Helping Adults With Intellectual Disabilities Understand Death and Express Grief

When Tom and Mark lost their mother Mary, their grief was extreme. Both men, now in their 40s, have Fragile X syndrome (FXS) and struggle with communication because of their intellectual disabilities. Mary had cared for every aspect of their needs and now they had to adjust to life with their aunt and uncle. Continued on page 2

2,661 reasons to lend... mend... send...
310.543.3440 | providence.org/ptcf
Understanding Death and Expressing Grief

Continued from page 1

For six months, Tom and Mark were uncooperative and rebellious. Then their aunt called TrinityCare to ask about our bereavement programs.

Senior bereavement counselor, Shirley Perkins MSW, ASW, came to the family just in time. Shirley has decades of experience and her strategy was to create a group experience for the bereaved sons that would not be overwhelming for the aunt and her nephews. She implemented the Ad Hoc Network Simulation Model, a group format she adjusted to the bereaved participants’ ability to engage in a structured environment and provided a safe place for all participants to express their feelings. Shirley, the bereaved sons, their aunt, and Shirley’s intern, Adam, formed the group. Shirley started with the “ping-pong” approach: each stating their name, why they were participating, and going around the group for each to answer. They started with 10 minutes, building on the success of each session, until Tom shared, “My mom died.”

Shirley learned over nine months that the sons believed their mom “is happy now. She is with their dad and the dogs, at the beach,” and both continued to say, “she is happy.” It was later learned that the phrase “at the beach” and “their mom was happy” meant that mom, their father, and the dogs were all “with God in heaven.” They knew they had lost their mom, and neither parent was coming back.

Tom made a connection with Adam, who used to live in Palm Springs, where his mom took them frequently for vacation. They interspersed topics related to their specific interests. For example, Tom liked to look at RVs on the computer, so some sessions were about RVs. These sessions also provided Tom and Mark with positive male interactions and helped them validate their feeling that men could show grief.

Shirley then connected with the case manager at the Harbor Regional Center and the interdisciplinary team for a meeting with the bereaved sons and their aunt to discuss their care plans. Shirley helped to coordinate multiple agencies as Mark and Tom learned many Activities of Daily Living skills, including cooking and cleaning the house and the yard. Both men had been working on their jobs for years and walking about a mile from home to their employment sites. Both had job coaches assigned by the Regional Center, who helped them at the outset to acclimate well in their new work environments.

As of this writing, Tom and Mark continue to live in their homes by dividing tasks between them. They have the support of their family along with an in-home support service provider for several hours each week. Shirley continues to be a constant, positive presence for both men.

Tom and Mark’s family have expressed their appreciation for the support of Providence TrinityCare Hospice Bereavement Service. This outcome was only possible through this wonderful family’s perseverance, the excellent Harbor Regional Center staff, and their powerful networking with Vocational Rehabilitation and other community agencies. With their help, the TrinityCare Hospice Bereavement Department and the bereavement team dreamed and accomplished what some might think impossible.
Letter from the Executive Director

Dear Friends,

We had a great time together on Saturday, October 8th. Layla’s Walk attracted more than 400 people to enjoy a beautiful morning full of smiles in honor of Layla Paige and the 3,000 other children we have served in TrinityKids Care. We also raised more than $100,000 to support TKC’s efforts throughout Los Angeles and Orange Counties.

As the days get a bit shorter, we’re drawing closer to the end of the year and our Light Up A Life celebrations. We hope you can join us on November 29th in Costa Mesa or December 1st in Torrance. Visit foundation.providence.org/ca/trinitycare/events/light-up-a-life for all of the details and how to join us.

I have been with the Foundation for about four months now and I want to thank everyone for the incredibly warm welcome I have received. You all have created a special community and I am privileged to be part of it. I look forward to seeing many of you in the next few months as we wrap up a very successful 2022.

Best,

Matthew Seela
Providence TrinityCare Foundation
Executive Director

Letter from the Bereavement Chair

Dear Friends,

Who cares for those who care? May seem like an odd question. Maybe because we do not consider those who provide care of needing help themselves. Yet a spouse, family member or friend is on the front line providing loving and physical care with unbroken devotion, often for an extended period. Taking charge of someone dying is emotionally heavy and physically draining. And then there is grief and loneliness. Yet those giving care often keep quiet, enduring on without asking for help.

TrinityCare understands this need. Its bereavement team is there to encourage spiritual and emotional healing through various programs.

I have a heart to ensure we not overlook the needs of our caregiving champions. Therefore, I chair TrinityCare Foundation’s committee for Bereavement Services with help from committee members Tom Komp and Anjie Villalobos. Supporting Bereavement Services is a priority for us. But we need your assistance in the continued funding of this essential program. Because of their benevolence in helping a loved one, the unsung heroes of care need our help. Let your benevolence help us to support them.

Sincerely,

Garre Garzerian
Providence TrinityCare Foundation
Bereavement Chair
Caregiver Spotlight: Nancy Langevin
Meet Nancy Langevin, TrinityCare Bereavement Services Program Coordinator

Nancy has been with Providence TrinityCare for seven years, but it was when the world shut down two years ago that she truly found her calling. That’s when she began her current position as Bereavement Services Program Coordinator, providing bereavement support for families and the community during the global pandemic.

When the pandemic hit in 2020, the Bereavement Team had a calendar of in-person events scheduled and families eager to start the process of working through their grief. When in-person meetings were no longer possible, the Bereavement Team quickly learned everything they could about Zoom and how to bring people together virtually. Nancy became so proficient that she began helping other organizations use the platform.

As word spread about the virtual services, attendance grew exponentially—and extended beyond the South Bay. We have attendees throughout LA and Orange Counties, and as far away as New York, where we are supporting both a parent and child.

Through this work, Nancy has learned to never take life for granted. Seeing what our families go through, her work has become more family-centered and focused. Her own father’s passing three years ago reinforced her understanding that grief is different for everyone. Nancy has great empathy for all of our participants.

Nancy is continually in awe of the program’s impact on participants. When she learned that some needed additional support after the group was finished, she pitched the idea of a workshop to address those needs. The team brainstormed and created a program called Moving Forward. The workshop addresses the fact that transitions are hard, that there’s no set time for grief, and it’s okay to continue to mourn.

Nancy feels blessed by an incredible team and their dedication to creatively serving the needs of the people in front of them. She loves the team’s synergy, passion, hard work, and ability to help so many people during the hardest time of their life. She finds the work extraordinarily rewarding and is grateful for the team.
PROVIDENCE HOSPICE AND PALLIATIVE CARE SERVICES ARE GROWING!

At Providence, our innovative hospice and palliative care programs for children, adults, and their families are available at locations throughout Los Angeles and Orange Counties, including TrinityCare Hospice in Torrance, Sea Crest Hospice in Costa Mesa, and St. Joseph Hospice in Orange.

Providence Hospice and Palliative Care services are considered the gold standard in the care of patients and families in need of end-of-life services or support for those with a chronic or life-limiting illness. We provide the full range of compassionate support to all our patients and families with nine clinical teams and a staff of more than 350 professionals. Much of this work is made possible by extraordinary people—donors, board members, and our larger community. As our work grows, so does the need for philanthropic support, and we are excited to introduce the new chair of our Orange County Philanthropic Advisory Board.

Dr. Julie Nisco-Madden is excited to lead our fundraising efforts in Orange County. She is a Doctor of Nursing Practice and an Integrative Health and Reiki Practitioner with a background in hospice and palliative care. She is passionate about increasing access to integrative health care and destigmatizing death in the United States. She is currently working as a director of integrative health and adjunct professor at Pacific and Regis Colleges of Complementary Therapies, Theoretical Perspectives of Advanced Practice Nursing, and Transition to Professional Nursing Practice.

In support of our Necessities of Life Program, Wendy Wolsleger and Janet deMichaealisi of Omega Society present a $10,000 gift to our Orange County representatives, Anjie Villalobos, Sally McCloskey, MSW and Dr. Julie Nisco-Madden.

Thank you Omega Society for your generous gift!

If you have an interest in our supporting or joining our work in Orange County, please contact Anjie Villalobos at anjanette.villalobos@stjoe.org.

This Is Hospice

Meet Dorothy Walker, aka Big Mama, and her son, Ray. Dorothy was her family’s matriarch. A master seamstress, she sewed everything from her daughter-in-law’s wedding dress and children’s church suits to her grandchild’s award-winning dinosaur costume. In many ways, Dorothy was the thread that interwove the fabric of her multigenerational family. Dorothy’s family emphasized their passion for preserving her memory, ensuring that future generations would know and understand their familial ties to this beloved woman. While on hospice, Dorothy was supported in living fully through the end of life. She lives on forever in those she draped with her love.

Photo courtesy of Rochelle Kock, MSW – Providence Sea Crest Hospice
Embassy Dinner

Over 110 friends and community supporters were on hand to bestow a special honor, The Glass Family Award for Philanthropy, Leadership and Service, upon Sister Terrence Landini, Sister Carol Pacini and the Sisters of Little Company of Mary for their dedication to and support of the programs and services of Providence TrinityCare.

Sister Carol Pacini, Regional General Supervisor and Sister Terrence Landini, Superior of the Little Company of Mary convent in Torrance, have dedicated their lives to caring for the poor and vulnerable during and especially at end of life. Their passion and dedication to home-based palliative care has allowed them to bestow upon Providence TrinityCare a $1 million gift to further expand the community-based palliative care program now and for future patients and families.
Light up a Life

Honor Your Loved One with a Star on the Tree of Life

In honor of National Hospice and Palliative Care Month, we invite you to place a star on our Tree of Life.

When you make your holiday donation in honor of your loved one, we will write their name on a special star and place it on our Tree of Life.

Your gift will help sustain the services that Providence TrinityCare provides throughout the year and bring comfort and warmth into the lives of our most vulnerable patients and their families.

Join us for a Special Tree Lighting Ceremony and Celebration of Life:

**ORANGE COUNTY**
Tuesday, November 29, 6:00 pm
Sea Crest Hospice
3187 Red Hill Ave
Costa Mesa, CA 92626

**LOS ANGELES COUNTY**
Thursday, December 1, 5:30 pm
Douglas & J. Glass Family Center
5315 Torrance Blvd, Suite B1
Torrance, CA 90503

For more information, visit: foundation.providence.org/ca/trinitycare/events/light-up-a-life