



Organ Donation: Collaborative Transitions

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Who we are and why we are here



We help families make meaning around a death by helping their loved one to give the gifts of life and health through organ and tissue donation.

We're honored to work with families who are able to think of others and do something kind and compassionate at an incredibly sad and traumatic time for themselves.



Family Support

- Honor quilts given to donor families
- Memory making:
 - handprints
 - ceramic hearts
- Cooper P.J. Project to honor our smallest donors



Collaborative Care for Donor Families

What potential organ donor families are experiencing is not normal grief, it is dissonant loss or traumatic loss.

This looks like:

- A sense of uncertainty and psychological inconsistency
- In traumatic grief, the brain is not functioning normally, so family members are able to retain only a small amount of the information given to them
- **Decouple – i.e. notification of death is separate from organ donation discussion.** Authorization for donation is obtained 71% of the time when decoupled vs. 47% when not

Collaborative Care for Donor Families

- Help families get ready access to information
- They need short, repeated explanations. Visual aids
- Close proximity to loved one. Frequent visitation.
- Most of all they need....***Time***
 - to accept the reality of the death (or non-survivability)
 - to process the information
 - to say goodbye in a meaningful way

Collaborative Care for Donor Families

Our roles:

Expert staff view the family conversation process as a well-defined sequence of conversations, with each participant understanding his or her role and responsibility, with the ultimate goal of benefiting the family.

Collaborative Care for Donor Families

Team Huddle-

- Donation coordinator and primary/palliative care teams coordinate the initial conversation and search for clues for appropriate timing
- Give the family some time to accept death or non-survivability after receiving news from health care team
- Have hospital staff introduce donation coordinator as someone here to talk with them about what happens next
- Bring up the opportunity for donation at the appropriate time during the conversation
- Be absolutely clear before the family conversation about registered donor status (first person authorization) and decide how to present that information to families in a caring, compassionate and very transparent way

Collaborative Care for Donor Families

Words are powerful: *ability, act of compassion and kindness, courage, honor, hope, legacy, opportunity, helping others, saving lives, selflessness*

Phrases:

- "You, your family and (donor's name) have the opportunity to touch and save the lives of people in need of a lifesaving transplant."
- "Your family and (donor's name) have the ability to keep other families from experiencing the pain and loss that you are feeling."
- "Recipients and their families tell us that they consider their donors and the donor's family to be their heroes."

Collaborative Care for Donor Families

- Emphasize the generosity and compassion of the family
- Tell stories of recipients and the good that can come to them
- Speak about the gratitude that recipients express - they often say that they will dedicate this second chance at life to honoring their donor
- Make sure the family & hospital staff have the best possible experience with donation. Always debrief about learning points and what we could each do better (if anything)

Collaborative Care for Donor Families – Case Studies

Should hospital staff bring up the topic of donation?

Why or why not?

If so, under what circumstances?

With what phrases?

Discuss.....

In summary-

- To offer compassionate care to families: The process must include a 'Healthcare Team' approach and joint accountability.
- Organ and tissue donation is not about statistics and outcomes: It is a process that is an integral part of the ongoing care of the patient and the patient's family.
- “No” to donation: Often, this is a rejection of the death and loss, not a “no” to donation.
- Donor families find comfort and solace from saying “yes” to donation.
- 22 men, women and children do not need to die today: Organ donation *saves lives*.

Thank you!

