
Empowering Families to Make Meaning From Loss with the Decision to Donate

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Caring For the Family

- When we enter into a helping relationship with a potential donor family we are walking into one of their most personal and deeply felt life experiences.
- Our Donor Referral Coordinators, Family Support Liaisons and In-House Coordinators have the responsibility and privilege to make the experience as meaningful as possible.

Caring for the Family

- We know families come into the hospital in a state of crisis, hoping that their loved one will survive no matter how horrible the injury.
- We are trained to pay attention to how families cope with trauma and stress and meet them where they are emotionally.
- Our best gift to them in the initial hours is time to digest what is happening and to be present to answer questions.

- We are patient with families who are unable to focus – because along with shock and disbelief comes confusion and the inability to concentrate.
- We recognize anxiety, panic and fear and are trained to be a calming presence.
- We are accustomed to dealing with a great deal of anger and blame and we are trained to listen without judging.
- Profound sadness is at the bottom of these emotions – we are there to bear witness to this and allow the families to feel.

We Learn From The Family

- We are there to teach the family about brain death and death after cardiac death determination (DCDD).
- Families teach us what this death is like for them.
- What brain death and donation means to them.
- What needs they have during their time at the hospital and beyond.

Empowering the Family

- Empowered families feel respected and nurtured.
- They know their thoughts and feelings matter during and after their decision to donate.
- They do not feel used, as if we were only there to get their consent or disclosure for donation.

Empowerment Starts Before the Donation Conversation

- We help families make choices about their physical needs.
- Offer the the choice to be near their loved one.
- Provide physical safety, especially in high profile cases.
- Give the family the choice to have time alone and honor their need for privacy.

- We create a safe space for emotional expression.
- Give families the opportunity to see people being gentle and respectful to their loved one.
- Give families the choice to participate in the care of their loved one in ways they are comfortable.

- We provide families with information when they are ready to hear it – they can deal with what they know, not with what they don't know.
- We provide consistent and accurate information in doses, clarifying information, and doing what we can to reduce cognitive demands on families.
- We make families aware of their options so they feel like they have some control in this otherwise, powerless situation.

Empowering Families with a Working Understanding of Brain Death

- We must overcome doubt and distrust and establish rapport.
- We are trained to create an environment where a family feels safe, cared for and understood – so that the conversation can be heard and comprehended.
- We are trained to be prepared for language barriers and know how to find the right words for this conversation.
- We often check for families perceptions of what we are saying, because we know that what we say and what they hear are often different since they are filtered through the lens of trauma and shock.

- It is our job to allow families to mourn – to outwardly express their feelings and we empower them to do so.
- We bear witness to their pain without trying to take it away and in this process we hope to help them reconcile the death of someone they love.
- We must explore the families fears and concerns, even after we have explained brain death.

The Slower You Go The Faster you Get There

- When we try to move families through this end of life conversation quickly, we deprive them of the opportunity to slow down and begin to integrate the experience into their reality.
- We are trained to offer comfort while sitting with them in their pain.
- We wait.
- We create the space for them to feel that they can make this important last decision on behalf of their loved one.

And sometimes, even with the best work we do, the answer is no.

What Does Research Say About Why People Say No?

- Those who did not receive understandable information about organ donation were more likely to say no.
- When families were not given the time to bring up concerns with hospital staff they were more likely to say no.
- When the hospital did not give them clear information about their loved one they were more likely to say no.
- When the hospital staff did not display respect or compassion they were more likely to say no.
- When families had not talked about donation previously with their loved one and did not know what their expressed wishes were they were likely to say no.

“A comparison of donors and non donors...showed that significantly higher proportions of donor family members recounted having had someone present who showed understanding, who listened, who was there in case of need and who gave them hope to go on. Differences between donors and non donors with respect to someone having them know that their feelings were normal approached statistical significance.”

Jaccard, James, Jacoby, Liva. *Perceived support among families deciding about organ donation for their loved ones: Donor vs. non-donor next of kin*. American Journal of Critical Care. 2010, pg. 52-61.

“When donation was mentioned first by a family member the donation rate was 98%. Being approached for organ donation by a transplant coordinator resulted in a high donation rate of 92%. Donation rates were significantly lower when approached by a hospital social worker (85%) or a nurse (77%)...The presence of a donor card was associated with higher donation rates (96%) than was the absence of a donor card.”

- The amount of time that elapsed between the time of the illness or injury and the time of being approached about organ donation differed significantly between donor and non donor groups.
- Elapsed time was significantly greater for non donor families (mean, 52 hours) than for the donor families (mean, 32 hours).
- Non donor families more often reported not having enough time to make the decision about donation.

What Would Families Change About the Donation Experience?

- More information about recipients
- Nothing needed to be changed
- More time to make the decision and be with the donor
- Expedition of the organ recovery process
- Feeling of having to “part and parcel” our their loved ones.
- Non-donor families said that doctors should not have “tried to bring him back,” and they were upset by unprofessional behavior of staff.

Most Important Factor in Donation Decisions

- Donor families said it was the “gift of life.”
- They indicated they thought they were following the wishes of the deceased.
- Others cited personal experiences in working with organ donation as a professional.
- Strong personal belief in organ donation.
- Non-donor families indicated that donating the organs of a child went against their “parental instincts to protect their child at all times.”
- Non-donor families felt their loved ones “had been through enough and felt like he surgery would prolong the process.”

Exley, M., Martin, J., White, N. *Why families say no to organ donation*. *Critical Care Nurse* 2002;22:44-52.

Additional Factors That Directly Influence the Donation Decision

- The approach used to introduce the idea of organ donation to the family.
- Collaboration among healthcare professionals.
- Whether or not the request for donation was made in private setting.
- The family's perception of the concept of brain death.
- Knowledge of deceased wishes or personal attributes
- Altruism in the donation
- Religious and cultural belief are the main reason certain ethnic groups refuse to donate

Themes Found in Donation Decisions

- Struggle to acknowledge death
- Conflict between understanding the concept of brain death and being able to accept this was the case for their loved one.
- Families report identifying signs of life (breathing, heart beat and body warmth) to give them a sense of hope their loved one would recover.
- A need for a positive outcome
- Perception that donation gave further meaning to the life of their loved one.
- There was a sense that their loved one was still living on through the recipient.

Manuel, A., Solberg, S., & MacDonald, S. (2010) *Organ donation experiences of family members*.
Nephrology Nursing Journal, 37(3), 229-237

Pediatric Donation Decisions

- One research study showed parents are more likely to agree to donation when the mention (not the ask for consent) is made by the health care team caring for the child.
- The close and frequent interactions with critically ill children foster a level of trust with the healthcare system, that is needed when considering donation.
- Parents were three times more likely to have favorable pediatric donation intentions when there had been a prior family discussion about organ donation.

Rodrigue, J., Cornell, D., Howard, R. *Pediatric organ donation: What factors most influence parents' donation decisions?* Pediatric Critical Care Medicine. 2008 March; 9(2): 180-185

- Donor parents reported that print media awareness of transplant success stories had a positive impact on decisions to donate.
- To maximize the likelihood of a favorable donation decision parents need to feel that the formal request is done in a way that is sensitive to the family's needs and that they are given ample time to make the decision.
- It also helped when parents knew that no matter what their decision, that the critical care team and the OPO would still be supportive of them

What Lifebanc Staff Hear from Families

- There are families who have been at the hospital for a long time previous to the donation conversation and are “done” and not prepared to stay for the process.
- People do not want to betray their families wishes and feel that they had a “close” relationship so they “would have known” if their loved one was in favor of donation.
- Their loved one “has been through enough.”
- Want their loved one “buried whole” especially if it is not a coroners case.

- People have had a “bad hospital experience” and did not feel cared for.
- People have expressed they are against transplantation because it did not work for them or for a loved one.
- We live in a capitalistic society and people are often out for themselves and lack a sense of altruism.
- When people are desupporting for DCD they want things to move fast and when they learn things cannot move forward quickly they will say no.

- People will also say no because they know their loved one did “not want to be on a ventilator.”
- Some people also say no because their loved one lived such a troubled life that they are worried (in spite of reassurance) that if their loved one was a donor they would make someone ill.
- Some families feel so helpless and they want to have the last decision for this person and that decision is “NO.”

In The End, What We Hear The Most is...

THANK YOU

- Once families make the decision to donate they are cared for and honored by Lifebanc through the Bereavement Services Department for 2 years. We also follow people who intended to donate but for some reason the donation was unable to come to fruition.
- We treat all donors the same. Organ donors, tissue donors and eye donors receive the same follow up.

Making Meaning From Donation – The Bereavement Services Department

In 2010 The Bereavement Department followed over 1500 Families

- Bereavement Department receives reports about families who will be in our care.
- Each week I sit in case review to hear organ cases, tissue cases and to hear how our DRC's dealt with their phone approaches.
- Family Support Liaisons (FSL) and Donor Referral Coordinators (DRC) let our families know they will be hearing from us in one month by phone.

If they need support sooner or resources immediately they call the Bereavement Department and we follow up immediately.

Reaching out By Phone – We Made and Received Over 3000 Calls in 2010

- Outcome letters encourages families to call the Bereavement Department if they want to talk.
- We call all of our families who want bereavement follow up at 1, 3 and 12 months after their loss.
- We often learn about their hospital experience, their donation experience and about their interaction with Lifebanc staff – I share this information as we strive for collaboration in all donation efforts.
- If we are unable to reach our families, each gets a handwritten card, with our business card, inviting them to call or email if they want to connect with us.

- 12 volunteers who have a connection to donation make 3 month calls.
- I engage them in an in depth training which includes”
 - grief reactions
 - traumatic loss
 - what it means to be a wounded healer
 - empathic listening
 - meaning making
 - engaged in role play
- I supervise them on regular basis and meet with them quarterly.

Reaching out By Mail

We Sent Out Close to 5000 Letters of Support and Resources in 2010

We send personalized letters to our families at regular intervals: one, three, six, nine, twelve, fifteen, eighteen and twenty four months.

One Month

- Characteristics of Grief
- General grief and bereavement websites
- Mourner's Rights
- Correspondence guidelines

Three Months

- Finding the "new normal."
- Counseling services in Lifebanc's service area
- Loss specific websites
- Specific loss information inserted for each family

Six Month

- Contradictory feelings during grief – moving towards acceptance
- Grief and Bereavement booklist
- “Living with Loss” magazine
- “Give and Grieve” newsletter

Nine Month

- A understanding of hope
- Self-Care: Wellness Wheel
- “Are You Taking Care of Yourself?”
- Next of kin survey

12 month

- Ritual and anniversary
- Ritual: Mark the Anniversary - Resource
- Quilt brochure to donor families

Fifteen Months

- Loss and opportunity for meaning making
- Lifebanc Volunteer Brochure

Eighteen Months

- Living in a “get over it” society
- Tools for Reflection on the Impact of Grief on my Life

Twenty Four Months

- Are you stronger in the broken places or are you in need of more support?
- Resource on the signs of complicated grief

Holiday Mailing with resources on coping during the holidays

Correspondence

- 607 letters between organ/tissue donor families and recipients

Recipient Updates

- 180 recipient updates

Counseling

- Grief counseling at Lifebanc, free of charge to our donor families
- 6 week grief support groups in our Lifebanc service areas
- Quilt N' Chat Program
- Quarterly Grief Education Seminars

Annual Donor Memorial Service

Active Donor Family Council

For more information:

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