

Interacting Personally with Palliative and Hospice Care Services: Lessons Learned and Expressions of Gratitude

By Susan Smith

"You may lose two or three of your grandparents this year," I said to my adult children in January 2024. My mother was in a rehabilitation center and had spent the previous 8 weeks either in the hospital or a rehabilitation center, transferring back-and-forth between the two institutions three times. Meanwhile, my father-in-law was told by his cardiologist in December 2023 that treatment for his heart failure, COPD, and stage 3B kidney disease had reached an impasse.

The phrases "palliative care" and "hospice care" were mentioned as options for both loved ones. As a former Intensive Care Unit Clinical Pharmacist, these medical approaches were not foreign to me. I was aware of the benefits these approaches provide to patients with serious illnesses. I saw first-hand how my patients' quality of life improved through decreased suffering. Thus, as a daughter/daughter-in-law, I was very much in support of transitioning to palliative care for both family members. But as much as I understood what utilization of these services meant as a healthcare professional, it was an entirely different perspective being a family member advocating for these services to my loved ones.



My Mom

My Mom had been extremely anemic which led to a gastrointestinal bleed and hospital admission in November 2023. Her red blood cell indices were abnormal and her spleen was significantly enlarged. Testing was negative for a hematologic malignancy, but her doctors wanted to

rule out a possible rare blood/bone disorder. She ultimately reached a point where she refused further testing or treatment. My Dad, three siblings, and I supported her in that decision. In late January 2024, she was considered stable and was discharged home with the recommendation to involve palliative care support. My sister (a physical therapist) and I understood the purpose of palliative care for our Mom's situation; but our Dad and brothers were less willing to accept this as an option, at least initially. Fortunately, they all eventually agreed to this transition.

Unfortunately, my Mom's health continued to decline and the palliative care nurse suggested we transition to

hospice care. This transition was happening much more quickly than any of us expected! My brother said Dad was resistant to this idea and would not make a decision until I arrived (to Ohio from North Carolina) for a planned visit the following week. Within a few days of my arrival, I pulled my Dad aside to tell him the nurse suggested Mom could be made more comfortable under hospice care. Knowing my Dad, I knew if I went into the conversation saying "this is what you should do," I would be met with resistance. Instead, I asked him questions. *Do you know what "hospice" means? What ideas do you have to lessen her suffering? Are you willing to consider having someone from hospice come to the house just to explain what they could offer and then go from there?* I patiently listened to his responses. He told me how this was very hard to talk about since they had been married for 62 years... how he always thought that since he was 5 years older, he would be the one to go first... how we wanted, above all, to do whatever we could to ease her pain and suffering. I then asked him if he was okay with me making an appointment for a hospice nurse to come to the house for an evaluation. With tears in his eyes, he nodded yes.

The first week of home hospice care was a very busy time with all the visits: nurse intake, aide, social worker, spiritual support, nurse, and physician. I was previously only aware of hospital-based hospice services; I didn't realize how many people would come to the house! I was glad I could be there in person with Dad for these visits, especially for the physician visit. I connected my siblings via conference call. My Mom had been spending most of her days sleeping in her lift chair. My sister and I talked later that she would have been mortified (from an etiquette standpoint) to know that she slept through almost the entire physician visit. The doctor said this was an indicator that Mom was in her last days. I followed the doctor out of the room and privately asked her how long she thought Mom might have left. She said weeks or just a few short months; Mom passed away 7 weeks later.

The support that home hospice provided was extremely helpful in terms of letting us know who and how to contact them, asking us if we needed more supplies (e.g., waterproof pads, gloves, moisturizing products, zinc oxide, a bedside commode, the hospital bed), and reminding us that we needed to take care of ourselves, too. When the social worker learned that Mom had been a registered nurse, she arranged a pinning ceremony to honor Mom. (They also provide military pinning

ceremonies as well). I discovered there was so much more to hospice than I ever knew! Perhaps one thing I should have known as a pharmacist, but didn't, was in relation to medication use, specifically opioids. With each visit, the nurse counted the oxycodone and lorazepam to ensure the available pills matched what had been prescribed. They also prescribed PRN medications including laxative, haloperidol suspension, atropine, and ondansetron. At first, we did not need to offer these to Mom; but when she hallucinated and became more agitated, we gave her the haloperidol. After I went back home, my Dad would report to me almost daily how everything was going, and when he told me he had to give her "the juice" a few times (his way of describing the haloperidol suspension), I knew my Mom wasn't having a very good day.

But then she did have some good days! She seemed to rally a bit at times. For example, she was interested in going outside on a sunny day in the wheelchair. The doctor had told us that despite an overall decline, she would have good days – and to be thankful for those good days. The doctor also told us that she would have less and less of an appetite, she would sleep more and more, and eventually she would not be able to get out of bed. It was hard to think of that on the good days, but the fact that we knew those eventualities made it easier to bear as each of those predictions came to pass.

Ultimately, we knew Mom's wish was to pass at home – not in a hospital or in strange surroundings. We honored that wish as she passed at home in the presence of my Dad, brother, and sister-in-law reading Psalm 23. My Mom believed in Jesus, so we know that on May 8, 2024, as she passed from this life, she entered Heaven to live eternally with Jesus.



My husband's Dad (Bob)

While these challenges were going on with my mom, my father-in-law Bob initiated palliative care services in January 2024 with his first physician clinic visit. I think because he was fairly ambulatory and very alert, Bob struggled with end-of-life concepts throughout the process. The physician gave him "homework" prior to his



next visit. Bob was to create goals and put them in three buckets: immediate, short-term, and long-term. He did his homework and asked all of us to provide input. Some of his immediate goals were to stay out of the hospital and address advanced directives, while short- and long-term goals included traveling out of town to visit friends and family, watching a local minor league baseball game uptown, or heading to the North Carolina mountains for an apple festival. We were able to help him do just about everything on his list – the only item he did not check off was a visit to the Billy Graham Library. From January to September, Bob had 7 palliative care appointments; my husband accompanied him to all of them. My father-in-law was able to ask questions to better understand what was going on, but perhaps the most significant benefit came when he was "given permission" to grieve for what was to come.

In October, Bob officially transitioned to home hospice care. Although he started at home – since he, too, wanted to pass at home - his hospice journey included two separate week-long stays in the hospice house. Bob was grateful to have a daily stream of visitors including his wife, my husband and me, our daughter, and our son and his fiancée. (Bob was an only child and my husband is an only child, too. So we are just a small - but mighty - family!) We brought him coffee in the morning and food throughout the day. We watched our live-stream church service with him on Sundays, fed him when he was too weak to feed himself, and fussed at him when he tried to get out of bed on his own. I didn't know the beds triggered an alarm whenever someone tried to get up! (We made a game out of keeping track of the number of times he got busted.) While we all felt safer with him being in the hospice house and receiving 24-hour high-quality care, we knew that he was desperate to get home. After overcoming a few logistical barriers, my husband and his stepmom made it possible for his Dad to spend his last 13 days at home. My mother-in-law was very worried that he would pass when she was alone with him. Praise God my husband was present with his Dad as he passed into Glory on December 7, 2024.

Lessons learned

As I lived through these trying experiences, I thought of several lessons I learned along the way. I've included a few of those here:

1. Learn what you can about palliative care and hospice before you or your family member needs it. Home hospice is free to individuals with Medicare coverage who meet eligibility criteria, but there may be state-specific requirements. It is worth having at least a cursory knowledge of these services now; not only for your family members, but also for your patients.
2. Donate to your local hospice care service. You can donate your time – just to sit with someone, take them for a walk, or read to them. You can donate money, gift cards, or even tickets to a play or sporting event. You can donate items such as clothes or hats, or handmade items - I am in the process of crocheting a lap blanket to donate to the hospice house.
3. Understand your loved ones' end-of-life wishes NOW. These are hard conversations to have for sure (admittedly, I have not had this conversation with my husband yet), but so necessary to avoid confusion and anxiety for everyone later. Ensure advanced directives are in place and discuss funeral arrangements while your loved one is still able to share their wishes.
4. Get on the same page with intimate family members. Of course, there will likely be differences of opinion here and there. However, on the big things such as affirming a loved one's desire for a "Do Not Resuscitate" status, it helps to be of one mind. We were very fortunate that for both family members everyone involved generally agreed with decisions that were made.
5. Consider securing external caregiver support, even for just a few hours a day a few days a week. Initially, my Dad refused to consider non-family assistance. While my sister and I helped our Mom with personal needs, our brothers were quite vocal in sharing with our Dad that this robbed us from spending quality time with our Mom. He finally agreed to permit the hospice aide to help Mom and eventually acquiesced to hiring a private aide to spend the night. My in-laws, on the other hand, were completely comfortable with any type of assistance throughout their hospice journey. This was a great reminder that everyone has different preferences. The hospice staff helped us ask the right questions to understand those preferences and worked with us to find the resources we needed.
6. Be present for your loved one who is going through their most difficult days. Take time to just sit with them. I spent several hours on many days just sitting in the chair beside my Mom or my father-in-law. At times I browsed through a magazine or crocheted an afghan while we watched TV or they

slept, but I could easily set those things aside to attend to their needs or listen to them when they had something to share.

7. Tell them you love them. Talk about the good times. Share special memories with them.
8. Talk about eternity! Read the Bible, pray, sing, watch online church. If you don't know whether your loved one will spend eternity with Jesus, there is no better time to share the love of Jesus Christ with them!

Expressions of gratitude

This past year was very hard and many tears were shed. Personally, I am extremely grateful for the support palliative care and hospice care provided to my family members. Professionally, I gained a greater appreciation for the breadth of services and individualized end-of-life care they provide. We were so thankful to have many wonderful people support our parents and help us navigate these difficult paths. We were comforted knowing that we honored their wishes and enabled them to leave this earth with dignity and delight for eternity.

"The Lord is my shepherd; I shall not want. He makes me lie down in green pastures. He leads me beside still waters. He restores my soul. He leads me in paths of righteousness for his name's sake. Even though I walk through the valley of the shadow of death, I will fear no evil, for you are with me; your rod and your staff, they comfort me. You prepare a table before me in the presence of my enemies; you anoint my head with oil; my cup overflows. Surely goodness and mercy shall follow me all the days of my life, and I shall dwell in the house of the Lord forever." Psalm 23 (ESV)



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