A day in the life of a hospice caregiver:
Stories of love, devotion, laughter & courage

Also inside,
Hospice of the Panhandle named Large Business of the Year by Martinsburg-Berkeley County Chamber of Commerce
A Message
from Margaret Cogswell, CEO

Stories share Hospice of the Panhandle’s mission

As CEO for Hospice of the Panhandle, I naturally spend time looking at lots of numbers. Some of them make my eyes cross and some of them are strong indicators at where we are being successful and where we need to concentrate our efforts. But I’ve always felt one of the most important ways to understand hospice care is through the use of stories. Stories are the most powerful tool we have to help each other understand our experiences. After spending 28 years at the helm at this agency, I have heard so many touching and compelling stories! There have been stories of bravery – a soldier who fought in World War II, sharing his memories of being shot at by the enemy. There have been stories of compassion – a nurse who travels out to a patient’s home in the middle of a snowstorm, and who sits with the patient and then his family long after the patient passes away. And mostly, there have been stories of love – a young patient in his early 40s saying goodbye to his two young children and wife who hold his hand at his bedside.

I am moved by all these stories – some that I witness, and some that our staff share with me. These experiences are what continue to motivate me, and I hope they will motivate you - to keep supporting our organization in large and small ways, to volunteer, and to share this work with others.

I recently had occasion to recall an old story, an experience I had back in the early days of hospice when I was the only paid staff member and we had a handful of volunteers. We had a patient in our program with whom I was familiar and something told me to stop by to see the patient and family. That wasn’t something I did regularly and I don’t recall why I chose that particular day or time. When I came to the patient’s home, it was clear to me that the patient would die very soon. I was able to stay with the patient and family during this time. While this happened more than 25 years ago, I still recall the loving way the family gathered around the bedside and how members read Scripture together and recited prayers. I was a witness and a participant in a “good death.” Recently, another member of this same family died and hospice was able to serve the family once again.

How our program has evolved, changed and improved since that first death! Once again the family was at the bedside and incredibly supportive of each other and the patient. I was not present, but one of our incredible hospice nurses was at the bedside, and she, too, was moved by witnessing this family.

Over the past 35 years, countless families throughout the four-county area have been touched by Hospice of the Panhandle’s care. I was reminded of that again last night as person after person congratulated me at the annual Martinsburg-Berkeley County Chamber of Commerce dinner. Hospice won the large business of the year award. We are so incredibly humbled by the award. It is a true testament to the dedication, compassion and care that our staff and volunteers have for our patients and families. Hospice staff and volunteers are witnesses to strength and courage. We see the good and sometimes the bad. Our lives are changed by our work and I, for one, would not trade it for anything else.

As we celebrate National Hospice Month throughout November, please join me in retelling your stories of Hospice – the experiences you’ve had and how they’ve changed your life. They are powerful tools that help others receive this very special care.
As the volunteer coordinator at Hospice of the Panhandle, I see every day how volunteers make a difference in the lives of our patients. My favorite stories are the ones where volunteers help to make a final wish a reality. These wishes can be simple or more complicated, with a lot of detail involved in some. Over the years, several have remained in my memory as if they happened just yesterday.

There was the patient who really wanted just one more taste of squirrel gravy. One of our volunteers happened to have a squirrel in the freezer and made the gravy for this patient. He took only two bites but those two bites were the best to him.

Another favorite is a nursing home patient who wanted to ride a motorcycle before she died. Once again, a volunteer (with a motorcycle and a sidecar) rose to the occasion and made this sweet patient’s dream come true. She wore the biggest smile that day!

A recent favorite of mine was a patient who had a last wish before he died. He wanted to sit on a beach and eat oysters just one more time. Being in the Eastern Panhandle, this was quite a big request – not many beaches nearby!

One of our volunteers offered to take him to the next best thing to a beach - the lake at Cacapon State Park. Our very own Hospice of the Panhandle chef prepared oysters to the patient’s liking and the volunteer provided the transportation and company for the day. They sat on the sand, ate oysters and talked. The patient said it was the best time he had had in such a long time.

These are just three of the many stories that could be shared. Volunteers play such a vital role in the services and care we provide to our patients and families. They help grant final wishes, brighten a day with a visit, provide assistance with cleaning, transportation and respite, and provide a loving presence at the bedside of a dying patient. Plus they do so much more!

Being a volunteer coordinator is such a blessing! Working with the most caring, self-less, and giving people and coordinating them with patients who are living their final days in the way they desire, is such rewarding work!

If you have never had the opportunity to volunteer in any capacity and experience the internal reward you get, you should consider becoming a hospice volunteer today. We would love to have you join our team!
November is National Hospice Month!

To celebrate, our staff are giving you a sneak peek into a day in their lives as a hospice caregiver. Some will make you laugh. Some will make you cry. All will share some of the challenges and victories that we experience every day with our patients and their families.

Getting that one chance...
By Danielle Ruble, RN, BSN, Access Team Leader

One shot. It’s just one shot, one visit, one conversation, one chance to earn your trust and confidence in our skills and ability to provide excellent care to you or your loved one.

Being an access (admissions) nurse for Hospice of the Panhandle means meeting new people every day. It means teaming up with physicians, being a patient advocate, and riding a new roller coaster of emotions every day. It means having difficult conversations and guiding members of our own community in the right direction.

Being an access nurse is difficult but very rewarding work. We are the first Hospice of the Panhandle employee to visit a home. It’s our voice, our words, and our empathy that can effect whether someone is able to accept Hospice care into the home. In just one visit, we describe the Hospice philosophy and goals, we assess an individual’s current condition, and work to individualize one’s plan of care. Visits can be completed in the home, hospital, nursing homes, or personal care homes. We recognize that whatever the type of home a person resides in, it is someone’s personal – and sometimes very private - space for the patient and family, and we are privileged to be invited.

When it comes to working at Hospice of the Panhandle, I often hear “Oh, it takes a special person” or “I don’t know how you do that.” Our patients, who have life-limiting illnesses are often so very tired, They feel drained and emotional. So do their families.

The decision for them to seek palliative (also known as comfort) care is also very personal and often includes discussion with patients’ closest support systems.

The fact I’m asked to be a part of these moments is beyond fulfilling.

So, to those of you who have called – more than 925 of you in 2015 alone, thank you!

Thank you for trusting me, thank you for sharing your story with me, and thank you for giving Hospice of the Panhandle that one shot.
Lasting love and devotion
By Erin Rouse, Inpatient Team Leader

One of the great pleasures in my job as the inpatient facility director at Hospice of the Panhandle is witnessing a family’s love and devotion. One particular family that I got to know over the course of several months was especially devoted to a wonderful patient of ours, who spent nearly three months with us.

Before coming to stay at the inpatient facility, the patient had had three hospitalizations for recurrent urinary tract infections and sepsis. She came to the IPF as a residential patient at the beginning of July. When she was admitted, her prognosis was not good; her life expectancy was thought to be days to weeks.

However, something remarkable happened. Over the next few days, the patient became more comfortable and began eating a little more. She became stronger! The patient’s husband rarely left her side, and was delighted to see her more like her old self. Her children came to visit. They spent time in her room, watched TV, laughed and held her hand. They used the family kitchen, enjoying family meals together and grabbing a cup of coffee when needed. In the family living room, one of the children from out of town was able to work – the facility’s free Wi-Fi helped him to do that.

Over the course of the patient’s 2½-month stay, her husband of 65 years spent every night with her. The staff brought another hospital bed in the room so that he could sleep right next to his wife. What amazing love and devotion! The staff and I were so touched!

After the patient died, her daughter sent a thank you note expressing her gratitude for the care that was provided to her mother. In her note she said that Hospice’s IPF staff was excellent, caring and compassionate. Not only did team members care for her mother, but for the entire family as well. Each time a staff member would leave the room, he or she would not only ask the patient if she needed anything. Staff would also ask the patient’s husband and any family members in the room had any needs as well.

The daughter said she was touched by the fact that not only was their mother receiving excellent care, but so was her father!

We were privileged to take care of both! This beautiful family allowed us to share a sacred special time. And we are grateful.
One of my favorite Broadway musicals is a show called “Rent.” I first made the trip to New York City to see this production when I was in college. I was profoundly moved by its powerful message. Several of the principal characters are facing the reality of having a terminal illness. Yes, there is anger, sadness, and fear - emotions often present when accepting one’s own mortality. But more importantly there is laughter, hope, and love.

In the end, the characters who are dying teach their comrades who are not ill, as well as the audience, how to live. Those who were terminally ill did not let their disease define them but instead embraced life. I walked out of that theater grateful for the reminders: Live life to its fullest. Cherish every moment. Take chances. Love big and hard. In the end, friendships and family are the only things that really matter.

I would have never imagined at that time that my career would offer me these same reminders each and every day. I am also eternally grateful for the opportunity to learn from those whose time on this Earth is drawing to an end.

While I do not meet every patient Hospice of the Panhandle has the honor of serving, I do hear every name and often hear stories that bring so much value to the work that I do. Every week the hospice teams consisting of nurses, chaplains, aides, bereavement staff, volunteer staff, and social workers meet. Every meeting starts out the same way.

We reflect on each patient who has passed away the prior week. Each team members has the opportunity to share. We share funny stories, stories about the patient’s accomplishments, our favorite memories from our home visits. We talk about the loved ones and caregivers; we acknowledge all that they gave, how they showed love in the most incredible way, and who they lost. And then there are the times that we mention the lessons we ourselves have learned in the process of caring for this individual. After the reflections have concluded, team members pour colored sand into a large glass vase. Layers of color week in and week out create a diverse and beautiful display representing those valuable lessons, those fond memories, and most importantly the celebration of life that we have had the privilege of sharing.

Five hundred twenty five thousand six hundred minutes
Five hundred twenty five thousand moments so dear
Five hundred twenty five thousand six hundred minutes
How do you measure, measure a year?

In daylights, in sunsets
In midnights, in cups of coffee
In inches, in miles, in laughter, in strife
In five hundred twenty five thousand six hundred minutes
How do you measure, a year in the life?

How about love?
How about love?
How about love?
Measure in love

- From the song “Seasons of Love” from Rent
During the week of November 9 - 13, Hospice of the Panhandle placed a flag around the flag pole for each veteran who passed while under our care since Veterans Day, 2014.

145 flags were placed.

Thank you to the families of these veterans for your sacrifices.

Thank you to veterans and their families everywhere for your service.
Knowing what matters most

By Julie Sayre, Social Worker

At the end of life, families and patients often come across obstacles that are preventing them from reaching goals that they may have in order to provide the best care for their loved one or themselves. It is my job to help them overcome those obstacles and focus on enjoying the time they have left, without worry.

I am the social worker at the Hospice of the Panhandle Inpatient Facility, which gives me the opportunity to work with our patients at our facility as well as in their homes. Recently, we had a patient who was living by himself and received care assistance only from his neighbor. This gentleman, “Tim,” (not his real name) did not have any local family.

Tim had decided that when he was no longer able to care for himself he would like to go into a nursing home, but first would like to find placement for his dog. Tim had a 5-year-old dog named Hercules that he rescued. But Tim really credited Hercules for rescuing Tim from a deep depression. Many of us count our pets as our family, and to Tim, Hercules was no different.

As Tim declined, he continued to care for his dog, even better than he cared for himself. Tim had become so ill that he was not able to easily get off the couch or take his medications. But he was still taking good care of Hercules. I had visited Tim at his home to talk to him about if it was time for him to come to our inpatient facility while we would look for permanent placement for him. Tim declined my offer because he didn’t have a place for Hercules to go. I returned the next day to talk to Tim. He was so ill that day that he could not get off the couch. Tim agreed to come to the inpatient facility only when I promised I would find a new home for Hercules.

Within four days, we found placement for Tim and I searched diligently for a new home for Hercules. A few days later, we found a forever home for Hercules and Tim, his loving owner, passed away the same day. I would like to think that he was comfortable knowing his “family” was going to be well cared for.

Whether it is obstacles surrounding long term placement, concern for family members, or even providing emotional support through difficult decisions that are made at the end of life, it’s my privilege to be that support.

Hospice of the Panhandle Grief Support Services offers individual and group counseling free of charge to anyone who has experienced the loss of a loved one.

The Center for Grief Support offers these groups regularly throughout the year:

- **Loss of a Husband**, Thursdays, 1 - 2:30 p.m.
- **Suicide Loss Support Group**, 2nd & 4th Monday of each month, 6 - 7:30 p.m.
- **Parents’ Support Group**
  - 3rd Monday of each month, 6 - 7:30 p.m.
- **Circle of Hope (beginning in 2016)**
  - 2nd & 4th Thursday of each month, 6 - 7:30 p.m.

For more information about our Grief Support Services, please go online to www.hospiceotp.org, email dspeis@hospiceotp.org or call (304) 264-3902.

Support groups that run at set times during the year:

- **Coping with Grief & the Holidays**
  - Tuesday, December 8, 1:00 - 2:30 p.m. & 7:00 - 8:30 p.m., Romney
  - Tuesday, December 15, 1:00 - 2:30 p.m. & 7:00 - 8:30 p.m., Kearneysville
- **Grief through the Lens of Love**
  - Tuesdays, March 8 - April 26, 6:00 - 7:30 p.m.
- **Remembrance Ceremony**
  - Sunday, April 10, 2:00 p.m.
- **Labyrinth Walk**
  - Monday, April 25, 6:00 p.m.
  - Monday, May 30, 6:00 p.m.
A day in the life of a grief counselor

by Daniel Speis, Grief Support & Spiritual Care Services Coordinator

A grief counselor typically starts his or her day in their office reviewing emails and voice-mails and reviewing their appointments for the day.

At least once a week he or she will meet with one of the patient care teams where they will provide consultation as needed, and receive information about family members with whom they should provide outreach to following a patient’s death.

The counselors will then meet with their appointments for the day, which may include counseling appointments with individuals or perhaps sitting with and leading one of the support groups. The counselors will also allocate time to provide outreach by phone to family members who have been referred following the death of a patient.

Following this outreach, the counselor will then gather appropriate grief literature and either schedule a time to deliver the material in person or drop it in the mail, depending on the preference of the individual with whom they have spoken.

As a grief counselor, I often hear questions like, “How do you do this work,” or “How do you keep it from affecting you?” I also hear statements like, “I could never do what you do,” and “It must be so hard.” Yes, it is difficult to sit across from someone in complete agony and despair after losing a young child in an auto accident, or a husband to a violent suicide, or a parent to disease that was only diagnosed a month ago! It can be difficult to be a bystander looking into the red-rimmed eyes of another human being whose world has been turned upside down and a piece of their heart torn away, and who wants nothing more than to feel the warm embrace of their loved one again, and knowing that nothing I do can return that individual’s world to the way it once was; yet feeling their pleading for me to do so all the same.

In order for me to do this work I must first understand that I cannot “fix” the situation. Someone has died and I cannot bring that person back; which truly would be the only “fix.” My experience and training has taught me that when this kind of heart-wrenching experience happens, the only way to heal the pain is to feel the pain and work through it. Although many people can do this on their own and with this support of friends and family, some people need a little help when the grief is too intense. As a grief counselor, my task is to guide people; to help them understand their individual grief reactions and to process and cope with the pain. I help them find ways to adjust and adapt to a world without their loved one while at the same time maintaining a meaningful continuing emotional bond with that person. These are the tasks of mourning; this is the work of grief.

But I also know that grief counseling isn’t something I do to people; it is something I do with people. Grief work is an active interchange requiring the person I’m working with to be an active participant. In doing grief work with people, I often start to see signs of integration, adaptation, and healing of pain before the person I’m working with sees those signs. Like a mirror, I can then reflect those signs back to my client and in turn, plant seeds of hope that they can and will survive this awful experience. As time passes I get to watch those seeds grow. I never attach myself to the belief that I can fix the pain; a belief that would only leave me hopeless from my own despair of feeling like a professional failure. Instead, I know that I can only help a person learn to cope and live in spite of the pain, to find their new normal, and to learn that although things are now very different and very difficult, they can be ok again. I have witnessed this happen time and time again with people I am working with, and although this process can be slow at times, it is where I find satisfaction and the joy in my work. This is how I can keep doing what I do.
Having those conversations

A couple of weeks ago, while I was at the hairdresser, I listened to my stylist have a very matter-of-fact conversation with a woman whose hair she was styling. Actually, the woman, a lovely brunette in her early 70s, who I had seen many times over the years, was wearing a wig. My hairdresser was styling that.

The conversation focused on the woman’s schedule for the next few days – the trip to the hairdresser, to the grocery store, to the hospital for a chemotherapy treatment and finally, to the funeral home to make her final arrangements.

I was stunned - stunned by the fact that this woman, who while clearly fighting a terminal disease, was looking ahead to her future in such a matter-of-fact way. When I spoke to my hairdresser about the woman after she had left the salon, I asked about the woman’s prognosis. My hairdresser said it wasn’t very good, but that the woman wanted to continue to undergo treatments (her physician had given her a year to live if she treated her cancer aggressively, about three months with no treatment). A widow with an adult son (who had accompanied her to the hairdresser), she seemed completely at ease talking about her plans, with a person who obviously knew her well.

Kudos to her! This is always so difficult. I think of times in my own life, when family members were facing similar challenges. I have a very early memory of my paternal grandmother – “Aida” was my name for her. A strong woman of Eastern European stock, she walked about a mile and a half to daily Mass. I have a photo on my windowsill that I look at every day, taken when I was probably about 4. Aida’s gray hair is pulled back in a wispy bun, she’s wearing a warm sweater, her cane is in front of her, her “sensible shoes” are front and center. I’m seated on a stool right next to her.

At the end of her life, she suffered from heart disease. I have a strong recollection of the last months of her life, when she was bedfast. She had a strong desire to stay at home (even in the days before hospice was well known in the U.S.). She told her husband, as well as my father, his brother and four sisters exactly what she wanted, where she wanted to be – in her bed, in her bedroom, in her home of 50+ years. She also told them what she wanted her funeral to be like.

I think of many hospice patients I’ve met over the years – and their families – who struggle with their illness, their anger, their sadness. But I’ve also witnessed many who are just like my Aida, and my friend at the hairdresser – patients and families who have the “difficult” conversation, know what they want, and how they want to spend their final days. In many of these cases, hospice helps facilitate the conversations. And we can do that not only for hospice patients, but for anyone in the community by assisting them put advance directives in place even before they face a life-threatening illness.

If you have questions about advance directives, give us a call.
Yes! I would like to remember or honor my loved ones this holiday season by dedicating an angel or light in their memory or honor.

Please choose:

- [ ] Print name of person you wish to remember or honor:         In Memory or Honor?
  - [ ] Veteran?

- $100 Angel
- $10 Light

______________________________________________

Memory Honor Yes

- $100 Angel
- $10 Light

______________________________________________

Memory Honor Yes

- $100 Angel
- $10 Light

______________________________________________

Memory Honor Yes

If dedicating more than three angels or lights, please attach a separate sheet of paper listing additional angels or lights desired.

There will also be a special section of lights for veterans being recognized by their families.

Those recognized with a light will be remembered or honored with a white luminaria. Those being recognized with an angel will be remembered or honored with a handcrafted, personalized angel and gold luminaria. Angels will be mailed to those who dedicated them following the ceremonies. In the case of inclement weather, ceremonies will be held the following week.

Luminarias will be available for purchase and dedication at each ceremony.

As always, proceeds ensure that all Hospice of the Panhandle patients have the support, medications and equipment necessary to help them enjoy the holidays and all year long with their loved ones.

For more information, please call (304) 264-0406 or (800) 345-6538 or go to www.hospiceotp.org.

Yes! I would like to remember or honor my loved ones this holiday season by dedicating an angel or light in their memory or honor.

1 Please choose: 2 Print name of person you wish to remember or honor: 3 In Memory or Honor? 4 Veteran?

- [ ] $100 Angel
- [ ] $10 Light

______________________________________________

- Memory Honor Yes

- [ ] $100 Angel
- [ ] $10 Light

______________________________________________

- Memory Honor Yes

- [ ] $100 Angel
- [ ] $10 Light

______________________________________________

- Memory Honor Yes

If dedicating more than three angels or lights, please attach a separate sheet of paper listing additional angels or lights desired.

5 Please place my angels/lights in: 6 I have enclosed a check for $_______ for _____ angel(s) and/or _____ light(s). (Please make checks payable to Hospice of the Panhandle or purchase online at www.hospiceotp.org/donate.)

- [ ] Berkeley/Jefferson County
- [ ] Hampshire County
- [ ] Morgan County

7 Your name: __________________________ Phone: __________________________

Mailing Address: __________________________ Email: __________________________

8 How should your name be written on the tag? (Please be brief. Space is limited.): __________________________

Please mail to: Hospice of the Panhandle, 330 Hospice Lane, Kearneysville, WV 25430.
Thank you to all those who have helped hospice patients and families by hosting fundraisers:

Artifex Hair Salon
Blue Knights WV V and Main Street Martinsburg
Country Roads Tire & Auto
Hampshire County Hospice Auction committee and donors
Jim & Bertha McCoy and the Troubadour Lounge & Park
Martinsburg Noontime Rotary
Morgan County Clergy Association and Hospice Liaisons
Gently Used Purse Auction donors

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