

# Overcoming Survivor's Guilt:

## Strategies to Help Recipients Understand the Positive Impact of Donation

### TODAY'S PANELISTS



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# Continuing Education Information

## Evaluations & Certificates

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### Nursing

The Organ Donation and Transplantation Alliance is offering **1.0 hours of continuing education credit** for this offering, approved by The California Board of Registered Nursing, Provider Number CEP17117. No partial credits will be awarded. CE credit will be issued upon request within 30 days post-webinar.

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- You will receive a certificate via email upon completion of a certificate request or an evaluation
- Group leaders, please share the follow-up email with all group participants who attended the webinar.



**Deanna Fenton**  
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## Need Assistance?

Contact Us via Zoom Chat, or  
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# Meet Our Moderators



**Talia Giordano** MSW, LCSW  
Director, Family Services and Caregiver  
Lifeline Program



**Sarah Moran** LCSW, CCTSW  
Clinical Social Worker



# Meet Our Presenter



**Lara S. Moretti**

LSW, CT

Director, Family Support  
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# Overcoming Survivor's Guilt: Strategies to Help Recipients Understand the Positive Impact of Donation

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Director, Family Support Services  
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# Learning Objectives

1. Identify two contemporary grief theories that relate to the grief of donor families.
2. Define survivor's guilt in transplant recipients and how that impacts physical and emotional health of recipients.
3. List several techniques to support transplant recipients and help them cope with their feelings of guilt.
4. Summarize grief theory and demonstrate practical language to use with recipients post-transplant.
5. Describe anecdotal donor family experiences that can be shared with recipients and, in turn, provide enhanced support for a recipient who might be experiencing survivor's guilt.

# Agenda

- \* Grief and Donation
- \* Survivor's Guilt
- \* Challenges facing recipients
- \* Questions and Discussion

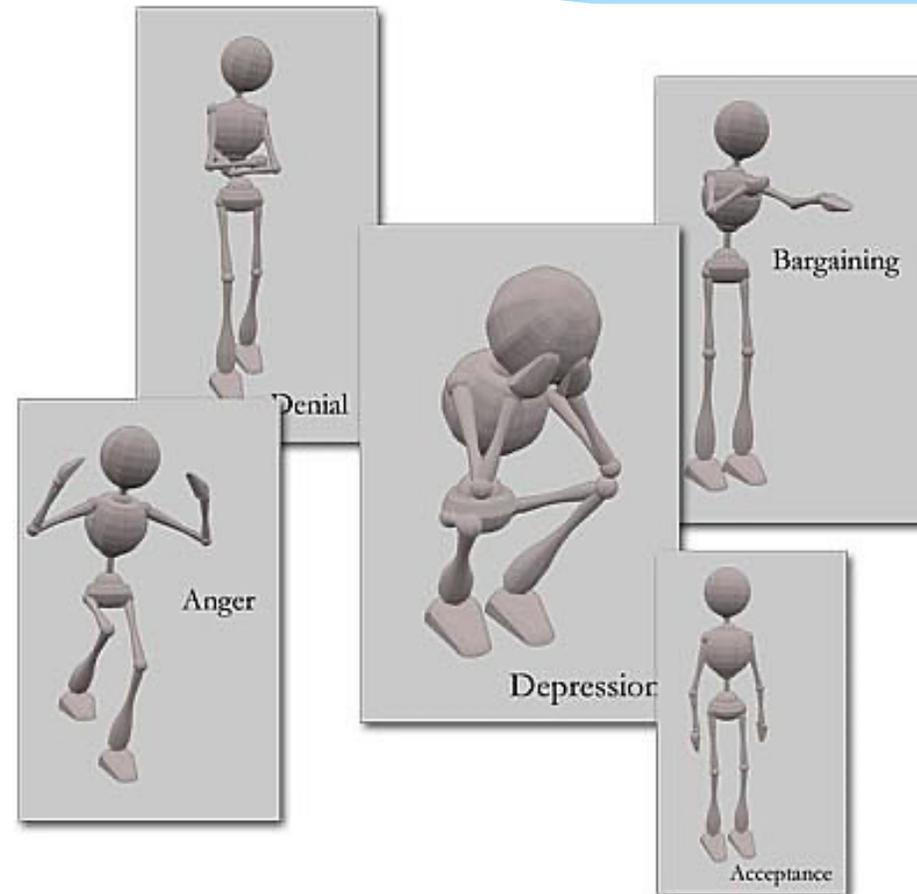
# Supporting Donor Families



- \* Loss and grief are primary
- \* Timing of the conversation
- \* Compassionate care before, during and after donation

# Elisabeth Kübler-Ross's Five Stages of Grief

- \* Denial
- \* Anger
- \* Bargaining
- \* Depression
- \* Acceptance



# William Worden's Tasks of Mourning

1. To accept the reality of the loss
2. To experience 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

# Meaning Reconstruction

- \* “Meaning finding” or “turning to already-existing frameworks of meaning”
- \* “Meaning making” or “making sense of loss”

Neimeyer, 2007

# 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

# Unique Bond Between Donor Families and Recipients



# Positive Impact on Donor Families

- \* Empowerment
- \* Fulfilling their loved one's decision
- \* Changing the ending of the story
- \* Lasting legacy

# Survivor's Guilt





# Survivor's Guilt

Why me?

Why not me?

Why did I survive when others did not?

- Life-threatening situation and living to tell about it
- Feeling unworthy or undeserving
- Co-exist with other responses

# Post-Transplant Challenges

- \* Not feeling “worthy of the gift”
- \* Expectations regarding a speedy recovery
- \* Medical complications or graft failure
- \* “Good enough” stewards

# Recipients in their own words

## Our initial questions:

What organ did you receive?

What, if any, thoughts did you have about your deceased donor when you learned you would be needing a life-saving transplant?

Can you share what some of your feelings were after receiving the gift of life?

## Our follow-up questions:

Is there anything that would have been helpful for you to have learned before or after your transplant in coping with your feelings of guilt?

What, if anything, has helped you come to terms with the guilt you feel/felt?

# Recipients in their own words

It was something I struggled with for a long time and initially prevented me from getting on the waiting list.

I didn't want someone to die so I could live, especially knowing my donor would most likely die tragically and unexpectedly. I prayed to God that he take me instead so my donor could keep living.

I was not sure if I personally wanted to just die, or if someone else should die so I could live. I never had so many mixed emotions in my life

I was very grateful and happy to receive the transplant and still very much feel that way! But I felt a lot of sorrow for the family that lost their loved one. I really didn't know how to feel and I felt guilty being happy.

I felt thankful to be alive but guilty because I got to live and my donor didn't. I also felt an overwhelming desire to give back as a way of showing my thanks and gratitude.

# Recipients in their own words

I think what would have been helpful is better understanding of the process of [deceased] donation and more understanding on how difficult this was for me from the social worker I worked with.

I never talked to my team about how I felt but I spent many days and nights talking to my husband.

I don't even remember if the subject of guilt was addressed. I'm not saying it wasn't -- only that I don't remember. Guilt and other emotions definitely should have been addressed during pre-transplant appointments.

Meeting with donor families truly changed my perception. Hearing the stories and getting to know the experiences from the donor family perspective I believe would help a lot of transplant patients.

Prayer, meeting donor families and hearing their stories ALWAYS helps!!

Volunteering with the OPO has been very helpful. Both recipients and donor families work together and my interaction with them has helped me deal with any feelings of guilt.

# What Can We Do To Support Recipients?

- \* Accept what you are feeling
- \* Know you're not alone
- \* Relief and appreciation can coexist with your guilt
- \* Grieve those who died
- \* Do something with your guilt
- \* Don't get stuck on the 'whys'
- \* Embrace life

# Challenge and Reframe Thoughts

- \* Somebody died in order for me to live.
- \* I don't want to be a disappointment to them.
- \* What am I supposed to do now with this second chance?
- \* While waiting: I don't feel comfortable praying for someone to die.
- \* What families say to us.

# A donor mother in her own words



Charles Grugan, Jr. and family

Thank you.

Questions?

# A Special Thanks to Our Presenter



**Lara S. Moretti**

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# Q & A

QUESTIONS & ANSWERS