Why Should I Write?
Encouraging Recipients to Write to Their Donor Family

Lara S. Moretti, LSW, CT
Rebecca Simon, LMSW

• Lara S. Moretti, LSW, CT
  Supervisor, Family Support Services,
  Gift of Life Donor Program, Philadelphia, Pennsylvania
• Rebecca Simon, LMSW
  Family Resource Program Coordinator,
  Pacific Northwest Transplant Bank, Portland, Oregon

Agenda
• Introduction to Donor Family Aftercare
• How Grief and Donation Intersect
• Roles in the Correspondence Process
• Challenges and Opportunities with Correspondence
• Discussion
Who are Donor Families?

- Families whose loved ones died and donated their organs, tissues, or both;
- Families that would have liked to donate, but couldn't due to medical or other reasons;
- Families that did not donate, but might have, had they been given the opportunity

Supporting Donor Families

- Providing compassionate care for families before, at the time of, and after donation
- Loss and grief are primary – not the donation process

Worden’s Task in Mourning

1. To accept the reality of the loss
2. To process the pain of grief
3. To adjust to a world without the deceased
4. To find an enduring connection with the deceased in the midst of embarking on a new life

Worden, 2009
Meaning Reconstruction

• According to Neimeyer, “meaning reconstruction in response to a loss is the central process in grieving.”

• “Meaning finding” or “turning to already-existing frameworks of meaning”

• “Meaning making” or “making sense of loss”

Neimeyer, 1998, p. 110

Continuing Bonds

• Continuing bonds involve ongoing connections through a dynamic, internal representation of the individual who has died

• Such bonds can enable an ongoing presence of that individual in the inner lives of the bereaved that may provide solace, comfort, & support

Klass, Silverman, & Nickman, 1996

Supporting Donor Families

• Aftercare Services
  — Typically provided by the recovery agency
  — Counseling/Support Groups
  — Donor Remembrance Ceremonies
  — Donor Family Events & Memorial Quilts
  — Referrals to community resources
  — Updates and correspondence
The OPO Role

• Review for confidentiality
• Copies for our records
• Forward to appropriate person
• Resource for recipients and donor families

Correspondence Process for a Recipient

• Recipient can write at any time
• Anyone in the recipient family can write
• Letter, cards, photographs
• All correspondence is sent to the local OPO
• Transplant social worker as a resource

The Transplant Center/OPO Bond

• Life altering process
• Informative organizations
• Ambassadors to the donation experience
The Transplant Center/OPO Bond

• Connect people through the most unique of circumstances
• Change in language used by recipients and the pressure to write.
  — never saying that a donor is “living on” in a recipient.*

* Donor families, distinctive secondary losses, and “second death” experiences
  Corr, Coolican, Maretta, Simon, Progress in Transplantation, September 2011

The Unique Donor Family and Recipient Bond

Correspondence benefits not just the donor family but also the recipient.

• Continuing Bond for donor family

• Becoming steward of the gift for recipient.

Challenges of the Correspondence Process

• Systemic issues
  — Different practices at transplant centers/OPOs
  — Misconceptions

• Personal issues
  — Not ready to write
  — Will never write
Ideas to Encourage Correspondence

• Simple is sometimes better.
• OPO provide cards at holiday times or at time of transplant

Ideas to Encourage Correspondence

• Website for sending letters
• Guest speakers at recipient support groups
• Correspondence Brochures

Discussion

• What are your biggest obstacles and concerns with correspondence?
• What have been successful ways you have assisted recipients with correspondence?
• What can your OPO community do to help support you?
WHO IS THIS INSIDE OF ME?
Introducing and Validating the Conversation
Barbara Levine, MSW, LICSW
Brigham and Women's Hospital
Boston, Massachusetts

Literature: Common Themes
• Guilt / Survivor’s Guilt / Regret
• Gratitude
• Responsibility / Good Stewardship.
• Personality Changes (fear of/recognition of)
• Donor Characteristics (fear of/recognition of)

Recipient Views of Donors – 3 sets of Attitudes & Coping Styles*
• Complete Denial
  - Recipients never think about donor
  - Denial of emotions toward donor
  - No need for information about donor

*Attitudes of Patients Before and After Transplantation towards Various Allografts, Schlitt et al, Transplantation, Volume 68(4), August 27, 1999
Recipient Views of Donors – 3 sets of Attitudes & Coping Styles*

**Partial Denial**
- Recipients decline information due to perceived emotional stress.

**Cope with Reality**
- Sense of connection with unknown donor
  - Gratitude
  - Sorrow
  - Desire to know more about donor

Social Work Interventions
- Open the topic for discussion!
- Recipient → Donor-family correspondence
- Pre-transplant preparation
- Donor Remembrance ceremonies

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