

# FAMILY *to Family*

## SEWING *Compassion*

**INSIDE:**

Addressing Compassion Fatigue • Putting Families at the Heart of Care  
Growing through Grief • Sewing Compassion



Family Hospice  
Part of UPMC

Dear Friends,



As this difficult time wears on, I am especially grateful that you are lending some time to our fall edition of "Family to Family." The toll of the pandemic on caregivers, both professional and family, is top of mind for us, and, as you will see, this has informed much of what we are sharing across these pages.

The risk of compassion fatigue among caregivers has been intensified by the uncertainty and disruption of the COVID-19 pandemic, which has adversely affected how people are able to care for themselves. With support from the McElhattan Foundation, Family Hospice is presenting a free continuing education opportunity featuring Rocky Bleier, decorated Army veteran and Pittsburgh Steelers Super Bowl champion. Rocky speaks from a place of deeply personal experience on the subject of perseverance. The occasion is sure to be memorable. Learn more on page one.

And speaking of memorable occasions, a wedding anniversary dinner organized by our staff for a patient and her husband provided a wonderful chance to celebrate one

family's heritage. We were honored to do so on behalf of the Panos family, whose wife and mother, Mary, was under our care. As you'll read on pages two and three, this is just one way the multidisciplinary team supports families, who are considered as important as the patient and at the very heart of hospice care.

Our cover story features volunteer Pat Deleonibus. Her myriad of talents, from baking to sewing to music and more, is applied to the benefit of families in a variety of circumstances, including after the loss of a loved one. Her sense of vocation is inspiring to me, and I am so grateful to count her as a member of our hospice team.

I hope, you, too, will be inspired by the efforts of Family Hospice staff, volunteers, and benefactors who are improving end-of-life care in our region. Your support makes all the difference in what is possible today and in the future.

*Gratefully,*  
**Jennifer Vennare**  
*Vice President of Operations*

## GRANT FUNDS EQUIPMENT FOR RESPIRATORY RELIEF

Just breathe. We've heard the phrase countless times as a reminder to slow things down when there is too much to handle. For many of our patients, this advice isn't easy to follow, and we need to provide respiratory support. Those with cardiac disease, COPD, respiratory failure, lung disease, and pulmonary fibrosis have restricted air flow and require assistance.

With the help of a generous grant from the Snee-Reinhardt Charitable Foundation, Family Hospice has been able to purchase two AIRVO™ machines that will improve quality of life for patients. An AIRVO™ machine supports oxygen and air blending, delivering heated high flow for symptom management as patients switch to a regular tube. It is a viable alternative for patients who don't want invasive ventilation or who are intolerant to it. This machine can ease the transition from a hospital to a house, to our inpatient unit, or wherever a patient chooses to receive care.

The additional benefits of the AIRVO™ machine are reducing hospital admissions and the number of days in a hospital, improving quality of life, increasing endurance, reducing adverse events, lowering respiratory rate and work of breathing, and improving mucociliary clearance.

"AIRVO™ will enable us to improve clinical outcomes for patients with end stage respiratory failure," remarks Elena Nosal, director of clinical operations.

**"We are grateful for the Snee-Reinhardt Charitable Foundation grant and look forward to incorporating this machine into our overall care plan for providing the best quality of life possible."**

**Elena Nosal**  
*Director of Clinical Operations*

# ADDRESSING COMPASSION FATIGUE

In any health care profession — an environment that demands high amounts of empathy and compassion — compassion fatigue can develop over time. By investing in education and resources to address compassion fatigue, Family Hospice is helping empower caregivers to recognize and combat this fatigue.

Words like "caring," "compassionate," and "empathic" are found throughout job descriptions for any health care worker. These characteristics are vital in putting patients at ease, handling difficult situations, and connecting with others. Traversing emotionally-draining interactions multiple times each day can be difficult. Typically, this fatigue occurs when a person is not caring for themselves and not separating themselves from the care they give.

Ed Lewis, Family Hospice manager, volunteer and bereavement services, makes an important distinction in understanding compassion fatigue. "It's different from what we recognize as burnout. Burnout is feeling drained from work stress and can be experienced by anyone, while compassion fatigue strictly applies to those in a health-related setting."

Ed continues, "It's important to acknowledge compassion fatigue and check-in with oneself. There is no shame in experiencing this, and admitting it can kickstart healing."

Healing looks different for everyone. Carving out time to pursue passions and hobbies, something that is stress-free and enjoyable, is recommended. The healing process can include travel, exercise, gardening, religion, walks in nature, painting, writing, art, etc.

The key is to engage in hobbies that center and nourish oneself.

As with so many things, COVID-19 disrupted many people's means to healing. Additionally, the pandemic created an immediately more intense work environment with unique stressors and greater demands, minus the usual outlets to release built-up emotion at day's end. Gyms and businesses were closed, travel restrictions were in place, people were physically distanced, relationships were in distress, and the loss of life was greater.

In the absence of familiar coping mechanisms, caregivers have to figure out how to restore balance.

This is one of the many reasons compassion fatigue needs to be addressed and discussed now more than ever. "There is a cost to caring for others," says Ed, "and there is a desire to help, to listen, and to care, which makes health care workers and caregivers so special. Having an honest conversation with oneself or with a loved one about compassion fatigue is a place to start."



## AN EVENING WITH ROCKY BLEIER Running on Empty: Caring for Yourself While Caring for Others

Free community program • Dinner included  
Two CE credits pending for MD, RN, SW, NHA, and PCHA  
Wednesday, November 3, 2021, 4:30-7:30 p.m.

Register by October 29:  
<https://cce.upmc.com/running-empty>

For more information, contact [meduhoc2@upmc.edu](mailto:meduhoc2@upmc.edu).



# Putting Families AT THE HEART OF CARE

Supporting the family and caregivers connected with an individual under hospice care is not an afterthought. It's at the very heart of the hospice philosophy and calls for expertise, just as with the care of the patient. In fact, it's not unusual for health care providers to seek out hospice on behalf of their patients expressly for the purpose of family support. Every member of the hospice team who interacts with a patient and family lends their skills to this principle.

Mike Panos is a devoted son to parents Mary and Peter, who both reside at Asbury Heights in Mt. Lebanon. Mary has been a patient with Family Hospice for approximately a year and is followed by nursing, social service, and spiritual care staff. Mike says his mother has benefitted from the extra care and attention that the hospice team provides, particularly as it pertains to her emotional well-being and comfort.

When asked what hospice has meant for him as a family member and caregiver, Mike doesn't hesitate to respond. Referring to Stacey Schaeffer, Mary's RN case manager, Mike says, "She's been a god-send. She has taken so much off my shoulders." He describes how she not only provides excellent clinical care, but she also coordinates so many details related to his mother's daily life and wellness, from appointments with the dentist to the beauty shop to the podiatrist, all while keeping Mike apprised of her progress. "She doesn't miss anything," says Mike.

To that point, earlier this year, Stacey and the team organized an anniversary dinner for Mary and Peter. As Mike described it, "Everything was very tastefully done, with china, real silver, and music. Stacey bought flowers for my father to give to my mother. We are Greek, and the meal was Mediterranean food. It was all tailored to things they like and really reflected who my mom and dad are."

Stacey emphasizes that, especially for the last year, the support that hospice provides to the family has been critical, particularly in a long-term care environment like Asbury where COVID-19 has made it necessary to restrict visitation. "Families have had to make decisions about their loved one's care sight unseen.

"Establishing a strong line of communication and collaboration with everyone already involved in the patient's care has provided reassurance to families trying to adjust to changes," says Stacey. "You have to meet people where they are, allay their fears, and allow them to catch up. Then you can work together to address evolving priorities."

When it comes to care at the bedside, hospice home health aides play a huge part in supporting families. Carrie Morgele has met countless families in this role with Family Hospice. She says she approaches each family in the same manner. "I treat them the way I would want my family to be treated. I want to build their confidence and to reassure them," says Carrie. "We use language and recognize things that

are second nature to us but might be foreign to them. I want them to know they are doing a good job."

Spiritual care is another means by which hospice can support families. Marlaena Cochran, spiritual care specialist, explains, "Often a patient and family are in a different place in accepting the prognosis and in what they believe about life and death. Spiritual support can help bridge those gaps and address those fears and anxieties."

Marlaena's most powerful tool in this regard is not religion or even faith necessarily, as some might expect. "I firmly believe in the power of presence. If I have been able to hold space for people to be present to themselves, to feel what they need to feel and to say what they need to say, I can see in their body language that they can relax a bit and be real."

Julie Erali is a social worker and colleague to Stacey, Carrie, and Marlaena. Her work with families typically takes two forms: helping them secure additional resources

in the care of the patient and providing emotional support. "Often patients express more concern for their families than for themselves. They worry about the redistribution of tasks and the anticipated sadness after they are gone," says Julie. Social workers can help with conversations about those practical concerns. Additionally, the hospice benefit includes follow-up and support to families for 13 months past the death of a patient.

Julie recalls a daughter who cared for her mother meticulously for many years, largely on her own. When Julie reached out to her after her mother's death, the daughter expressed, "I'm so relieved my mother has died. Is that okay?" Julie knew the power of saying that outloud to someone who would listen without judgement. "There are so many things we want to accomplish for our families, but in the end, when someone tells me I'm a good listener, that's when I know I've made a difference."

*Editor's note: Mary Panos died as our newsletter was going to print. With her family's permission, we hope we do honor to Mary's memory.*

## Growing Through Grief

**Growing Through Grief** is an educational support group facilitated by Family Hospice's bereavement department. This group will explore the bereavement experience and discuss the ways to move through the grief journey.

**Please call 412-572-8829 for more information.**

Funding for this program is made possible by a generous grant from Friends of Family Hospice.



# SEWING *Compassion*



Many of those who are engaged in the work of hospice describe it as a calling. This holds true for volunteers as well, who play an important role as part of the hospice team. Volunteer support can take numerous forms, from direct patient care to staff support to bereavement care for caregivers and family members impacted by the patient's illness and loss. Just ask **Patricia "Pat" Deleonibus**, who has applied her many talents to hospice volunteering with meaningful results.

A volunteer since November of 2014, Pat currently supports Family Hospice's inpatient unit in Lawrenceville in multiple capacities. She describes how she found her calling to be present with the dying while visiting an ill parishioner connected with her church community. "That experience helped me recognize my comfort with end-of-life circumstances and made me want to explore that opportunity further," says Pat.

Pat recalls visiting patients in their homes during her early days of volunteering with Family Hospice. "It often involved patients and families and I talking, watching television, and just laughing together," says Pat. "The simple gifts of home and normalcy really matter."

Now, volunteering at the inpatient unit, Pat connects with those she visits by listening to their stories and fond memories. "It's such a gift to see people as they are, to learn who they are and what has been important to them, and to share in their spirit," says Pat.

For those patients unable to speak, Pat sits with them, holds their hands, sings a hymn, or reads from a religious text, if she knows a patient's faith is important to him or her. From time to time, Pat even pulls out her flute and plays for the entire unit.

Even during the COVID-19 lockdown, when Pat could not visit patients or staff, she would bake treats every Monday and drop them off to the unit. Pat tried out lots of recipes and ingredients and

joked about her improvisations. "If the staff really liked what I prepared that week, there was no guarantee that I could make the same thing again!" Pat laughed.

As Pat can attest, visiting patients is only one of the many ways to volunteer with Family Hospice. When a patient dies, the family can provide some of their loved one's clothing items to be sewn into a remembrance pillow. Families provide t-shirts, button-down shirts, flannel shirts, and even ties. Pat has sewn many pillows, all with designs and materials unique to that patient.

"I lay the pieces out on my dining room table until a design speaks to me," says Pat of the pillow-making process. She sometimes adds a zipper or uses the button closures on the item so that the pillowcase can be removed and washed. She sews on the pockets from the shirts so those loved ones can place their hands in the shirt pocket. The effort put into each pillow does not go unnoticed; recently Pat received a thank you note from a family in Australia.

Beginning this fall, Pat will be applying her sewing skills to the Holiday Memorial Dove campaign. New this year is the option to have a dove sewn, similar to the remembrance pillows, to bring comfort at home.



*Remembrance pillows*

More information on the holiday remembrance dove program can be found on our website, [FamilyHospicePA.org](http://FamilyHospicePA.org), under News and Events.

Clearly, Pat enjoys using her talents to help others. "I never really thought about having a calling, but this is what a calling feels like," says Pat. "It's who I am and what I am supposed to be doing."

If you would like to explore volunteer opportunities with Family Hospice, call **412-651-1602**.



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Go Green! If you would prefer to receive your copy of our newsletter via e-mail, sign up from the home page of our website or contact **Helen Stickney**, Development Assistant and Donor Database Manager, at **412-572-8457** or **stickneyhe@upmc.edu**.

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## *In Remembrance and Love*

Join our long-standing tradition of remembering a loved one with a dove this season. We have a number of ways and levels by which to participate. Learn more at **FamilyHospicePA.org**.

Proceeds benefit patient care, fund programs, and educate the community about the benefits of hospice care.

*Holiday Doves 2021*