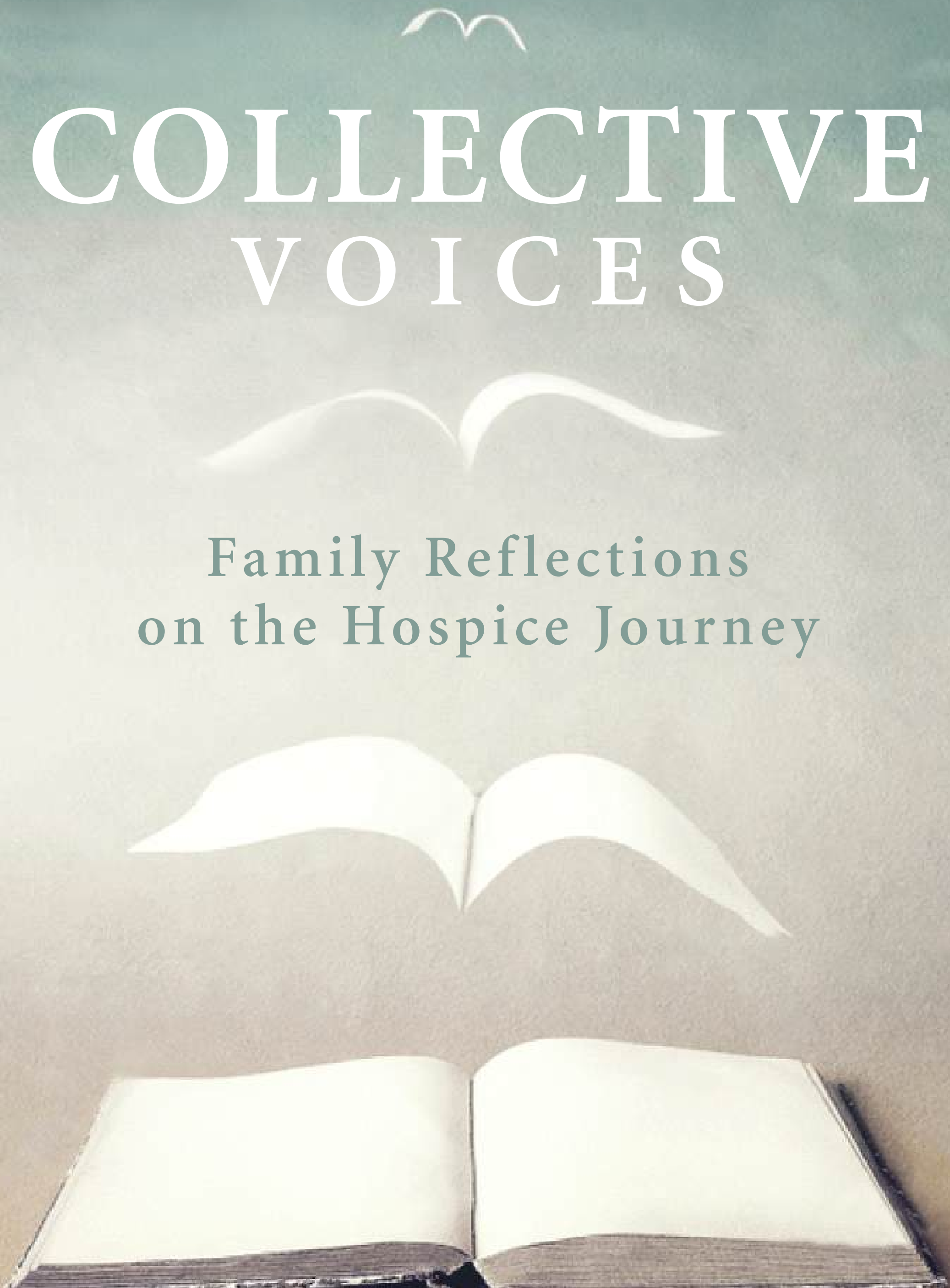
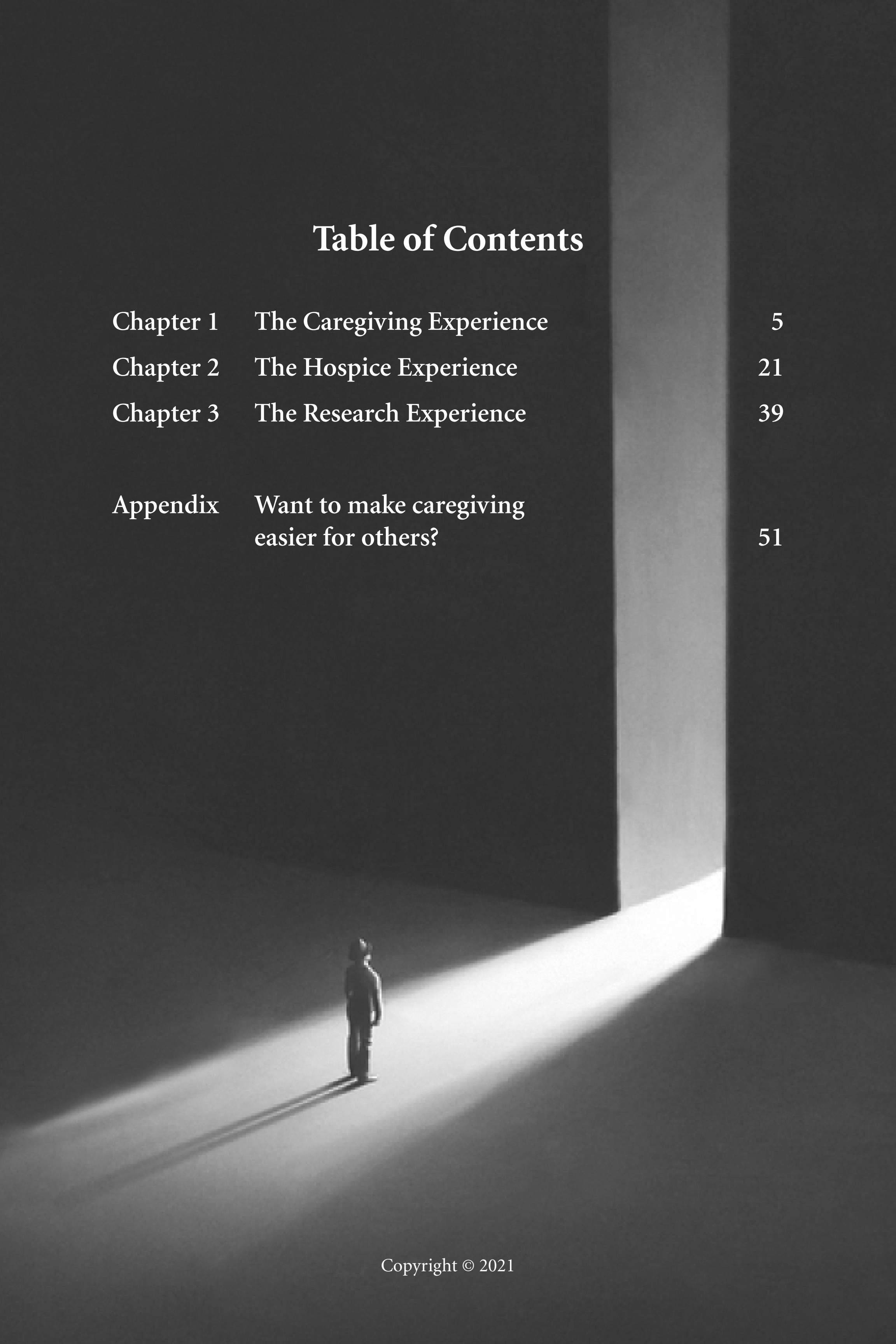
COLLECTIVE VOICES

Family Reflections on the Hospice Journey



Debra Parker Oliver and George Demiris



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To our Readers,

Over the years, we have been privileged to bear witness to the stories of thousands of family members and friends who have cared for loved ones during their end-of-life journeys. These caregivers have trusted us with their perspectives, joining our mission to improve the caregiving experience. The purpose of this booklet is to honor the family voices by sharing them with you. We hope these letters and notes will assure you that you are not alone in your feelings and experiences. We have collected these experiences over twenty years of research in hospice. The voices are real; we have carefully edited them to preserve their meaning and emotion. Research does not always occur in a laboratory and is not always directed toward finding a cure for disease. Our research explores ways to better support individuals as they try to cope with challenging situations. Our team partners with your hospice to develop services that are tested and trustworthy, providing support and making your difficult journey a bit easier. We hope this little book brings you comfort and moves you to join our mission to help those who, like you, choose to assist family, friends or others as they complete their final chapters.

Respectfully,

Debra Parker Oliver
George Demiris

CHAPTER 1

The Caregiving Experience

Dear Debbie and George,

Four years out from my caregiving experience, the sentiments expressed here ring so true. It is as if my husband died yesterday. Even with time and distance from the culminating event, I feel such relief and validation reading these testaments. Individually, the letters remind me of the day-to-day and day-after-day life of a compassionate caregiver. Collectively, they provide evidence that I wasn't alone in living a complex mix of emotions then and even now.

The act of caregiving, honestly, comprises the most challenging time of my life. In those moments, what I needed most was to hear "you are not alone," "these feelings are normal," "you can do this"—even on the days when you are sure you can't, "you will get through this—there is another side, and you will make it there," and "trust yourself."

These letters offer reassurance for those in the midst of caregiving. During the inevitable dark nights, I hope that these personal accounts provide an invisible chorus of previous/current caregivers who are expressly, and emphatically, sharing the same feelings, fears, and doubts. I was there, too. I wondered how it was possible to love someone AND not know how much longer you could care for them. I wondered how it was possible to love someone AND admit that they drove you absolutely crazy sometimes. I wondered how it was possible to love someone AND want them to be relieved of their suffering. I, too, questioned whether or not I could do it one more day.

Caregiving is so unbelievably hard as is the uncertainty inherent in disease progression. May these shared sentiments provide some comfort and advice in times of need:

- All of the feelings—sadness, anger, hurt, frustration, relief, desire, impatience, overwhelm, joy, heartbreak, paralyzed, gratitude—are normal.

- Use the life preservers, whatever/whoever they are in your life.

- Learning to ask for help is a lifeline and an essential survival strategy.

- You aren't expected to have all the answers, and there will be days when you don't get things right. It is okay.

- Limits and restoration are critical. In those times when you can't take it anymore, let yourself give up, give in, and/or give back to yourself… for a moment.

- Tears and laughter offer endless relief.

- Recognize and grieve the losses along the way as you notice personality changes and physical limitations in your loved one and experience relationship shifts and role reversals.
- Feel their love—to the best of your ability—and, on the days when you can't see the forest (love) from the trees (prescriptions, falls, insensitivity), take a moment to try to imagine/remember it.
- Don't lose yourself. Know your boundaries and limitations; they become invisible if you don't stake and adhere to them.
- Be gentle with yourself and grant yourself grace.
- Forgive.

Warmly,
Courtney

I've never been a caregiver before. You don't know it until you become one, but being a caregiver is really hard. There are so many hardships! Is what I'm feeling normal? Sometimes I just want to give up, but I have to keep going. It's my first time, and I have had so much to learn.

I had to navigate a lot of things including my grief, family issues, and logistics. I didn't feel prepared. I wish I'd had more time, more resources, and more help. But I also know I could only do so much, and I got to say goodbye.

Caregiving is the hardest thing I have ever done, but it is also the greatest thing I have ever done. I don't regret one minute of it. My sister moved in with me before she passed away. I'm divorced, and my kids are grown. As hard as it was, we had the best year and a half together. Just being there was the greatest gift I could have given her.

I have been a caregiver for many years, but early on there was less I had to do. I was there but, now I REALLY have to be there giving a lot more care. I am helping Dad have a good death. He had a good life, and I want him to have a good death, too.

Dear Debbie,

We have a large extended family, which meant a lot of company. In Mom's final week, we tried to schedule everyone so someone was there all the time, but I was the main caregiver. It was hard. Mom had a one-bedroom place, so when someone would come in those last days, I wanted them to have privacy with her. When she got so ill and she knew she was dying, she got a little paranoid. She wanted all the company, but then at the end she asked, "Why are they coming to see me now? What do they want?" People she had not seen in years showed up. The paranoia was not her. I was put in the middle which was very hard. It was a lot caring for her, and then I had to monitor all the visitors.

Warmest regards,
Susan

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Dear Debbie,

I kind of had an idea of what caregiving would be. The reality was not too far from what I imagined. My patience was frazzled and worn at times. I thought maybe it would be better if Mom went to a nursing home. I would catch myself screaming or hollering at her or talking and being disgusted. I was just worn out, and I was not always very nice. I didn't mean to be that way, but I was. I had to be honest enough with myself to know where

I was. Mom and I were close my whole life, and I could not have imagined having her anywhere else but at home for her last days. I wanted to make sure that I looked at every day like I was going to a job. I had to make sure that the customer (Mom) was satisfied, and I wanted her to be happy. I wanted to make sure I always tried to treat her wonderfully. I hoped I was doing as good by her as she did by me when I was a kid growing up. I'm sure I tried her patience an awful lot back then.

Regards,
Josephine

Some people are thrust into this very emotionally draining role of caregiving and often come from various, difficult backgrounds. Everyone is presented with different problems depending on their situation. If I can provide others with ideas or solutions based on my experience, I think it could be highly beneficial for other caregivers.

Dear Debbie,

Although we were initially given a life expectancy of three to six months for my father-in-law, I was also told it could be shorter. By the time he got to our home, we figured we would have longer than we did. When symptoms and behaviors started occurring, they happened at a faster pace than we were expecting. From the moment hospice started, they told us the kind of things to look for and how to best manage his care every day. We found ourselves calling more and more to ask questions about medications. There's a fine balance between trying to make someone comfortable and having to take charge and say "you can't do this right now." That is something I did not expect. My role was pretty defined when my father-in-law was able to talk or communicate for himself. But when he was in pain and became confused, it was different. So how do you balance? How do you find that line between keeping them comfortable and alert? That was a big thing I learned, and it's important for anyone who becomes a caregiver to be prepared to face. You must understand that what you're doing for comfort for your loved one requires you to sometimes step up and say, "You know I have to make this decision, and I think it's in your best interest."

Best wishes,
Grace

Dear George,

When caregiving, there are things which I needed to do and things which I had to plan on. I couldn't seem to get anything organized around here because of what was going on. Everybody kept running in and out. I wanted to get the bed out of the front room and into the bedroom, but that required manpower. It was hard to get the kids over here to help with any of that. It was a lot, being a caregiver, a lot. I learned to rely on help from others because I couldn't do it all. It is a lot.

Kindest regards,
Steven

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Dear Debbie,

Being a caregiver is the hardest job anybody can ever undertake. You give up your own life, your own needs, your own wants and desires. You put everything on hold to care for someone 24 hours a day, non-stop. At times, I felt like I just wanted to walk out the door and keep going. Many times, I'd just sit and cry. It was so overwhelming. As soon as I would sit down to rest, my husband would need something. He tried to be very easy to take care of, but he couldn't help it. I was so tired and exhausted that I was extremely short with him and everyone else. It was beyond imagination. I would never want anybody to have to go through that taking care of me. I've told my kids, "Never. Don't do it. Just put me in a nursing home." It's easy to get frustrated being a caregiver, and there are days that you say things that you don't always mean. Six months later, I look back and say, "I can't believe I said that or felt that way." I needed to express it rather than just go crazy.

Thank you,
Betty

Dear George,

Caregivers can use all the help they can get. The financial worries and frustrations are one big stress added to lots of others. There are lots of discussions in healthcare about what has been cut or what the government and employers should cover. I think that a lot of the times, those decisions are made extremely hastily, with other priorities in mind, and no real concern for how they affect patients and caregivers. And the result is that, at the tail end, nobody can make sense or understand these things. It's already hard enough to just take care of our loved one. The more complicated and ambiguous this stuff is you pile on a person, I think the more difficult it is to make them feel that they actually can do some of these things.

Kindly,
Charlie

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Dear Debbie,

I appreciate the chance to share my experience as a caregiver for my husband. I was most surprised that the chemo would change his personality completely. About three days after chemo, he would turn into this person I did not know. After being married to him for 25 years, this was very hurtful for me. I'm not always the most patient person in the world. We would go to bed at night, and we would say, "Look, we're going to have a better day tomorrow. We're not going to be at each other's throats every time we turn around." That's what it did to him.

Best wishes,
Sherri

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Dear George,

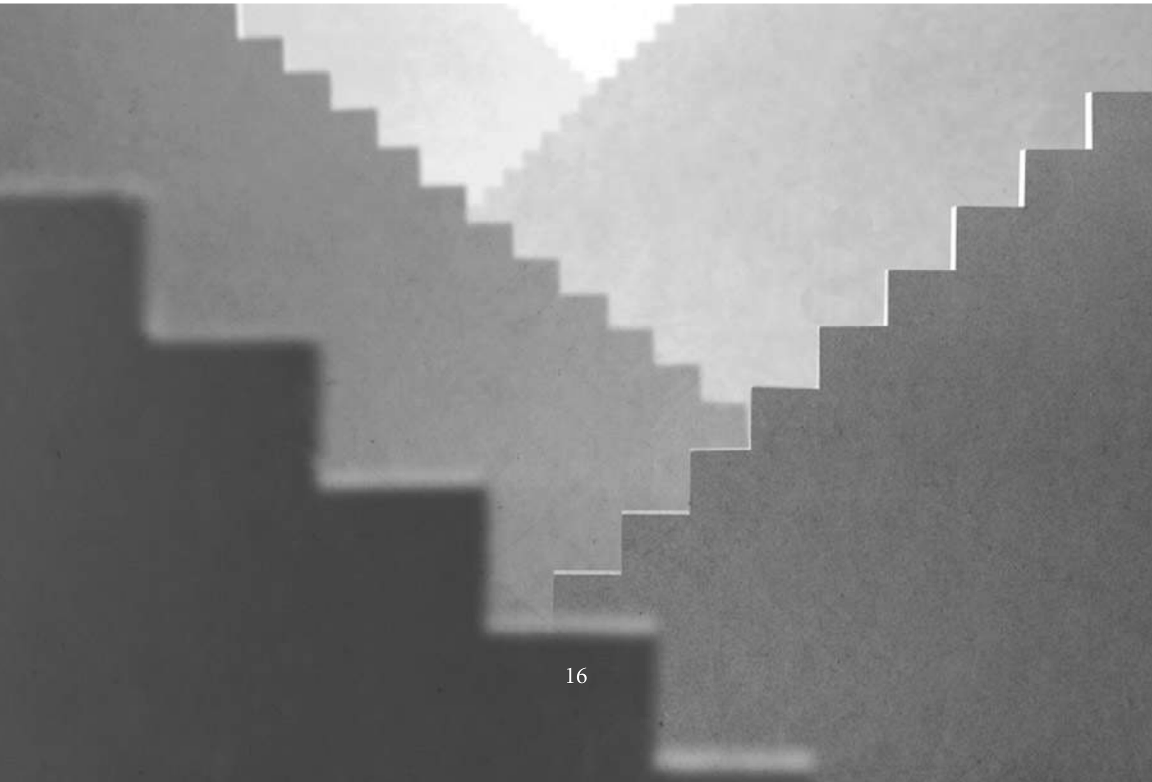
I was able to sort of put everything else on hold to be a caregiver… all day… every day. I have been absolutely shocked at how overwhelmed I was with the whole process. I mean the disease process, itself, was just so overwhelming. Then you add the medical care system on top of that. And then you've got the everyday household stuff like making the house run and making sure there's food and heat and the right equipment. Things change, and you have to move stuff around. There's just so much. There are so many things that you once took for granted that just don't work. "I've always done it this way," you say, but then all of a sudden, you no longer can.

Regards,
Lucy

Dear Debbie,

I never imagined me doing this, but caregiving just seemed like it came comfortably for me. I don't know why. I was doing what I was supposed to be doing, caring for my husband. At one point he said, "You know you can get paid for this." I replied, "Why would I want to get paid for something I'm supposed to be doing? I promised for better or worse. Honey, I'm doing what I'm supposed to. I'm taking care of you." He did not want to be a burden. I just felt as his wife, it was my responsibility to take care of him.

Sincerely,
Michelle



Dear Debbie,

I never thought of myself as a caregiver. That suddenly changed when he became incredibly sick. We got the wheelchair and then eventually a hospital bed. We had always been very, very active. Our lifestyle seemed to change overnight, and we couldn't even go for a walk. I think through the whole process, I felt good that I knew what to expect next. Our nurse was amazing. She was always a day ahead of preparing us for what to anticipate.

Respectfully,
Ester

I don't think of myself as a caregiver. I am a wife and a mother. And I guess this is what you do for the people you love… to take care of your family. I don't have medical skills. I freak out when I see blood, so I had to learn a lot. I had to be brave.

Dear Debbie,

It was up to me to make the phone calls to reach out if I thought something was changing as I was the one there with her. Because of that, I felt like I was in control of Mom's care, for better or worse. I think I'm a fairly intelligent person and since I had managed her chemo meds for so long, I think that familiarity made it easier. I think that if I hadn't had that background, it would have been an awful lot, awfully fast. One time, I had to give her all of the meds. I called hospice and they told me it was time to do the morphine. Mom lost the ability to stand within three days of hospice care. By day four, it was so hard because I did not know what to do. Even if I could help her, she couldn't stand. Her physical change happened so quickly.

With appreciation,
Marilyn

Caregiving is one of the hardest jobs in the whole world, even when it is your own mother dying. It's an isolating experience. And I felt really alone. But I also appreciated the experience. It is a lonely journey, but it is also a gift.

Dear Debbie,

I'm lucky because I was a nurse's aide years ago. What I learned back then came into use as my husband's caregiver. The only suggestion that I would make for anybody who will be in the caregiving role is to do a one-day training. This quick training on what could happen and how to do things would be hard, but it would also be so beneficial. People could learn how to turn their loved one in bed, how to change a diaper, or how to put on a condom catheter. As a former aide, even I was learning stuff. My husband couldn't use his right side, and we were trying to figure out what would be the best solution for him when he became incontinent. That's when our nurse, our main nurse, suggested condom catheters instead of doing the full foley. Once we got the sizing worked out, I no longer needed to move him. This was beneficial because the constant moving and rolling over had caused my husband a lot of pain. Plus, for one person to have to do that to a grown adult is not easy. I listened to the hospice team, and we made the decisions together.

Yours truly,
JoAnne

Normally, I would not ask anybody to come help me, but I am very much aware that I need help right now. I can’t seem to do it all by myself. Caregiving wears me out too much. It is kind of like I’ve got this mental block. I’m exhausted; just leave me alone; let me be exhausted.

Chapter 2

The Hospice Experience

Dear Debbie and George,

I'm pleased to share my story and introduce this chapter related to experiences with hospice. People sometimes remark that there are very few things certain for us in life. Birth, death, and taxes are all common responses. Clearly, the comments in this chapter demonstrate that being responsible for another's care until the end of that person's life is also an experience many, if not most of us, will undergo. However, when, for whom, for how long, and under what circumstances is hard to know. Like those whose stories follow this introduction, I am thankful hospice can make bearable much of the uncertainty that comes with caring for a terminally-ill family member or friend.

Even before my father was sick, I assumed I would eventually play a large role in caring for at least one of my parents someday; I just did not expect it to happen as soon as it did. When my dad's cancer was diagnosed, my family was devastated. In what seemed like a matter of seconds, we simultaneously learned not only that he had cancer, but that it was an aggressive type that had metastasized to his liver. Before we could even think to hope for a cure, we learned our father would not survive his disease.

This meant that hope for a full recovery had to be reshaped into other dimensions of hope that could co-exist with the reality of our father's impending death—hope for spiritual comfort and peace; hope for no pain; hope for a sense of purpose, meaning, and belonging; and hope for both a continued and a reignited sense of connection with others. Moving forward, imbuing myself with this new sense of hopefulness—rejecting despair in the midst of death—and having the strength and ability to embody it while watching Dad suffer was the hardest job I ever had to do. I would have been far less graceful in this effort without the support of hospice.

Enrolling Dad in hospice was a decision fraught with sadness, fear, and doubt—for all of us. Despite being familiar with palliative medicine, my ability to convince my family, and myself, that enrolling Dad in hospice still gave us space for hope was challenging, especially for Dad. But it turned out that the phone call I made that day set in motion the development of one of the most vital and supportive relationships my family and I would have as we journeyed through the last five months of Dad's life.

Hospice gave us many gifts. They taught us important end-of-life caregiving skills; they provided knowledge and understanding about the dying process; and they helped bolster the emotional strength we would need to persevere. When we were frustrated and exhausted, they offered compassion. When Dad was in pain, they quickly provided instruction and support for bringing him relief. When we had to make hard decisions about medications, nutrition, and palliative medical procedures—or about acquiring home health devices that would improve Dad's care, but also painfully symbolized his rapid decline—they responded not only with quick advice and/or delivery, but more importantly they provided encouragement and helpful reinforcement when any of us struggled to accept the current reality. Whenever we were fretful about what was to come, they offered up a roadmap for the journey—reminding us of the course, when needed, but also helping us reroute if circumstances required it.

The greatest gift hospice provided my dad was his dignity in dying. The nurses were authentic in their efforts to get to know my dad—the way they interacted with him in each visit or phone call warmed my heart. They talked with him about what interested him and the usual goings-on or mundane aspects of daily life. They readily joked with him, matching his sense of humor and accepting his gentle teasing. They spoke directly to him, not about him as if he were invisible or incapable of understanding. They helped him maintain his hygiene and taught us, as well, how to perform these most intimate and personal tasks with ultimate grace, compassion, and love.

As readers of this chapter will see by these notes and letters, I, like others, found that hospice provided the support we needed. With that support, in the end, we were able to feel confident and secure in knowing Dad experienced what most of us eventually anchor our hope to when a terminal diagnosis evokes mortality salience—a good death.

Blessed,
Jacquie

Dear Debbie,

Hospice was helpful to us. For example, the social worker helped by answering all of my husband's questions. I was able to sit back and observe as she gave credence to his concerns and tried to help him. The nurse was fabulous by helping us understand what was going on. I would always go to our nurse and ask why this was being done or how I should do something, and she would always explain everything so I could understand where we were.

With gratitude,
Jill

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Dear George,

If I had to do things over again, I would have had hospice care begin earlier. It was only when I started to drown that I finally called them in. We're a family who tries to take care of our problems and not reach out into the community to get help but, when you get to a point where you're just not going to be able to solve a problem anymore, you need someone who has a background in the area, understands what you are going through, and knows immediately what to do. That is when you have to swallow your pride and go out and get some help.

All best,
Roger

Hospice has been uniformly very responsive. They communicate among themselves, which is very helpful for just kind of keeping the momentum of things going when they all know what's going on instead of just the person you spoke to.

I liked that hospice would work together with me to come up with a plan to keep Mom's pain under control. She didn't want to sleep, but she also didn't want to be in pain. Hospice helped us find a way to let her have a normal life rather than sleeping in the chair all day.

Dear Debbie,

The hospice team was excellent. They treated my mom so well. I don't even believe she would have held on that long if it wasn't for hospice coming there and giving her that boost of life at that moment in time. I got to see Mom two days before she passed. I got two days with her. The first day she was alert and then the second day, she was kind of out of it. But, when I got there, she opened her eyes. I don't know if she thought she was dreaming. And she just gave me the biggest smile in the world, and she just touched my face. I said, "Mom, I'm here!" She just was so happy, but I knew she was leaving. My mother was one of those types of mothers; she prepared me for all of this before the time even came. So, I thanked her for that because I wouldn't have been able to go through all that in the way that I did if she had not prepared me. When the hospice team came in, they came to my house, met with me, and prepared me for a lot of things. I'm thankful for all of that. It got me through.

Thanks again,
Joyce

Dear George,

One thing I like about hospice is they don't demand that you need to do something specific. They do not say, "If we're going to give you our services, then you have to accept this or you have to accept that." Everything is an offer. "Here, we're letting you know what we have for you if you want to use it." I think, especially when it comes to hospice care and end-of-life situations, there are unprepared families and prepared families.

With appreciation,
Matt

Dear Debbie,

I appreciated hospice working on Mom's pain. There were times I called and got immediate help. The nurse would give me directions on what to do, and each time I called, the pain was taken care of. I needed help in understanding the process like knowing when we needed to give her pain medicine and what was enough but not too much. The team was helpful in giving me confidence that I was doing the right things. I was very satisfied with hospice. They were extremely helpful, and I learned a lot through it. I felt supported and in control for the first time. It was wonderful to not be dependent upon going to the emergency room; that experience was never good. I felt like we had a team supporting us and that we could do this. They were very helpful.

With thanks,
Doug

Dear Debbie,

Our theory was that the people of hospice understood what we were about and what we were trying to accomplish. They obviously have more experience than what we ever dreamt of having with people who are transitioning from an earthly life to a life hereafter. I live out-of-town and couldn't provide what Mom needed. My sister was in town. I needed the emotional support even though I was not right there. My sister realized about two weeks before Mom died how important hospice was. She originally had the idea that hospice would make dying easier. And, to a point, that's true. But the other side of it was she didn't realize how much benefit it was going to be for her. And I think when we got within that last two weeks, my sister really began to understand. I will tell you that if hospice has a cheerleader for them right now, it's my sister. Originally, I know my mom and sister thought hospice meant that the end is here. I said, "Well, Mom, the truth is the end is here today. I could walk out of your apartment, get in my vehicle, be in an auto accident, and could be dead today. To think that you're staring death in your face is really a misnomer because we all do it every day. We just don't think about it." Mom's concern was having a lot of people coming in, and she did not want that. It was really kind of funny because after the first two weeks, she looked forward to them coming. She realized it wasn't all about a medical issue but about emotional support she needed that she wasn't getting from doctors. Because that's not what they were looking at. I think if she were here to tell a story, her story would be, "If I did this all over, I'd do it again, because it was the best thing that happened for me."

Respectfully,
Sue

Dear George,

Hospice was as quick to respond as anything I've ever dealt with. One time I had to call on a Saturday around midnight or 1:00 a.m. I got a call back within 30 minutes. Somebody even came out the next day who wasn't our regular nurse to help us with something. And they did just like they said they would. They were on time; they were ready to go. I never felt like I couldn't call them. They would always have an answer or a solution. I kind of felt in the back of my mind that I could call that number any time and get the help I needed. So, they were great.

Sincerely,
John

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Dear Debbie,

My sister was fairly young, only 54 when she died. It went very quickly at the end. She was on hospice for almost a year and a half. She was mobile and able to walk until the final two weeks. The last few weeks she was so sick, she could not get out of bed. Hospice was wonderful. My sister was fortunate that she had the same nurse for the entire one-and-a-half years. She and the nurse became very, very good friends, and I became good friends with her, as well. The nurse just kept adjusting to every setback and was able to manage my sister's medications. I started working from home a lot and was making sure that she did not have any additional questions.

Sincerely,
April

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Dear George,

Every time the nurse visited, or even the woman who bathed my mom, they would pull me off to the side. They would share one of their stories, keep me abreast of what was going on, let me know how my mom was doing, and check to see how I was doing. They made sure to do this every time before they left. We would talk for a minute or two. So, they were really good with that. They were really concerned with everybody.

Kind wishes,
Betsy

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Dear Debbie,

Hospice was very good. Mom really enjoyed the minister coming over because he would pray with her. We also had about three nurses and an aide who would come and give her a bath, take care of her general cleanliness, and change her sheets and stuff like that. They're really wonderful and were able to just roll her over and make the bed. It was really nice to deal with them. We've had a great experience with the hospice here. I think it was important to have somebody to talk to about things. You know that they're there if you need somebody. They are always saying if you need me, call. They make you feel welcome to call at 3:00 in the morning.

Fondly,
Georgia

Dear Debbie,

My mom really appreciated the hospice chaplain's visits. The chaplain brought over a blanket for her. When I came over after the chaplain had gone, my mom said, "Look at this blanket." She really appreciated that spiritual nest that the chaplain provided. I think it was the day before my mom passed away. My mom was unconscious, and the chaplain provided some guidance for my aunt and me. She told us some things that we probably should be doing at that point to prepare for my mom's death which nobody else had said. So, I really appreciated the chaplain, as well.

Faithfully,
Jo

Dear George,

When you're in the middle of all this, with all the emotional stuff that's going on, it might be challenging for someone to really stop and look at each issue. Each person is different. For some people, they're still grappling with the potential loss of their loved one and all the weight of everything else in their life. Hospice helps people get to that place, really look at it from another perspective, and help pull them back and kinda go, "OK…Wait a minute. Let's work on this together."

Thanks,
Patty

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Dear Debbie,

The hospice nurse would hug me and then was hands-on caring for my husband. She was very loving, and I think my husband liked that. He talked about having somebody to help us do the journey. The nurse would be here forever, and I know it put her behind on her schedule. When he died, I called because I was in tears. I didn't know he was dying; I knew he was unresponsive. I thought "What in the world did I get myself into? Why did I think I could keep him at home?" and they were so good. Anytime I called after hours, they would send someone over.

Yours truly,
Carol

They were there for me, and they provided guidance. I would not know what was going to happen next or how things were supposed to work. They told me, "This is what usually happens; here is how we deal with this; and we are in this together."

Dear Debbie,

My husband had esophageal cancer and his care was extremely difficult. I was up all hours of the night. I never knew what was going to happen. After many trips to the hospital, hospice was the biggest relief in the world. They would come when I needed them in the middle of the night. They would advise whether further steps needed to be taken or not. The bath aide helped me tremendously by taking that responsibility off my shoulders, and it just gave me a little more rest. It was great. I can't think of anything they could have done better; they did everything to make sure that his comfort was taken care while still taking time to listen to my needs.

He could not keep food down because of the radiation. I had to know if a certain medication was helping or not. It turned out that anti-nausea medications gave him bad hallucinations. He had problems with bowel blockages. He lost 50lbs during that time, so I had to make constant decisions regarding his health. My husband was a veteran, so I had to try to coordinate with the VA and the public hospitals. I had a lot of problems. By myself, without hospice, there wasn't one decision that was easy. For my husband, everything was a crisis. He went from sitting in a chair to having heart problems or throwing up. It was just constant. He had to go three times a week just to receive fluids because he couldn't eat enough and didn't drink enough. He took two bites and started throwing up. It was a very rough time.

When hospice started, I quit having to take him to the doctors, to anything. Everything went through the hospice, so it meant both of us could stay home and rest. He didn't have to go do all these tests and do all this stuff that they required, and they helped me straighten out all his medications Once we took him off of about 15 different medications, he started doing a whole lot better. I had a good experience with hospice. They did great.

All my best,
Gertrude

Dear George,

I felt really good with hospice. I think that they're easy to contact. I mean, they got back to me right away if I called the triage nurse at the hotline number. They've been responsive when we needed to have assessments done at the house. And even though it wasn't a scheduled visit, they were willing to come over and just do a quick assessment. They actually did that on Christmas Eve Day. It was very helpful because it gave us peace of mind going into a holiday.

In memory,
Karen

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Dear Debbie,

I would need to call, and hospice was always here immediately. I never felt alone in the process. Hospice got us a bigger wheelchair that was more suitable so Mom would not slip over. As soon as I said, "This is not working for us," they got on it. Within the day, we had another wheelchair delivered that helped support her more. If there was a need, they continuously helped every time. The team were like family. I felt like they knew my mom and her medicine. I could see that I was wearing down, and things were getting more emotional for me. I knew my mom inside and out. Like I just knew her looks and everything. The hospice staff was very kind. I know they see this all the time, but I had never seen this before. I felt like I was in control, but I really don't think I was. I think they were; they just let me believe I was in control. They could see my face, and I think they had complete empathy for me. Everybody who was in my home was wonderful. They treated me with utmost respect and validated every feeling and fear that I might be having. I never felt like I was alone. It was an excellent experience. I would recommend it a thousand times if I could. It was a wonderful thing.

Regards,
David

The one thing with hospice that gives me comfort is that they respect Mom's wishes. This is what she wanted. This is what we're doing. And it takes that pressure off, feeling like, "Oh, my gosh. Should I be still feeding her if she'll eat it? Should I be doing this?" And they make it known that it's OK to let them go.

What little bit we had of hospice was wonderful. They were a lifesaver for me. I knew I could call them, and I would get a response immediately. As a caregiver, that was great comfort. I know my dad was angry with me, probably because I was a safe person to be angry with. I know he was not really angry with me, but just angry with the situation.

I feel very well-supported, not just by the social worker and the chaplain, but by all the members of the team. And they're all willing to talk about whatever I need to talk about. It's a wonderful feeling of support.

Dear Debbie,

I had a really good hospice team. I loved the fact that they helped me get my husband changed. They even showed me pointers on how to best change him. So yeah, I had a really good team. They always asked me if I had questions and then answered all of them. They were concerned how I was I doing and how I was holding up. I felt like I was in the middle, and they kind of took the lead with one of the nurses in charge. That was fine. Then there were other times where I felt like I was in total control. About 1:30 in the morning, I just got up out of my bed, I went in there, and I talked to my husband. I told him it was okay if he wanted to go. I think within the next hour, he was gone. So, hospice really helped me and prepared me for that.

With respect,
Sheila

Dear Debbie,

I worked with hospice constantly. They were truly my right hand. They let us continue our normal life. If I needed a refill of his medicine, the hospice doctor would take care of it. When it became evident that he didn't need that cholesterol medicine or that vitamin or whatever it was, we talked about not doing it any more. It was all our decision. Together, we would talk about it when the nurse was here. He wasn't on hospice that long, but it seems like she was here three times a week. And when the nurse wasn't here, the bath lady was here. I really felt like we had tremendous care. A chaplain reached out to me. The hospice nurse was never, ever, ever in a hurry. She gave us 100% attention. It's as if I was her only family that she was involved with. I felt like I was in the lead, but they guided us. When he got sick, I was the one in control and the one who took care of him. As he got sicker, the kids became more involved, which gave me the support that I needed. The grandkids were here, too. They'd come and sit and read to him.

Thankful,
Kevin

The hospice staff were there for me, and I'm glad Mom was in their care. They were patient with my questions, really helpful, and then when my sister would visit, they would answer the same questions again. She was not there every day like I was, but they helped the whole family.

Chapter 3

The Research Experience

Dear Debbie and George,

I'm honored to introduce your chapter about participating in research. In reading through these notes, my experience is very similar. After hearing about the opportunity to participate in your research, I decided to say "yes" because I figured whatever I'm going through might help somebody else. I saw it as a benefit for those coming behind me. I wasn't sure what I was going to be getting into, but I just figured the more people along on my journey, the better. To my surprise it has not only given you things to benefit others, but I have also benefited. Looking through these letters, I can see I was not the only one.

Answering your questions every couple of weeks in the surveys helped me to be aware of what I should expect or what I could expect as a possibility with my emotions. The questions kind of helped put into perspective where my hospice team were coming from. They helped me to feel more grounded in what I am going through. I mean things are the way they are. I'm dealing with three of my children going through things as well. There's so much stuff going on. I would say that the research questions were pretty pertinent questions and mostly answering them just helped me just to keep my focus on myself as I'm always focused on my husband's situation rather than mine. I realized I need to be aware of how I'm feeling, what I'm doing, and how I react to things. Just answering the questions made me aware so that I gave myself more grace to go through stuff. Again, others report having similar reactions.

I was surprised that there was research that focused on me. We were always approached before about research for my husband. I felt special and like what I was experiencing was important, not to mention the fact the research, itself, helped me. I would encourage other caregivers to take a chance and give a little time to yourself by participating. Having a study focused on me and my feelings will surely help people understand the problems and challenges of being a caregiver. Participating helped, the intervention helped. I encourage all caregivers to give it a try. Thank you for the opportunity.

Sincerely in appreciation,
Mary Ann

> **I didn't know what I was getting myself into, so when the researcher said this might help others in the future, I thought, "Yes." There are so many people in this role, with different stories and different situations, but there is some collective wisdom. I mean with all these different experiences, this can help others.**

Dear Debbie,

I wanted to participate in your research because I felt like it was something that I could benefit from and maybe help some other people. I didn't think it would be a burden because I had a lot of free time. I was just kind of sitting around the house all day with my dad. So, I was available. Some of the questions actually did make me think because for the most part, I don't really give a whole lot of thought to my own emotional well-being. I just go through the motions and do what I have to do. But some of them made me think about my own thoughts on my emotional state.

Thanks,
Peggy

Dear Debbie,

I participated in your research because I felt like I had nothing to lose, and if it helped people who were in the same position, then why not? I thought it might help me learn the ways to handle what was going on because it was all new taking care of somebody who was dying. I didn't know how much time I would have since she required 24/7 care. Those questions you asked made me more aware of the burden caregiving put on me. I think I was more honest than I thought I would be. I just didn't want Mom to see anything and think she was a burden. She was my focus. I don't think people realize how much it takes to be a caregiver. And I think the questions kind of brought that out more. It's a big, big role with many responsibilities.

With thanks,
Steve

It helped to know I was helping others. I was glad to take time to think of your questions and the surveys. They got me thinking about problems and solutions. I wondered what I could learn from this and how I would advise others in that situation. I enjoyed it.

Dear Debbie,

I think the study will be helpful for others. I wanted to be involved because of the outcomes and care factors. I didn't think it was a burden to participate. The study helped me pay attention to Dad's needs, as well as mine. Being a part of the research not only affected him, but it also affected me. It kind of changed the way I was doing things. For example, sometimes Dad would be in a lot of pain. I didn't really know how to address it in order to help him. The study helped me to recognize his needs. I think everything that you focused on really helped a lot.

All the best,
Mike

Well, it was my pleasure to participate in your study. I believe in studies. I believe in research. I participate when I can because I think that anytime you can help, you should. I feel like I learned a lot from it and that maybe my experiences were helpful to others.

Dear Debbie,

My mom isn't the first person I have taken care of. I know that families have a hard time trusting people and getting the answers they need to get for their loved ones. And so, I was hoping through my participation that I could lend a little light on areas of need that caregivers may have. The surveys asked questions about how I was feeling. Even during the phone calls, they would ask me if there was anything that I needed, if I felt that Mom's treatment was going okay, stuff like that. I thought that that was beneficial because most caregivers, especially family, don't know what to do. And they don't want to upset their loved ones, but at the same time there are certain things that need to be done and they need support in doing that. Some of the questions were a little personal, but I understand why you asked them. I did feel that the study was very good. And I'm hoping that through my participation, you come up with a program for caretakers to be involved, and have answers to their questions, especially if it's family members or close friends. I would say that I'm more patient with my mother because I was in the study. I try to see things from her point of view. It's not easy to do that, but just tried to understand, be supportive, and let her do what she can.

Fondly,
Rose

I wanted to participate in your study. How do I help you help the people who are afraid, or uncomfortable, or embarrassed? People who feel tired, guilty, and very sad? If my experience counts, I want to help.

Answering the questions forced me to take what was in my head and actually make it so that it was understandable to other people. When you're feeling something emotional or overwhelmed, sometimes it can be very busy in your head. By talking about it, you can make it more understandable and relatable with other people.

Dear Debbie,

If it can help somebody, I'm willing to help. Because I answered the surveys honestly, it made me think about what was going on. How I kind of internalize it and am just sort of going through the motions. After reading the questions, the researcher gave me a lot of tools to use with my mom. As she was passing away, she didn't know where she was. And so instead of correcting her, for example, we just let her be in the house she thought she was in from our younger years.

Cordially,
Barbara

I decided to join your study because I think that when you talk to somebody out loud about issues, instead of just kind of thinking about them in your head and trying to figure it out, it helps. It was good to talk to somebody like a third party that's not involved. New options and ideas come up. It may not even be something that they said but just the fact that you're talking to them about it.

Dear Debbie,

I wanted to participate because I knew it was through the University, and I went there. I wanted to give you guys as much data as possible. But the other thing is that I wanted something good to come from my mom's illness and her death. I thought that if even just participating in something like this could make a difference in somebody else's life, my mom's memory could still be alive. I was positive that good was going to come from it. I thought that maybe I was going to get more resources or hear about some different things that maybe I would have not heard about if I didn't participate in it.

Sincerely,
Brian

Dear George,

Well, I guess foremost, it was nice to have somebody else, another shoulder, to cry on and somebody to talk to. Somebody with a sympathetic, nonjudgmental ear. Our talks always came around to that and my primary caregiver issues. So, I enjoyed just having the outlet of talking to your researcher. Another benefit was going through the exercises we did to come up with a plan for solving problems in a more structured way because that isn't something that I would normally do on my own. And the survey questions got me thinking. It's not a way that I normally think, and I think it could be helpful for others in my situation.

Kind wishes,
Al

Dear George,

I participated because I was able to think through things and learn about new tools that can help me and help others. I had never participated in research before. I didn't know my experience and my opinions matter, but the researcher said this is helping other caregivers and helping hospices to come up with better services. And that feels good.

Best regards,
Lucy

Dear George,

I really liked talking to the researcher a lot. It helped validate some things for me. I enjoyed talking about what I was feeling with somebody else. Even if it wasn't in-depth, it helped me to kind of problem solve. It wasn't just about me doing it. It gave me tools to sort of say, "Oh, wow. That is a big deal. Let's look at that." Or to help me see that maybe that isn't a big deal. Or to figure out how is that in context with what's going on? It has helped me troubleshoot and given me some reflection on what was going on for me.

All the best,
Rachell

Dear George,

The fact that someone was interested in my experience as a caregiver, that someone actually came to me and asked me if I would want to do something like that was wonderful. I just thought it was kind of odd that someone would research on the caregiving experience, you know? It just seems like something that you automatically do by yourself, in your brain, and I didn't think anyone was ever going to actually research my situation. So, it was kind of interesting, just the fact that someone wanted to research the experience, that whole thing. Someone wanted to take the time to understand what I was going through. I will be interested to see what the results of this research are.

In appreciation,
Ken

I participated in your study so I would know that what I am going through, what I feel, and what the issues are might help researchers figure out ways to support others in the future. That is a big deal. But this also helped me because I got to think and be more aware of how I am handling things.

Want to make caregiving easier for others?

— Opportunity to Participate in a Research Study —

The Hospice Caregiving Research Network is a long-standing interdisciplinary team of researchers from Washington University in St. Louis and the University of Pennsylvania committed to studying ways to support caregivers in hospice. We are looking for ways to improve the caregiving experience and help those who care for a dying loved one cope better. We are currently running several studies; if you are interested to find out more about these opportunities and see if you qualify for any of these studies, please contact ***** or email at ****

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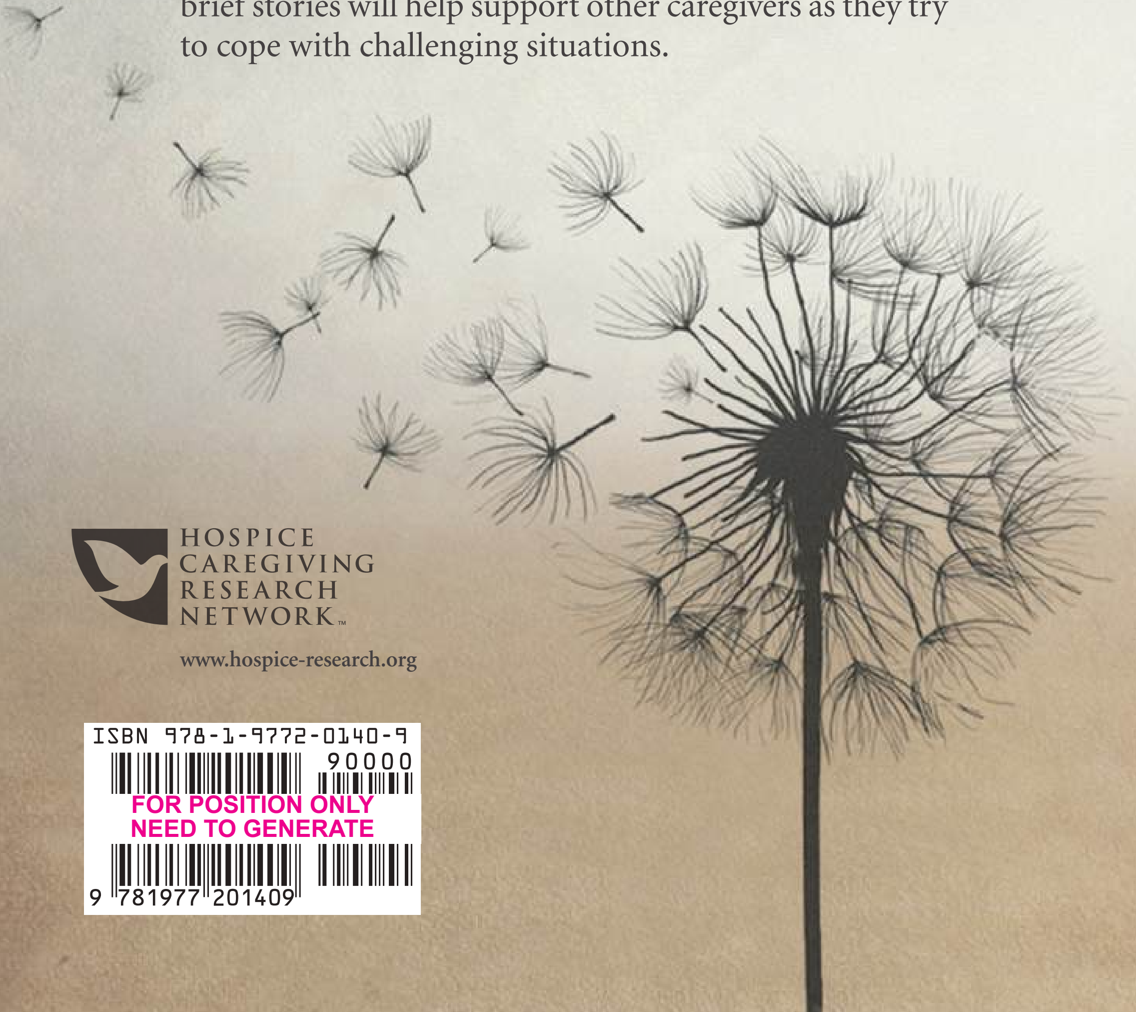
COLLECTIVE VOICES

Family Reflections on the Hospice Journey

Debra Parker Oliver, PhD, MSW and George Demiris, PhD, FACMI are part of the Hospice Caregiving Research Network (HCRN). HCRN is a long-standing interdisciplinary team of researchers committed to intervention research to support caregivers.

In COLLECTIVE VOICES, they share letters and notes from some of the many who have cared for loved ones during their end-of-life journeys. It is their hope that the brief stories will help support other caregivers as they try to cope with challenging situations.



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