

Multigenre Report Writing: Hospice

Sandra Hadick

Hospice: Cover Letter

Introduction:

In October of 2001, I began training as a hospice volunteer. My initial motivations were somewhat selfish. I wished to do a creative nonfiction thesis for my master's degree and felt that hospice would be the perfect place to collect stories. It had long seemed to me that older people had wonderful, and often insightful, stories to tell but that outside their immediate families they were rarely listened to, or recorded, in any fashion. In addition, impending death commonly causes a level of introspection that is not routinely engaged in. I was terribly interested in learning what these patients had to say; what stories they might choose; what wisdom they might share, now that they were faced with the final days of their lives.

I also felt that this would allow me to put my writing skills to work doing a service for patients and their families that they might value and treasure for many years to come. I had done volunteer work before and, since returning to school, I was missing it a great deal. This would enable me to squeeze some personally satisfying volunteer hours into my hectic schedule as a student and busy mother.

Where I had miscalculated, I soon learned, was in the ability of the hospice patients to record their thoughts and stories at any length. As it turned out, the vast majority of the patients were, sadly, too far along in their illnesses to have retained even the small amount of physical strength required to impart their stories or share their thoughts. Those that did have the strength and desire, generally choose to speak directly with their loved ones, rather than having a "stranger" record their words on paper.

However, by the time I had finished my volunteer training I was hooked. Despite the fact that my thesis project would not work out unless, I reasoned, I was willing to take a decade to work on it, I wanted to continue as a hospice volunteer. The people I had met during my training were truly wonderful, compassionate people who genuinely desired to help others. Simply walking in the front doors gave me a sense of being in a unique place sheltered from the hustle and demand of "normal" life and where people cared about others and wanted to help in any way possible.

When a class presented me with the challenge of writing stories about a family or community group, I thought almost immediately of hospice. This time, however, I could focus my writing efforts on the volunteers instead of the patients. I had already learned that every volunteer had interesting stories to tell and I believed that the volunteers were, themselves, in many ways uniquely interesting.

The individuals, myself included, who are drawn to work as volunteers at hospice are those that believe very strongly in, and are deeply committed to, hospice principles, whether through personal experience with the death of a loved one or some other reason. It was my strong belief in basic hospice philosophies, combined with my admiration for the people who work there so tirelessly, that drew me to pick this topic for my paper.

I began by contacting the volunteer coordinator for hospice, Carol Weimer, in order to get initial permission and for her suggestions about who I should speak with. In Carol's usual way of going above and beyond to help, she immediately not only suggested two names, but called the individuals for me in order to introduce my project and ask permission to give me their contact information. In less than an hour she called me back to tell me that both volunteers had agreed to let me interview them.

The first volunteer I interviewed, Howard Burger, is one of the most active volunteers at Hospice of Dayton and has been a volunteer for over eight years. Howard welcomed me to interview him at home and he was delightful to speak with, telling me a number of interesting stories about the things that volunteers do or have done. My second interview was also conducted at the home of my interviewee. Marietta Adams (who requested that I not use her real name) was one of the few, brave, initial volunteers and labored with Betty Schmoll to bring the hospice program and its ideals to Dayton. She has been a volunteer for twenty-five years and was able to share with me how hospice was started in Dayton and many of the initial struggles that its founders faced.

Since I interviewed one of the very first volunteers, and one who had been with hospice the better part of a decade, I choose for my third interview a volunteer who had gone through the training with me just a year previously, Tom Krakow. I was interested in finding out if his perspective as a "new" volunteer would differ from that of the others. Tom and I spoke at the hospice facility and, like the other two volunteers; he shared with me some interesting stories and unique experiences. Tom seemed to share the same sense of commitment to, and personal satisfaction in, his efforts that Howard and Marietta expressed.

Additionally, I interviewed Carol Weimer in order to gather some background information and to ask a few questions about volunteers such as the screening, training process, etc., and followed up with Howard Burger on some details of his experiences. In the process of interviewing the people for this project, I was again struck by what caring, giving, and special people these are. Though I hesitate to paint them as heroes, in my mind, they certainly are. They do this work quietly, without recognition or reward except for the gratitude of families and their own personal sense of "having given something back."

My hope is that this project will illustrate the necessity and importance of the hospice program as well as the graciousness, benevolence and generosity of its volunteers. And also serve to acquaint some who are unfamiliar with hospice and its principals with the important work that is being done by those involved in the hospice movement. As some have said; in the end we will all need far more grace, good will and help than we have ever given or earned ourselves. I am thankful for those who give regardless of, and without thought to, what has been earned and I applaud their efforts.

-Sandra Hadick
November 17, 2002

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Hospice: Poem

Patient Two

They sit by my bed when I am awake, family
Or some one that acts so, holding my hand.

One comes in her wheeled chair.²

The bed is soft, the blankets warm around me,
Outside the birds visit the feeder picking out their lunch

I can see through the trees to the stream.³

At night the girl wheels about her squeaky cart;

Books, magazines, blankets, soda, candy⁴

What more could you want?

Sometimes there is the black woman with the rolling keyboard,

She will play your favorite song or sing a sad, antique hymn.⁵

There is a man with kittens or a woman with collies

if that is your thing. They do not bite or scratch.⁶

They bring food sometimes but I do not eat, except a bit of soup

Or a little ice cream now and then.⁷

The nurse takes my pulse, washes my face and body,

Adjusts the heat, moves the vase closer to my bed

So I can see the pretty flowers⁸

And gives away tiny, purple pills or peace in a syringe.

I feel little or no pain.⁹

When the doctor comes, I make him feel better

And tell him I am ready.

But what is ready and how do you leave this place

When all you love is here?

And who can rage when all the power is out?

I sleep.

When I feel well I sit in the whirlpool,

The lady rubs oil on my back and feet,¹⁰

The little ones come and sit on the bed,

The clown does his magic trick,¹¹

The Pastor prays his quiet prayers,¹²

And I wait.

Hospice: Telephone Log

Attention: Linda Koeppen, Director

Phone Log: Carol Weimer

June 3rd, 2002

Transcription of a call placed to Dr. James Tracey, Miami Valley Hospital, on Monday, June 3rd at the request of Mrs. Joyce Boorman and her son, Nathan Boorman: ¹³

Nurse: Good Morning, Drs. Mayer, Clark, and Tracey's office.

Carol: Hello, this is Carol Weimer calling for Dr. Tracey please.

Nurse: Dr. Tracey is with a patient; may I take your number and have him call you back?

Carol: I would really appreciate if I could talk to him now. This is the fourth time I've called and he has not returned my call.

Nurse: And what is this about?

Carol: This is about one of his patients. I'm calling from Hospice of Dayton.

Nurse: Let me see what I can do.

Dr. Tracey (sounding abrupt): Hello.

Carol: Hello Dr. Tracey, this is Carol Weimer from Hospice of Dayton. I've been asked by the family of Glen Boorman to contact you.

Dr. Tracey: Yes, Ms. Weimer, I've already talked with Mr. Boorman's family and we have agreed to forgo your services at this time. Thank you anyway.

Carol: Ah, well, Dr. Tracey, I just spoke with Mrs. Boorman and her son a few hours ago and they told me again that they would like to have Hospice become involved with Mr. Boorman's care.

Dr. Tracey (exhaling loudly): Ms. Weimer, I have been through this with the Boormans and do not wish to rehash it with you. I am Glen Boorman's physician and I will oversee his treatment.

Carol: Dr. Tracey, are you aware that the involvement of Hospice does not preclude your treatment of Mr. Boorman? You would still be his primary attending physician should you and the family choose so.¹⁴

Dr. Tracey: Well then, I see no reason for the interference of Hospice with my patient and I chose not to use their services. Thank you and have a nice day.

Carol (hurriedly): Excuse me Dr. Tracey, please don't hang up. Can you tell me if you consider Mr. Boorman's illness to be terminal? ¹⁵

Dr. Tracey (sighing): Yes, Ms. Weimer, Mr. Boorman's treatment options are nearly exhausted but it does no good to tell the patient and family that. Now, my office is very busy today.

Carol: And do you understand, Dr. Tracey, that the role of Hospice is to deal with every aspect of the patient's final days, including counseling and support for the patient and his family members? Does your office normally provide counseling and support services?¹⁶

Dr. Tracey:(pause) Are you implying that my office does not meet the needs of the patient?

Carol (slowly): Dr. Tracey, if you were not an excellent doctor and completely trusted by this family, they would not have told me of their wish for you to continue to be the physician in charge of Mr. Boorman's care and treatment. They're not seeking to eliminate or replace you as the primary physician here, (pause) only to make their loved one's final days the most peaceful and comfortable that they can be.

Dr. Tracey: As Mr. Boorman's doctor, I do not see the need for Hospice to be involved.

Carol: I understand your objections Dr. Tracey, but you should know that Hospice of Dayton has been doing this for twenty-five years. We were founded in 1978 by a local nurse named Betty Schmolli¹⁷ and our only goal is to provide quality palliative care and support for the family and friends of our patients. We see the whole person, and seek to meet their physical, psychological, spiritual and practical needs in any way we can. In addition to that, we see the patient and his whole family as a complete unit to be cared for.¹⁸ (pause) You must admit that is simply more than even the best doctor's office can do.

Dr. Tracey: Perhaps I and my staff provide more help and support for my patients than the average physician.

Carol: After talking with you Dr. Tracey, I'm quite sure that you do. However, in addition to our paid staff of professional nurses, doctors, social workers, and counselors, Hospice of Dayton currently has 380 active volunteers. That is nearly one volunteer for every patient. Some of the things that we do down here besides pain management and seeking to make the patient as physically comfortable as possible, include massages, art therapy, pet therapy, holiday celebrations and social events for the whole family, running errands for the caregiver, helping with household chores and hosting support group meetings. I'm sure you are an excellent doctor, Dr. Tracey, but I doubt you have ever done a patient's laundry, come to their house and cooked breakfast for them, or washed and styled their hair when they, or their caregivers, were simply too exhausted to do those things.¹⁹

Dr. Tracey: Well...of course, I can't do all that but...

Carol: Dr. Tracey, really, you should consider the family here also. In many ways they are the ones that benefit the most. All of our services are completely free for them and we provide support services and counseling for up to 13 months, longer if they feel they need it.²⁰ In the past year alone, I've seen two weddings and a birthday party for a twelve year old girl held here, numerous wine and cheese parties for the families, an egg hunt at Easter, dinners for Thanksgiving and Christmas and a summer camp for the children and grandchildren of our patients.²¹ That is not to mention the day to day things that volunteers do to make the patients and their families happy and comfortable. (pause) Just today some one was able to locate a certain type of rabbit for a patient. Apparently, it was something that the patient had eaten as a child and a family member wanted to make it for them one more time.

Dr. Tracey: You certainly are convincing Ms. Weimer.

Carol: Yes, Dr. Tracey, I apologize. I have taken a great deal of your time but I am very passionate about Hospice and the work we do here. May I mention one more thing to you?

Dr. Tracey: Yes, I suppose....

Carol: If Hospice was involved, Mr. Boorman and his immediate family would have a great deal more autonomy and control over the circumstances that he spends his last days in. Rather than dying in the hospital, quite possibly alone, Mr. Boorman could die at home surrounded by his loved ones. Hospice would come into the home and provide the family with all the help they might need.²² If, however, he or his family chose to admit him to the inpatient unit, he would be in a lovely private room. His room would have floor to ceiling windows with a beautiful view and a birdfeeder right outside. The room would be decorated and filled with fresh flowers every day and on his bed would be a big, soft comforter and down pillows. His family would be surrounded by caring personnel that was available twenty-four hours a day and would prepare them for what was going to happen and stand by them throughout the process.

Dr. Tracey: Well, Ms. Weimer, you could sell a stereo to a deaf man. Seriously though, (pause) while this all sounds wonderful, I am not a doctor who wants to give up on his patients. I cannot in good conscience tell Mr. Boorman to relinquish the fight and go some where to die. I'm a doctor, Ms. Weimer, my job is to heal.

Carol: What may I ask, Dr. Tracey, are Mr. Boorman's odds for recovery (pause) in your estimation, of course?

Dr. Tracey: Slim, probably none at all to be honest, but as we know, the odds are sometimes beaten.

Carol: Well, that would remain the same whether or not Hospice became involved. Hospice is not a death sentence or a way of "giving up on" some one. While it's true that our patients must be considered terminal for Medicare approval, fully five percent will recover from their illnesses enough to be discharged from Hospice care.²³ I have seen miracles here, Dr. Tracey.

Dr. Tracey: Yes, well, uh hum (long pause) and the Boormans told you that this is what Glen wants?

Carol: Yes, Dr. Tracey. I spoke with Mr. Boorman directly and he expressed a strong desire for our services. (pause) And really, that is what matters isn't it? What the patient wants. Shouldn't some one who is facing a terminal illness have the right to decide for himself what their final days will be like? Given the chance, Dr. Tracey, wouldn't you want the dignity and respect of deciding for yourself?

Dr. Tracey: Hm...well, of course. Okay, fine, send the paperwork to my office.

Hospice: Menu

Clyde's Bar-B-Q Barn

Starters:

1. Clyde's Special Chili- Hot and Spicy and Full O' Beans

Cup-1.99 Bowl-2.99

2. Corn Chips served with Black Bean Dip 1.99

3. Cheese Quesadilla- Two kinds of Cheese, Served with Sour Cream and Salsa 2.89

-With Barbecue Chicken add 1.50

Sandwiches: Your Choice 5.95

Served with Seasoned Fries and Creamy Slaw

1. Pulled Pork- Sweet and Tangy, Served on an Onion Bun

2. Barbecue Beef- Clyde's Speciality, Slow-Cooked, Tender and Juicy

3. Chicken Breast- Grilled and Served with or without Barbecue Sauce

4. Hamburger- ½ pound, Ground Round with all the Fixin's

-with cheese add .50

Platters:

Served with Warm Cornbread and Your Choice of 2 of Granny's Delicious Side's

1. Pulled Pork- Only the Tenderest, Piled High with Plenty of Clyde's Sweet and Tangy Sauce 8.95

2. Barbecued Ribs- Slow- Cooked 'til They Almost Fall off the Bone

Full slab 13.95 Half slab 10.95

3. Ham Steak- Bone-in, Grilled with a slice of Pineapple 8.95

4. Half a Chicken- Marinated and Spit-Grilled, With or Without Barbecue Sauce 9.95

5. Clyde's Special Barbecued Beef- Juicy and Tender, Soaked in Barbecue Sauce 10.95

Sides:

Fresh Green Beans Cooked the Old-Fashioned Way with a Bit of Bacon Grease, Escalloped Apples with Cinnamon, Baked Potato with All the Extras, Sweet Tater Casserole, Creamy Cole Slaw, Slow-Cooked Collard Greens, Shoepeg Corn, Creamed Spinach

Desserts: Your Choice 3.95

Ya'll Can't Leave Without One of Granny's Homemade Sweets

1. Deep Dish Apple Pie- Served Warm
2. Rhubarb Pie- Sweet, Just Like Ya'll Remember
3. Chocolate Layer Cake- Rich and Moist
4. Berry Cobbler- Fresh from the Oven

- Any of the Above Served Ala Mode add 1.00

**All of the Meals at Clyde's are served with warmth, good cheer, kindness, listening, caring, helpfulness, smiles and a prayer.²⁴

Hospice: Diary

November 11, 2001

Dear Diary,

I've never seen anyone come here so alone. It seems fitting that they brought him in the middle of the night; shortly after midnight, transferred by ambulance on a collapsible steel gurney. It was so cold; one of those nights where it seems the only thing between you and the stars are the wispy clouds of your breath. I felt, standing outside as they unloaded the patient, like I could fall upward into the sky.

We had the room set up and ready for him, of course. The thick comforter on the bed was freshly washed and I could smell the Downy from three feet away. I had pulled the drapes on the big windows open so he could see the stream down below, lit up by the bright star shine. The lamp on the bedside table was turned to a soft warm glow and the dresser held a large vase of baby roses, heather and carnations that volunteers had gathered from the donated arrangements sent that afternoon from Tobias and Son.

I couldn't believe it when they transferred him from the gurney and took the blanket away. He had nothing but the skinny thread poor hospital gown on, not even underwear or socks on his old brown feet.

The only thing he seemed to come with was his own dignity. He was awake and looked deliberately at each of us as if calculating the combined weight of our souls. His stare seemed to ask for compassion, but not for sympathy. I'd bet he was once a man of pride and position, just by the way he held himself. How he came to be here without the usual family and friends around, I can't hardly imagine.

November 12, 2001

Dear Diary,

Joyce, the head of our nursing team, spoke with my new patient's doctor for a long time today. It's clear the cancer is eating him up quickly. He was starting to refuse food or drink before he even left the hospital. He is getting ready to die. He won't be with us long. A mixed blessing for me: I won't get overly attached: I won't suffer when he is gone. People think we don't feel these deaths, but we do. Knowing that death is coming doesn't make you not care about your patients!

What the doctor at the hospital didn't tell Joyce was that our patient spoke no English. We were all surprised when he began to speak clearly and insistently in Spanish last night. He looked at each of us in turn as we stared; no doubt our mouths were hanging wide open. It has been awhile since one of our patients was still able to speak coherently, let alone so forcefully. If we'd known ahead of time we could've arranged for one of the Spanish-speaking volunteers to be present when he arrived. There are volunteers for everything one can imagine that a patient might need. I knew that even at that hour, if we called, some one would come out but I hate asking too much of our volunteers; they give so selflessly already.

Unfortunately, none of us night shift nurses knew enough Spanish to translate for him.

After a bit, he seemed to tire and resign himself to the fact that we couldn't understand or talk with him. He settled back into the down pillows that we arranged behind his head and slept. With most new patients we have a lot to do: arranging and putting away their belongings, bathing and dressing them, taking care of their teeth, hair, skin and nails, keeping track of their meds and treatment programs, consulting with their doctor and comforting their family and friends. But with this man, there's almost nothing to do for him after his short nightly bath. Sometimes I feel slightly anxious; as if I've failed him in some important way.

November 13, 2001

Dear Diary,

When I arrived last night, the halls were already hushed and shadowed. I took a minute to pet Arlene and her daughter Farrah, the pet therapy Collies, and to say "hello" to their trainer Marie, then I went straight to my new patient's room. As silently peaceful as the halls had been, my patient's room, in comparison, seemed to hold a party. Three people were standing around his bed. Two were volunteers. One, named Howard, I know quite well since he is one of our most active and usually works at the center several days a week. The third man I had never seen. He stood, as I entered the room, and introduced himself as a representative of the local Cuban association. "This," he said with a proud flourish of his arm toward the bed, "is Sir Enrique Manez; he was an esteemed doctor in our great country."

Despite my surprise, I was pleased to take the patient's hand and shake it. How does it happen that a man who is loved and honored in his native country turns up in a hospital in Dayton with dirty bare feet, no clothes on his back and not a penny to his name?

"Mr. Manez," the man continued, "has been in America searching for his grown son and I'm happy to say that our organization has located him in Tallahassee, Florida. Soon, Mr. Manez will be on a plane to Florida." I was surprised to hear that the mysterious man was leaving so suddenly but I could see a glimpse of contentment had settled behind his eyes and I was happy for him.

Howard explained, as the Cuban representative left, that one of the Spanish speaking volunteers had translated for our patient that morning and Carol, the volunteer coordinator, had reached the Dayton Cuban Association early in the afternoon. By evening, the man's son had been located and the organization had purchased, with funds from their treasury, a single plane ticket. "Pretty smart guy, that Cuban man, he didn't tell me they booked the red-eye flight until after I said I would drive up there," Howard laughed and winked at me. I knew Howard well enough to know that he didn't really mind. His time was his own and Howard was always saying that this volunteer work was his true calling. He claimed he received far more in return than he gave.

The patient was unusually alert the rest of the night, dozing off briefly only once or twice. About two in the morning, I roused Howard from his nap in the patient's lounge chair and took from the bag the clean underclothes, slacks, shirt and shoes the other volunteer had purchased for Mr. Manez. Together, Howard and I washed and dressed our patient and combed his hair, telling him as we worked

how handsome he looked and what a fine time he would have. I always talk to my patients when I bathe them even if they can't hear or understand a word. It just doesn't seem right not to. As he was ready to be wheeled out, Mr. Manez took my hand and though he couldn't speak to me, the warmth of his gratitude was clear in his gaze.

November 27, 2001

Dear Diary,

I went in early last night; I always enjoy Thanksgiving on the ward. The whole downstairs smells and feels like coming in the back door of Grandma's warm fragrant kitchen in the dead of winter. The families of all our patients are there, just happy to be piling their plates high with Maxine's tremendous pecan stuffing and mashed potatoes and, most of all, to be able to spend one more holiday with their loved ones. Each and every minute is precious for them.

When all the excitement is over and all the little grandchildren, nieces and nephews dressed in Sunday finest are home sleeping in their beds; all that's left is the sweet lingering scent of Maxine's specialties. That is the time I love to walk from room to room. The patients, those that aren't worn plum out from all the excitement are replete, sleepy and satisfied with the enjoyment of seeing their friends and family lovingly content and stuffed full of holiday goodies. It is usually a good time for them; a chance to spend time with relations that can't always visit. Most patients are rallied enough that I find few are really in a bad way that day.

I really think the best part for me last night though was when Carol told me that she'd received a call from Tallahassee on Wednesday morning. Come to find out, Mr. Manez had only lived a few days after arriving in Florida but according to his son, they were very good ones. His son was overjoyed to be with him in his final days and to have the chance to make peace and "say his goodbyes."

Mr. Manez was leaving this world the same way he entered it, with nothing but the love of family. In the end, what I have learned from working here, and from my patients, is that this is all that matters: the only thing that really counts for anything. It gives me a lot of joy to know that we helped Mr. Manez when he had nothing and no one else to help him.

People are always asking me why I want to work at Hospice. With the nursing shortage, they say, I could go anywhere. They're probably right but what they don't understand is the joy that we get when we are able to help patients like Mr. Manez. It is not that I never question or doubt my work. You can't see that horrible white face of death without feeling scared and doubtful. People always think that patients die with a peaceful look on their face but many look scared, hurt or bewildered. Still, for me, working here has a reward of its own. Tomorrow night, Joyce told me, we will have three new patients on the ward.²⁵

Hospice: Birthday Invitation

It's A Party!²⁶

You're Invited!

For: Katy Haggerty's²⁷ Twelfth Birthday!

When: Sunday, July 21, 2002, 2:00 to 4:00 pm.

Where: Hospice of Dayton Cafeteria

Please come and make this a special day for Katy!

Call Carol Weimer for gift suggestions or if you would like to donate refreshments

258-5539

Hospice: Obituary

Obituaries

CLARK, Timmy

Age 8 years, of Kettering, passed away November 3rd, 2000 at Hospice of Dayton. He is survived by his mother and father, Janice and Richard Clark, little brother Steven Clark and grandparents Joyce and Ralph Clark of Clearwater, Florida and Mildred Walters of Raleigh, North Carolina, Aunt and Uncle Rob and Mariann Clark and numerous cousins. He is preceded in death by grandfather Davis Walters and Uncle Jim Walters. Timmy had bravely battled cancer for nearly two years and kept his sweet and sunny disposition until the very end. The last few weeks of his life he spent riding around Hospice in his little red wagon spreading good cheer to the other patients and staff. Timmy loved baseball, especially the St. Louis Cardinals. He also enjoyed drawing pictures for those he loved and baking desserts with his mom. Prior to his illness, Timmy was a student at Smith Elementary School. A memorial service will be held at 12:00pm Monday at Hazel-Cline Funeral home where funeral services will also be held on Tuesday at 10:00am. with burial to follow at Heartland Cemetery in Dayton. In lieu of flowers, the family requests that contributions be made to Hospice of Dayton.²⁶

Hospice: Help Wanted Ad

No- Pay, No- Benefits!

Immediate openings! Are you a mature, compassionate and sensitive individual with a flair for interpersonal communication? Are you a caring individual willing to listen empathically for long periods of time? Are you courageous, patient, and giving? If so, Hospice of Dayton has immediate openings for volunteers.²⁷ Job duties may include some or all of the following:

- **homemaker assistance**
- **babysitting**
- **running errands**
- **transporting patients**
- **flower arranging**
- **organizing and coordinating various social events**
- **conducting tours**
- **public speaking**
- **filing paperwork**
- **addressing outgoing mail**
- **assisting in personal care and grooming**
- **long periods of active listening or silent hand-holding.**

Compensation includes reorganizing of personal priorities, learning the importance of openness and sharing, participating in a family's most tender and intimate moments, valuing sustained relationships, not to mention gratitude and personal satisfaction!²⁸ No pay and no formal benefits included. Experience is not necessary but personal loss is a plus. ²⁹ If this sounds like you, call 937-256-4490, or stop by 324 Wilmington Ave. in Dayton, for your application today!

(3 personal references, 18 hours of training, and yearly TB tests required) ³⁰

Hospice: Letter

August 11, 2002

Dear Janet,

Well, you were right. This certainly has been a roller coaster of a year! When I started training as a hospice volunteer I had no idea what I was getting myself into! Just like you said, it can take over your life! There is always so much to do! The people here are lost and don't know which way to turn. You never feel like you can say "no" to need like that! Especially since I remember how I felt what Sam died. I was so alone and I didn't know where to get help or who to trust. You were so far away with your own family to worry about. When hospice came in they took care of so many of the details- coordinating his doctor care, having the nurse come, bathe him, check his medication and see how he was doing. They made sure we had food in the house and Sammy had his medication. You probably remember me telling you all about it. It left me free to spend my time with him without worrying over all the little stuff. That was just what I needed! And the best part was the volunteer who used to come just to sit and talk with me. She assured me that all my crazy feelings were normal even when they seemed just the opposite!

It really meant a lot to me when she showed up the morning Sam died. She made all the phone calls, took care of everything, then just made tea and sat with me holding my hand and not saying a single word. Boy, it may not seem like much but just having her there with me until you and Jim arrived made all the difference! And I think you were right about my needing something to get me out of the house. Oh, I still miss Sam of course, but I don't feel that terrible empty purposeless feeling I did at first. Did I tell you? Just a couple months ago I finished the bereavement training! I bet you are surprised! I know I told you there was no way I was ever going to do that!

Well, I've already had a couple of patients and last week I lost the first one. I'll tell you, I was really scared! Death isn't usually pretty like the movies want you to think. This old man was delusional and kicking up a fuss like you couldn't believe at the end. Plus his wife kept trying to feed him stuff! She spent hours in the kitchen making these elaborate dishes 'cause "Harry loved this or loved that." Of course, he couldn't keep a bite down but she kept trying to feed the poor guy. That was her way of dealing with it and feeling like she was doing something for him when no one could, I guess.

Anyway, I was kind of hoping that I wouldn't be there when he finally passed away. I was a bit scared with it being the first time and all, but Carol called and said that it didn't look like he was going to last another day so off I went. His wife was really acting sort of crazy, walking circles around the bed and trying to shake poor Harry awake even though the doctor had sedated him. I thought I was in a bad way with Sam but that poor old gal was really scared and not at all ready to let go! When he passed too it was hard! He started seizing and making noise, then he lost control of his bodily functions. I was so relieved when the doctor arrived! And after that it went real quick.

I'll tell you Janet, after it was all over, it really was a touching thing to be in that house (despite the smell). It was a real privilege to see the tender way she spoke to him and brushed his hair off his face, and to hold her little frail shoulders when they took the body out. I stayed until their kids got there then I went home. I felt like I had been hit by a truck and I got under my quilt and just cried for about

two hours straight! But you know Janet, after I was all done with my cry I got up and I thought to myself, "Sue Ann, thirty seven years you worked every day in retail management and today you did the best thing you have ever done in your whole life!" And I felt so good! ³³

Anyway, Janet, I have to run and pick up a cake for one of my patient's anniversaries. I just wanted to take a minute to drop you a line to say "thanks" and it was a good thing I listened to you (for once anyway- ha-ha) about volunteering. I miss you so much and I wish you weren't so far away! Say "hello" to Jim and don't worry so much about me.

Love, your sister,
Sue Ann

p.s. Won't you think about flying out here for Thanksgiving?

Hospice: Endnotes

1. All of the printed quotations, except for the Rollo May quote, are taken directly from the hospice volunteer training manual and are accurate quotes from past patients and volunteers.
2. One of the most active volunteers, giving patient and family support, is wheelchair bound.
3. The founder of Hospice of Dayton, a local nurse named Betty Schmoll began hospice, in the late 1970's, after her mother had died an extremely painful and unpleasant death from cancer. Betty was supremely concerned that every thing possible be done to ensure the comfort of the dying patients. This was taken into consideration when the current hospice building was designed and built. Every patient room is on the ground floor with floor to ceiling windows, a garden view and their own personal birdfeeder which is filled twice weekly by a 96 year old volunteer. Every room has bathroom doors that swing in both directions, softer mattresses than hospital beds, and high quality linens including down filled comforters and pillows.
4. One of the services provided by hospice on their inpatient ward is a "snack cart" brought around in the evenings for patients and their families. The cart is stocked with various soft drinks, juices, snacks of all sorts, books, magazines, as well as things the patient might like such as extra blankets, pillows and slippers. All items are given completely free of charge.
5. A music therapist visits patients with a portable keyboard. She will play nearly any request.
6. A pet therapist also visits. In order to be considered for pet therapy, animals must undergo extensive training so that they will stay calm and completely non-aggressive no matter what happens.
7. One of the first signs that a patient is nearing the final days of their illness is refusal of food and drink (Connor 38).
8. Hospice receives nearly daily donations of flower arrangements from local funeral homes. Volunteers then dismantle the bouquets in order to avoid giving any appearance that it is a "funeral" arrangement. They re-use the flowers in casual fresh arrangements that are placed in patient's rooms or delivered by volunteers to the patient's homes.
9. Hospice programs in the United States began in Connecticut in 1974 and have grown to over 3,000 programs currently (Lattanzi-Licht 47). Hospice was founded on principles of "palliative care" brought from Great Britain. The World Health Organization defines palliative care as: "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social, and spiritual problems, is paramount. The goal of palliative care is the best possible quality of life for patients and their families" (Olson 7). As stated, one of the primary goals of palliative care, and therefore of hospice, is the control or elimination of pain for the patient.
10. Another service offered by hospice is massage therapy.

11. There is a volunteer at hospice who is a professional clown and dresses up for visits to patients and for the holiday parties that are held at the facility.
12. Stephen Connor in his book, Hospice: Practice, Pitfalls and Promise, asserts, "Providing for the spiritual needs of patients has long been one of the facets of hospice care that has set it apart from other health care providers" (23). At Hospice of Dayton there are professional chaplains and trained volunteer chaplains. In addition, the staff will make every attempt to contact the patient's own pastor or to find a representative of their personal religion should there not be some one on staff trained in, or knowledgeable about, their religion.
13. Stephen Connor states, "There is much confusion over the meaning of the word hospice. Some believe a hospice is a place where people die. Others simply associate the word with death and are uncomfortable" (3). This surprising point was illustrated for me when I interviewed Carol Weimer, the volunteer coordinator at Hospice of Dayton. She revealed that she spends a great deal of time on the phone with physicians trying to "talk them into" allowing hospice to become a part of their patient's care. This is my imaginary version of how one of those conversations might progress.
14. Another underpinning of the hospice philosophy is the patient's autonomy: their right to make important decisions regarding their care and treatment. Allowing patients to make choices for themselves is one of the ways hospice seeks to maintain the patient's sense of dignity and self-worth at a time they may feel out of control (Lattanzi- Licht 133-135).
15. In order to qualify for hospice care, patients must be considered to be within 6 months of death. Services for hospice are covered by Medicare and many private insurers, generally with benefits extending for a maximum of 18 months. However, hospice is funded primarily through private donations and is provided completely free of cost to any patient, regardless of ability to pay (Hospice of Dayton Volunteer Training Manual).
16. Hospice has professional and trained volunteer counselors on staff to provide around the clock counseling to patients and family members.
17. Betty Schmoll began hospice in 1978, with a staff of four nurses "donated" from local hospitals and a handful of volunteers. In the 25 years they have been in operation, Hospice of Dayton has grown to cover Dayton, Middletown, Highland, Warren, and Clinton counties.
18. Hospice is unique in viewing the entire family as one single unit for treatment (Lattanzi-Licht 29-34).
19. These are just a few of the things that hospice volunteers do regularly. Marietta Adams had a patient who was an elderly widower whose only family was the high school age granddaughter that lived with him. Since the granddaughter had to leave very early in the morning for school, and since the "meals on wheels" service that the hospice social worker had arranged for him did not come until afternoon, Marietta went to the patient's house two mornings every week to cook him a hot breakfast. Afterwards, she would stay to do light housekeeping chores for him and sit with him, "simply holding his hand, talking or not."

20. Hospice Bereavement services department follows and provides free counseling services to the families for 13 months after the death of their loved one. Services will be provided for longer if they are needed.
21. Wine and cheese parties for families are held at the facility once every month. Complete holiday celebrations with dinners, music and special visits (Santa, the Easter bunny etc.) are held on all major holidays and are open to the entire family. In addition, other social events such as weddings, anniversary parties etc. are held at the request of patients and their families.
22. The number of hospice patients in their, or other family member's, homes out number the patients actually housed at the facility by ten to one. Home care patients have access to all the same facilities and services as inpatients. They are provided with visiting care from professional nurses, aides and counselors who see to the physical comfort and psychological needs of the patient and their family. Volunteers provide for their other needs such as picking up prescriptions, groceries, light housekeeping or yard work, transportation to and from doctor's appointments, providing relief to their caregivers, and general companionship.
23. Approximately five percent of the cases that are admitted to Hospice, though believed upon admission to be terminal, recover sufficiently from their illnesses to be released from hospice care (as per interview with Carol Weimer).
24. One of the stories I was told concerned volunteer Howard Burger and a nursing home patient. The nursing home staff, concerned over their patient's apparent depression and social isolation, called volunteer coordinator Carol Weimer. Carol contacted Howard who then spoke with the patient asking him what they could do for him. During the conversation, the patient expressed a desire for a barbecue sandwich "like the ones I had as a kid." Howard made arrangements with the nursing home staff to pick up the patient and take him to lunch at a barbecue restaurant downtown. As the story is told, Howard and the patient had a fine time talking at length, reminiscing about "the good old days," and enjoying their lunch. Afterwards, the nursing home staff reported that the outing, after months of confinement and social isolation, had done wonders for their patient's outlook.
25. Another story, one that was told to me by Howard Burger, concerned a man that arrived at hospice without a single possession to his name. The man did not speak any English but hospice was able to find a volunteer to translate for him. The volunteer discovered he was here from Cuba, and wanted nothing more than to go to Tallahassee, Florida to spend his final days with his only family: a grown son. Carol contacted a local Cuban organization and found they were only too glad to help. From their treasury and other donated funds, the Cuban organization purchased a plane ticket for the hospice patient. A volunteer provided clothing to outfit the man for his trip and Howard volunteered to take him to the airport, finding out only later that the flight left at 3:00 am. Later, hospice heard from the man's son that he had died soon after arriving, but that the man and his son were very grateful for the time they had been able to share. This is my fictionalized account of what a hospice nurse might write about the event.

26. Recently, volunteers threw a party for the birthday of one of their patient's daughters. The mother was a patient on the inpatient ward and was very near death at the time of her daughter's twelfth birthday. Volunteers were concerned that some thing be done for the girl's birthday especially as it would be the last one that her mother would be alive for. They organized and threw a birthday party for her at the Dayton facility. I was told that many volunteers attended bringing gifts, cakes, cookies and ice cream. As well, a number of the Hospice nurses came in on their day off in order to try and make the occasion as pleasant and memorable for the young girl as possible.
27. All patients names have been changed.
28. Hospice gets few young, juvenile patients and these are the ones that many volunteers find more difficult and heart-wrenching. I was told a story of one young boy, a cancer patient, who was admitted to the inpatient ward for the last few weeks of his life. Shortly after his admission, he reportedly lost the ability to walk but being quite young, he intensely disliked being confined to a bed at all times. A volunteer, hearing about the boy's difficulty, purchased a new red wagon and outfitted it with a pad and pillows to make the boy comfortable. Up until very close to the time of his death, the boy was pulled by his mother, and other volunteers and staff members, about the ward where he became a favorite visitor for many at the facility. The wagon is still at Hospice where it is used for various purposes.
29. According to Stephen Connor, "The hospice movement in the United States was started by volunteers. All those who labored to bring hospice services to the United States did so on a volunteer basis....All who labored to start hospice did so because they believed that the care of the dying had to be improved and that hospice was the way to do it" (26). Since that time, funding has become available and consequently, many of the services that were once done by volunteers are now done by paid professionals. However, most still consider the volunteers to be the "heart" of hospice. The primary role of volunteers in most hospice programs continues to be working directly with patients and their families where they do just about anything to help. Many families value the services of the volunteers above those services which are provided by paid employees and experience care that is given without compensation: given only through a desire to help, as a powerful thing. Connor asserts, "The extra dimension of caring provided by volunteers has always been one of the most unique features of hospice care...also one of the features that has become hard to sustain" (98). Hospice of Dayton has been fortunate that it has not experienced a volunteer shortage and currently has approximately 380 trained volunteers; nearly one for every patient on their caseload. According to Carol Weimer, some of the qualities that Hospice looks for in volunteers include; maturity, empathy, an ability to listen, a caring and compassionate personality, strong interpersonal skills, patience, sensitivity and, above all, a desire and willingness to help others.
30. Every volunteer in my interview claimed to receive more in return than they gave and in general, hospice volunteers report a high level of satisfaction with their volunteer work and roles (Lattanzi- Licht 157). Volunteers tend to stay at hospice over extended periods and to say that their work at hospice has enriched their own lives and improved the quality of their personal relationships. As Howard Burger said to me, "people are so nice, so grateful; always

wanting to give me things, feed me, and other stuff. It gives me a good feeling and makes me feel like I am making a difference.”

31. Most, though not all, hospice volunteers became volunteers after suffering the death of someone close to them. Many have had personal experience with hospice being involved in the passing of one of their own close friends or family members. Hospice encourages individuals to wait at least one year after the death of their own loved one before volunteering.
32. All prospective volunteers fill out a lengthy application including three personal references, which, Carol assures me, are carefully checked. Then, if accepted, they must go through an 18 hour training program, usually held on three consecutive Tuesday and Thursday nights from 6pm until 9pm and offered two or three times per year. Topics that are covered in the training program include: learning and understanding hospice services and philosophies, concepts of death and dying as well as bereavement and support after the death, their role as a hospice volunteer, care and comfort of the dying patient, diseases and medical conditions, communication skills, safety and infection control guidelines, spiritual and psychological concerns related to death and dying, stress management, confidentiality and patient’s rights issues, and familiarization with the rest of the “hospice team.” Volunteers are also required to go through drug screening and yearly TB testing.
33. This letter is my composite, fictionalized effort at illustrating many of the sentiments shared with me by the volunteers that I interviewed for my project as well as others I have spoken with casually during the last year. Many volunteers report feeling that this is the most significant work they have done in their lifetimes. Howard Burger called his volunteer work at hospice his “true calling,” and Marietta Adams stated that her volunteer efforts for hospice have provided her deepest sense of purpose.

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