

Family-Centered Bereavement Retreats

Creating community among families and organizational partners on the bereavement journey

Nancy Cincotta LCSW, MPhil, ACSW
 Helena Gutierrez Richards LCSW, ACSW, OSW-C
 Keli Coughlin MS
 Sharon Eddins MDiv, BCC
 Kim Todd CCLS



Tom Coughlin Jay Fund Organizational Partners

Nemours.
Children's Specialty Care

Art with a Heart
in Healthcare

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Camp Sunshine Organizational Partners




JONATHAN BEECH
MEMORIAL CONCERT








- Family Donors & Foundations
- Community Resources
- Referring Centers

Learning Objectives

- Gain an understanding of the bereavement trajectory and the need for programming for families after the death of a child
- Gain information on how to develop a bereavement program to support families, generating information from two well-established bereavement retreats
- Gain a sense of practical tools and interventions to work with parents and siblings after the death of a child
- Gain exposure to a framework for collaborative programming between non-profit groups and treatment centers
- Gain an understanding of how to best respond to the needs of individual families

Bereavement Retreat Thinking

- The bereavement trajectory
 - What is the need for programming for families after the death of a child?
 - Do families "do better" when bereavement services are provided?
 - How do you define "better"?
- Why the retreat environment?
- How do we know it is effective?
- How do we know bereavement counseling is effective?

Models of Bereavement Support



- Individual Counseling
 - (Child and Adults)
- Support Groups
- Institutional Memorials
- Retreats/Camps*
- Online Communities

What is different?

In Groups


- Intentional
- Bereavement-focused
- Person-centered
- Verbal and cognitive processing
- Part of the day, not the whole day
- Must exist in other contexts

At Retreats

- Safe nurturing environment
- Family-centered
- Both therapeutic content and day to day living (being a family, having fun)
- Parenting
- Microcosm of daily family functioning and routines (and escape from routines)
- Community embrace
- Life taken care of (food)

Processes in Family Work

- Bearing witness to family narratives (sharing the story)
- Shared experience (lived memories of dx/tx, EOL, death, funerals/memorials)
- Living in the space of longing after the death
- Growing and grieving forward



Family Considerations


Adults



- Experiencing the worst loss
- Enduring losses (present and future)
- Disrupting family structure
- Sustaining emotional bonds
- Seeking "presence"
- Parenting after the loss of a child
- Finding your best self going forward
- Making meaning
- Finding focus and drive

Children

- Experiencing loss at different developmental stages
 - Cognition, memory, perception
- Shifting family roles (birth order, responsibilities, structure, etc.)
- Losing connection to sibling, to non-grieving parents, to love as previously experienced
- Revisiting missed or altered milestones (college)

Camp Sunshine



- Located in Casco, Maine
- Provides retreats combining respite, recreation, and support for children with life-threatening illnesses and their families through the various stages of a child's illness and bereavement programming
- 2,500 volunteers annually, 75 per session
- 16 year-round staff, plus Medical Director, Psychosocial Director, kitchen and challenge course staff, lifeguard
- 23 camp sessions in 2019, including 2 bereavement retreats (applications available)

Sample Program Schedule



Day One	Settle In, Meet your volunteer, Memory Family Dinner & Entertainment Family Bonfire - (family members together) (Comfort/Being taken care of/introducing fun)	
Day Two	AM Ice-Breakers/Kids and Adults separate PM Kids' competence building	
Day Three	Parents' Group AM/Dads' Group PM Ballon Launch Evening Talent Show	

Sample Program Schedule



	Day Four	Parents' Support Group AM Kids' Groups AM Family Free time (activities and down time)
	Day Five	Mothers' Group/Parents' Group (Sibs Speak) 9-12 Talking/Expressive Arts Group Wishboat Launch Celebration Show (November- Quilt Parade) Slide Show
	Day Six	Closing Parents Group Morning Kids/Teens' Group Program Lunch Happy Trails

Camp Sunshine: Tools and Interventions

Blend of Psychosocial Support, Recreation, Respite, Family Activities



- 5- and 6-day programs
- 8 support groups (parents, moms, dads, teens, kids)
 - Siblings as teachers, parents as mentors, family volunteers
- A built community of bereaved families
- Camp activities by age and whole-family activities
- Bereavement Activities: Wishboats, Balloon Writing & Launch (releasing, letting go, connecting, communicating), Quilt-making, Memory Table, Slide Show, Group Work program, Expressive Arts

Balloon Launch



Program Funding & Partnerships

- Think locally and globally
- The only way to get funds is to ask for funds...
- Many people will want to help with the bereavement program
 - Fundraising-Plunges-Pumpkin Festival- Suitcase party
 - Supplies/Specific to Activities (Wish List-website, printed materials)
 - Organizations
 - LLBean: sled dogs
 - Bryan's Dream: blankets
 - Road Rally
 - Mr. K: art supplies
 - Family organizations
 - Sing Me a Story (<https://singmeastory.org>)

Program Evaluations

- Survey
- Evaluation packet
- Family letters
- Notes and letters
- Online discussions



"My question is: Are we making an impact?"

Survey Responses: Parents' Words of Hope

- To see my daughter grow up, graduate, marry, have children, and outlive her parents.
- I hope our family can be whole again.
- I hope for the chance of giving birth to more kids.
- To be a good father — nothing else really matters right now.
- To be open to the needs of others and to accept the help of others.
- I hope to find peace and a balance between the sad memories and the happy ones.
- I hope to love more, appreciate more and... remember the very happy moments I had with my daughter.



Camp Sunshine Bereavement Program

Camp is a place where we can be with people that "get it"
People that understand how it feels to have lost a child.
We so appreciate the chance to get away from
"the real world" and be able to freely talk


Camp Sunshine Bereavement Program

Society cannot see the large part that is missing
from a parent or sibling that has lost a member
of their family. At Camp Sunshine we have
all experienced the same loss, we see each other
and understand that a part of us is missing.
At Camp Sunshine we can feel "normal" for
a few days each year.

Camp Sunshine Bereavement Program

This is a place where my son can
let down his guard and talk about
his sister, ~~his~~ his best friend. This is a
place where all of us can let down our
guard and say the names of our
children without fear of reprimand of
those who think it is possible to "get
over" a child's death and the future
lost when that child died.

Asking Questions & Giving Voice




1. What have you learned about yourself along the entire illness journey and since your child died?
2. What do you see as the value in telling your "Family Illness Story"?
3. If applicable, what do you feel have been the primary issues for the siblings in your family (and what have you learned about him, her or them)?
4. What do you value about the Camp Sunshine experience?
5. Is there a particular topic you would like to have discuss in the groups this week (or in the future)?
6. How do you currently use social media to support you on your family's bereavement journey?
7. How has Camp Sunshine helped your family since your child died? What other things have you found helpful?
8. What offers you hope since your child has died?

Grief Art



Quilting as a Clinical Tool



Quilting Narratives

Cathartic Activity

- Clothing tells the narrative through a different lens
- Memories of sight, smell, and touch activated
- What did the child wear to treatment?
- What is the child buried in?



Quilting as a Therapeutic Art Form

Growing Grieving Communities



Siblings

Activities

- Edible Art (Art near the heart)
- Rainbow Art
- Drawing in Three Dimensions

Groups*
Looked under the bed, in the closet, in the basement

Writing
College essays
One word exercise

Camp Activity Experience






One-Word Exercise




Tom Coughlin Jay Fund Foundation

- Serves pediatric oncology families in Northeast Florida, Southeast Georgia, New York, and New Jersey
- From diagnosis to recovery and beyond
- A non-profit organization whose mission is to help families tackle childhood cancer by providing comprehensive financial, emotional, and practical support
- 6 full-time and 4 part-time staff
- 230 volunteers on an annual basis



Tom Coughlin Jay Fund Bereavement Program

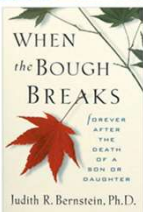


- Annual bereavement weekend for parents and siblings
- Hosted at a resort in the Jacksonville area
- Facilitated by psychosocial clinical staff from various pediatric institutions in the local area
- 40 volunteers, including clinical staff members
- Hosted by Tom Coughlin Jay Fund Foundation




Tom Coughlin Jay Fund Bereavement Program continued


- Send personalized card and book to all families upon death of child.
- Staff often attends funeral/memorial service.




Sample Weekend Schedule




Friday	Registration 4:00 p.m. – 6:00 p.m. Dinner & Entertainment
Saturday	Breakfast & Lunch Speaker & group discussion sessions for adults Special activities for children, adolescents & young adults. Family Project with Art with a Heart in Healthcare Dinner & Entertainment
Sunday	Breakfast A Service of Celebration and Hope*




* Extended family members are welcome to attend this service


Overall Theme of the Retreat 

- Photo Buttons
- Family gift
- Family Art Project
- Keynote speaker


The Story Continues... 

- **Theme** "Life stories and memories are by their very nature open-ended — they are never finished". – Thomas Attig
- **Family gift** – Black Tassel Oval Bookmark (personalized w/ child's name).
- **Art with a Heart Project** - Journals



Love is... 

- **Theme** - "Love is" - "When someone you love becomes a memory, that memory becomes a treasure". -Unknown
- **Family gift** – Lucite keepsake heart (Child's name)
- **Art with a Art Project** – Treasure Boxes



**Tom Coughlin Jay Fund
Bereavement Program**

"The feeling of pretending I'm OK is worse than the feeling of not being OK. I myself have gotten pretty good at covering up the debilitating pain of losing my children. Nevertheless, the pain is there. I swallow my anxiety in public, at my workplace and around friends and family. I have gotten so good at molding my mask that I have actually had someone tell me "well, you seem fine..." my response was "that's because I'm a grown-up and I have to." This weekend, I learned after 11 years, I DO NOT HAVE TO! It's my choice how I live with this unimaginable grief, pain, depression, anxiety and guilt."

**Tom Coughlin Jay Fund
Bereavement Program**

"These weekends mean more to the families and siblings than anyone could possibly imagine. It is a safe haven for emotions, feelings, thoughts and most of all companionship. We are always honored and thankful to get to attend this event. Thank you all who put your love and time to celebrate the lives of these beautiful children.
We love you all!"

**Tom Coughlin Jay Fund
Bereavement Program**

"Once each year a special group puts on a remembrance event. We get to let down our guard and share with others who have been through what we have. This might sound odd, but we've been blessed to meet wonderful people. People who we'd never wish "had to" meet us. To our "old" friends – thank you for the shoulder(s) and to the "new" friends, my heart aches for you. I hope we can be that shoulder."

Tools and Interventions- Whole Family

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- Friday evening activity to encourage connection among families.
- Family Memory Making Art Project
- Saturday evening entertainment such as drum circle, dancing, etc.
- Service of Celebration and Hope to conclude weekend with families hopefully feeling less alone on their island.



Tools and Interventions - Parents

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- Saturday morning keynote speaker followed by interactive activity
 - journaling
 - meditation
 - personality inventory
- Saturday afternoon separate mothers and fathers discussion groups



Personality Inventory



100 Acre Wood Personality Inventory which led to thoughtful discussion regarding gender differences and coping styles.

Tools and Interventions - Children

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- Saturday morning therapeutic activities
 - emotions picture frames
 - no-sew pillows
 - memory making bracelets/keychains
 - writing exercise with art therapy
 - candle making
- Saturday afternoon normalized/recreational activities
 - Bowling/Escape Room
 - Karate, Yoga
 - Movies
 - Bingo



Emotions Picture Frame




Celebration of Life and Hope



Order of Service

- Musical Prelude
- Words of Welcome
- A Word from Our Host
- Brief Reflection on Weekend Theme
- Musical Meditation
- Words of Hope from chaplains who have been present all weekend
- "The Faces of Our Children" slide show, which includes a phrase from each family about their child
- Candle-Lighting
- A Candlelight Blessing
- Musical Postlude

Appreciated by Families



- Opportunity to invite extended family members and friends
- The presence of additional team members, including physicians and staff
- A flower upon their arrival
- Opportunity to view display of photos and art projects prior to service
- Reminders of words from keynote speaker
- Video presentation [to a tune that coincides with weekend theme]
- Candle-lighting in the midst of "live music"
- Even appropriate humor!

Faces



"The Story Continues..."

Collaborative Programming
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Art with a Heart in Healthcare



Giving Tree Drum Circle



Peds Care

Program Funding and Partnerships
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- Share need, purpose, value in Remembrance Weekend
- Financial Support
 - Funding for grief support
 - Family foundations
 - Generous individuals
- Goods and Services
 - YMCA
 - Publix Aprons Cooking School
 - Trivia host
 - Yoga/Dance Studio

Program Evaluation

- Twenty question electronic survey sent out to families at completion of Remembrance Weekend
- Remembrance Weekend committee meets immediately following Sunday Celebration of Life & Hope service
- Ongoing feedback from social media, monthly support group, shared communication directly to retreat planning committee

Advocating for Programming

- Staff buy-in; importance of support by familiar team members after the death of their child; importance of programming for families
- Consider starting small, examples
 - a monthly support group for parents
 - reaching out to families (emails, cards, calls)
 - a memorial service
- Seek grant funding for a "pilot program" to show administration the importance of bereavement week(end)/retreat
- Understand the importance of providing access to bereavement services (part of care plan)(referrals)

What We Have Learned

Unanticipated Gains

- Group size is important
- Sunday service- ecumenical
- The importance of nurturing relationships among community partners that have evolved through the years
- Growth in local monthly support group for bereaved parents
- Creation of closed group on Facebook initiated by parents

What We Have Learned

Unanticipated Gains

- The value of long-term bereaved survivors to those newly bereaved
- The importance of revisiting memories
- The growth, strength, resilience of bereaved families
- Support groups yield support groups
- How much children have to say
- The unique burdens that bereaved siblings carry

Helpful tips

- Get parents and kids to hear other kids' voices (how hard it was for them)
- Get kids to hear other kids' stories (cemetery)
- Provide psycho-education given your experience (once)
- I love you because activity
- I think you are doing okay.... (how are your parents doing?)
- One word
- Photos
- Fun can be re-learned

Thinking and Conceptualizing

- Being open to learning and revisiting program effectiveness
 - When we are the teachers and when we are the learners
 - Appreciate parent and sibling wisdom
 - Acknowledging the value of mutual aid/professional support
- Why the retreat/group model?
 - Life replicates life — family, parent, sibling
 - Living with grief
 - Participation is intentional
 - What children carry with them
 - Reconstruction of memories
 - Misperceptions (stopping chemo)

Thinking and Conceptualizing

- Bearing witness to the bereavement journey over time
- Seeing families new in their grief journey and others over the long haul - how they grow
- Helping families see their own progress in revisiting the experiences of more recently bereaved families
- Thinking about how children change and the impact of that change on the family (tatoos)
 - Do you help children remember or support what they remember (is there a role for clarification?)?

Acknowledgements

Retreats could not be possible without:

- passionate clinical staff
- retreat employees
- dedicated volunteers
- generous donors
- caring community partners
 - families

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What can we learn from families

What I wish had happened...

"Someone had told me to tape my daughter saying, 'I love you, mommy...'"

Other things you have heard- panel? Audience?

Q & A Panel Discussion



CAMP SUNSHINE
www.campsunshine.org
35 Acadia Road Casco, ME 04015
info@campsunshine.org

TOM COUGHLIN JAY FUND
www.tcjayfund.org
PO Box 50798
Jacksonville Beach, FL 32240
info@tcjayfund.org

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nancycincotta@gmail.com

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Helena.Richards@nemours.org

Keli Coughlin MS
keli@tcjayfund.org

Sharon Eddins MDiv, BCC
Sharon.Eddins@bmcjax.com

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