are administering a first party disability trust, they are also considering that expenses cannot be paid after the death of the beneficiary and so they are asking beneficiaries, some of whom are quite young, to consider paying for a pre-need end of life plan.

End of Life Plans in and of themselves can and should cause the trustee to explore the religious and cultural considerations of the beneficiary. The treatment of the deceased body is deeply rooted in the rituals of many world religions and family tradition. A trustee must evaluate the expenditure from a budgetary and practical standpoint while also honoring the values of the beneficiary and their family.

As a beneficiary nears their end of life, there may also be disbursement requests that are related to their specific needs at that time. For example, a beneficiary may ask for additional caregiving and medical support that includes massage, music therapy, or other items promoting comfort and relaxation. A beneficiary may go so far as to request payment for medical aid in dying, which is a topic for an additional paper and presentation but must be evaluated in consideration with federal and state laws.

Finally, there are the more transactional considerations that a trustee must consider at the time of death. For a first party trust (both d4a disability and d4c pooled), the relevant POMS SI 01120.203.E.[1] states that the trustee is prohibited from making most disbursements after death, with only a couple of allowable expenses. It states as follows:

[1] POMS is the Program Operations Manual System; https://secure.ssa.gov/poms.nsf/lnx/0501120203

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.

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.

Further, some states Medicaid regulations may be even more restrictive at the time of death. For example, in Colorado, the trustee is not even permitted to pay for taxes or fees. No disbursements from the account are allowed post death. In addition, there are some third-party trust documents that do not allow burial or other expenses at the time of death or are silent on the burial expenses being paid. The trustee must proceed with caution in these situations as well.

For further understanding on the current issues surrounding the law of determining death by neurologic criteria, see the attached article by Christina Strong, and see also Greer DM, Shemie SD, Lewis A, et al. Determination of brain death/death by neurologic criteria: The World Brain Death Project. *JAMA*. doi:10.1001/jama.2020.11586.