

CHOOSING LIFE

The month of April brings a very important day for all of us associated with California Transplant Donor Network (CTDN), namely our annual Donor Family Gathering. This year we hosted more than 900 donor family members and friends And 150 recipients of organs and tissues and together we all celebrated the astonishing altruism of the human heart. We applauded the recipients who lined up on the stage to try to find words to express their appreciation for the gift of life they received ... And we joined the cheers of the donor families as photographs of their loved ones were projected onto a full-sized cinema screen ... We marveled as donor families and recipients met for the first time and became instant family ... And we returned home humbled by the knowledge that, as nine-year-old Sean said in the support group I facilitated that morning, “Everything can change in just a second”.

But that was not all that he said. Sean added, “And then we have to put that in the back of our heads and live our lives the best we can for the people who are not with us anymore”. With the wisdom of childhood, Sean had precisely described the paradoxical challenge that faces the families of potential donors and also affects the staff who work with them, namely to find strength and purpose in tragic circumstances ..and to choose life.

The Challenge

In the 1980s, Organ Procurement Organizations (OPOs) were established. Born out of their local transplant centers, they assumed responsibility for presenting the option of donation to families and providing medical management of donors. While hospital

personnel were often grateful to have that charge removed from them, they were also apprehensive about an outside organization approaching their patients and making such a request when the family was already emotionally overwhelmed. Our coordinators would often be told, “We don’t think you should talk to this family, they have already been through enough”. We understood and respected the hospital’s impulse to be protective and yet we had heard so many families express their appreciation for the opportunity to choose donation. Over and over they would tell us, “Donation was the one good thing that came from our tragedy; it gave us the strength to go on.” And we could never forget that seventeen people were dying every day on the waiting list, waiting for an organ that never became available.

That tension, between the protection and care for the grieving family and the desperate needs of recipients, is inevitable and indeed was most helpful in guiding us towards a protocol that would both respect the rights and the vulnerability of the bereaved and make sure that as many recipients as possible would receive the life-saving gift they were waiting for.

The Philosophy of the Family Team

The Family Service Team at CTDN is an ethnically diverse group that includes grief counselors, social workers and a psychologist who are committed to dynamic process improvement through monthly day-long case reviews and in-services. The first document developed by the team was a set of Guiding Principles that clearly articulate high standards of care for the donor family.

1. Excellent family care and excellent processes with optimal outcomes go hand in

- hand; these are not competing values or strategies.
2. For the family, their loss and grief are primary, not the donation, and all our interventions are guided by this awareness.
 3. We are **not taking** something **from** families, we are **giving** information **to** families about an important decision... to consider the possibility of saving lives through donation.
 4. As an organization we are confident in our belief that donation can be of inestimable long term value to bereaved families, offering them some meaning in their loss.
 5. As an organization serving an extremely diverse community, we acknowledge that any assumption that donation is the right thing to do is culturally influenced; different, deeply held convictions may influence decision-making by families from other cultures, and lead them to say no.
 6. **Donation is an extraordinary act of altruism at a time of intense tragedy.** When we empower families in every possible way, consent becomes their own decision, and the healing potential of the decision to donate is maximized.

Values in Action

In order to turn these lofty ideals into action we turned our attention to research and literature in the fields of Grief Studies and Crisis Intervention. In addition we analyzed the practice of those colleagues who were recognized as providing superior family care. A convergence of ideas and practice soon emerged.

CTDN coordinators meet families who are in shock and in the grip of the acute

phase of grief. Family members may manifest that grief in idiosyncratic ways that range from stoicism through unmediated despair to somaticization. What they have in common is disruption of their typical coping mechanisms and severe impairment of their cognitive functioning; in fact some experts estimate that functioning is typically reduced to around fifth grade level. Clearly, this is not an appropriate time to offer information about donation—rather, this is a time to identify the family’s needs and to offer the family emotional and practical support.

Maslow’s Hierarchy of Needs

As we began to explore how best to provide this, we noticed that our practices bore a striking similarity to Maslow’s postulated Hierarchy of Needs. First, the family’s safety and survival needs must be attended to, then their social supports identified and their spiritual beliefs and practices supported, all in a context of utmost respect. Then finally, the family is provided with the information about donation so that they can make their decision. Whether that answer is yes or no, it will be very momentous for many families, and would meet Maslow’s definition of a self-actualizing experience.

Crisis Intervention

A continued exploration of interventions that could strengthen these families led us to review Crisis Intervention theory. While not all family members will benefit from a uniform approach, long-term recovery from traumatogenic events can often be enhanced by reducing the individual’s sense of helplessness in the face of the crisis. The fundamental goal of Crisis Intervention is to help individuals regain their prior level of functioning, through empowerment of the family by offering choices, information and

respect.

We have incorporated the following principles of crisis intervention into our practice:

prompt support, stabilization of psychological and cognitive functioning (through emotional and practical support), **facilitation of understanding** (through timely and sensitive explanations and sharing of information), **focus on decision-making and problem solving** (through respectful support of the family's consideration of the option of donation) and **the encouragement of self-reliance** (through eliciting the family's wishes and ideas about how best to move forward).

Core Elements of Family Support and the Donation Discussion

These many considerations have resulted in a sequence of care that emphasizes collaboration between the hospital and CTDN to provide optimal support to the family at every stage.

Gathering and Sharing Information

- => Brain Death Discussion and Beginning of Family Support
- => Coping with Loss
- => Donation Discussion
- => Aftercare

Our goal is that every family should make an **Informed Decision** about donation (whether that decision is a yes or a no), so we offer the information about donation after we have helped family members begin to regain their prior level of functioning. We are careful to offer the information in a non-coercive way, so that if a family decides against donation, they will not be burdened by feelings of guilt or feel judged by us.

And we find that three out of four families choose the option of donation in the

midst of their own tragedy; we continue to be amazed by the generosity of the human spirit!

Donate Life California

In the past, families have often found it difficult to make the decision about donation when they were not sure about the wishes of their deceased family member. As of May 1, 2007, 1.3 million Californians have signed up on the state organ and tissue donor registry, and this is a source of great relief and comfort for their families when tragedy strikes. Occasionally however, families are shocked and distressed when they find out about that decision. In these situations, we turn our support to discussion of the challenge the family is experiencing, in accepting the decision their family member made. We take whatever time is needed to gently review their understanding and acceptance of brain death, to help the family to access social and spiritual support and to offer information about donation, paying special attention to dispelling possible misconceptions; we sympathize that it must be very difficult to be asked to support a decision they themselves would not have made. In almost all cases, after these interventions, the families are able to comfortably accept their loved one's choice.

It truly is a miracle that a family's decision to think of the needs of others in the midst of their own tragedy can result in life for seven or even eight organ recipients and countless tissue recipients. At the Donor Family Gathering I met a twice-bereaved mother who told me, "When I lost my daughter ten years ago, it was terrible...there was no comfort. But when my son died last year, I accepted the option of donation. Nothing can bring him back, but knowing that he was a donor keeps me in touch with life. It

makes all the difference.”

We are so honored to be part of the amazing circle of life that is the world of donation and transplantation.

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