

Preface

FOR TEN YEARS, MY husband lived with several health issues. The last two years of his life, a diagnosis of Alzheimer's was added to the list. I was his primary caregiver.

To preserve my sanity, gain balance, and cope, I got out my laptop and began to write, usually early in the morning. My writing culminated in this book, which opens the door to our experience: our vulnerabilities and insecurities as well as the positive and loving moments we shared. It upholds our belief in the resilience of human beings.

In life with my husband, I knew my role. I was introduced to others as "George's lovely wife." We married in a time of male dominance, at least in the circles in which we lived. George called me his helpmate, a Biblical term. I was to help him accomplish his goals. That was fine, but I always wanted to be more. After sixty years in that role, however, my "place" was etched in the stone of my psyche. George became an advocate for women's rights but sometimes found it difficult to practice that in his personal life. Though he was always kind, his schedule, his work, and his seven books all took first place, leading me to believe that he was more important than I. While I managed to

accomplish some things that I'm proud of—motherhood, my education, my profession—it all took second place to being George's helpmate. During the years of his declining health, I began to move past that thinking.

Observing the physical and mental changes in my husband over the years was painful. My academic and professional background is in behavioral science with a focus on dealing with loss. As medical people can tell you, their expertise helps patients; however, when the patient is their loved one, it is a different situation as an emotional element enters. My knowledge and experience around the topic of loss were helpful, but this time it was different indeed because the client was my husband. George's losses—and mine—were numerous. Writing helped me sort out my reactions and feelings. I believe it also helped me be a better caregiver—and person.

In the midst of this personal and marital crisis, our world was turned upside down due to the invasion of an international pandemic, COVID-19. It stormed into all lives, including ours. We wore face masks and were physically distanced from friends and family. Such isolation impacted George and me at a time when support was so important to our physical, mental, and emotional stability. As if the pandemic weren't enough, our country, the *United States of America*, became politically *disunited*. It was disheartening and frightening to witness such an absence of national unity. We also saw the killing of several African Americans by police officers, which resulted in

protests throughout the country. All of these events caused collective trauma. Consequently, our personal crisis was complicated by the national and international crises.

In this book I reveal difficulties but also the beauty and love George and I experienced on our journey. I share these writings with you with the intention of encouraging you, especially in your times of crisis. I hope that as you read this book you find the love and hope that was tucked in the cracks and crevices of our days. May you be strengthened and find peace in whatever journey you are on.

When you pass through the
waters, I will be with you;
and through the rivers, they
shall not overwhelm you.
—Isaiah 43:2

Introduction: THE MAN

PEOPLE WHO KNEW GEORGE well appropriately described him as a strong-willed person. Yet that strength was hidden behind a quiet, humble, and calm personality. He could be characterized as a steel fist in a velvet glove.

His profession was that of clergyman, one to which he was well suited. He sensed a call to living his life in the service of God. About twenty years into his career, he was deeply moved by the plight of marginalized people in our world: those in poverty and those treated unequally because of their race, gender, sexual orientation, or class. Ministry on behalf of them became his focus. His strong will was a valuable resource in the face of opposition by many, including people of faith.

When George and I met in our midtwenties, I saw the velvet glove but had no knowledge of or experience with the steel fist, the strong-willed man. It began to show itself when George chose to marry me. I was a divorcee with a young child—a fabulous child, I might add. The national church said, “No, you can’t marry a divorced woman and still be a pastor.” My first husband was a sociopath, but the church was not interested in why I was divorced. Its decision was a slap in George’s face after his nine years

of post-high school education to become a pastor. The church said, “Final decision.”

I did not want the responsibility or the reputation of ruining George’s career, so I believed we should not marry. However, because George was a strong-willed, think-outside-the-box person, and we loved each other, we married. His determination paid off: two years later the church changed its mind. It began to evaluate each request for ordination on its own merits. George went on to serve the church and the disenfranchised for over fifty years—with me at his side.

We were walking back to our apartment one April evening after dinner in our community’s dining room. The air was calm and balmy with a gentle aroma of spring blossoms. Since George’s walking was precarious and we were walking down a slight decline, he tightly held onto my arm. Without warning, he fell to the pavement, pulling me down with him. I could smell the asphalt as my head jerked back and bounced on the hard surface. I reached back and felt a large bump and then saw blood on my fingers. I managed to sit up and saw George lay unmoving on the pavement in front of me. Fear shivered down my spine. George needed help. I crawled at first, then stood and shakily walked back to the dining room. To my relief, people immediately came to my assistance.

Within minutes, two ambulances arrived, one for George and one for me. We were taken to a trauma center

because of my head injury. The care was swift. I remember that the emergency room staff wanted to cut off my shirt. I objected—I liked that shirt!—and said it could be pulled over my wounded head. Tests showed that my injury was not internal (I just had a grapefruit-sized lump on the back of my head) so my breathing calmed. I was discharged and allowed to go see George in a nearby room. When I arrived, he was arguing with a nurse, claiming he didn't need to be x-rayed, despite having severe pain in his hip.

My irritation rose as I listened to his stubborn resistance. Our two daughters arrived, and with our unified urging, George finally consented to x-rays. He had a broken hip and was scheduled for surgery the next day. Following his surgery and hospital stay, he was transferred to a rehab facility and then to assisted living. After seven weeks he was well enough to return to our apartment. He and I were so pleased that he was finally where he loved to be—settled in at home.

Then, something happened.

1. THE NEWS

THE NEUROLOGIST IN HER starched white coat said, “We have the results of your extensive neurological tests.” She looked with a steady gaze into George’s eyes. “They conclude that you have dementia.” She paused as she waited for this news to sink in. “We suspected so, but now we have the proof.” I noticed that she was beautiful. How could such disturbing news come from one so lovely?

“Do I have Alzheimer’s?” George asked in a small, husky voice.

“Yes,” she replied. The kindness expressed in her face comforted me. At least the bearer of bad news delivered it with gentleness. I heard it; I didn’t hear it. I believed it; I didn’t believe it.

“What should I do?” George asked, appearing somewhat perplexed.

“Nothing,” she responded with a beautiful smile. “Keep enjoying your life by being active socially, physically, and mentally.”

“Enjoy each moment? Each day?” I inquired. My throat was dry.

“Yes,” the neurologist affirmed, “do as your wife suggests, George. Enjoy each day.”

George sat quietly for a while and then asked, “What will happen?”

“Your memory will gradually get worse,” she responded in an even, unemotional tone. I felt a chill. The room seemed too sterile, harsh, and bright. There was no softness.

“Will I die from it?”

“You will not die from Alzheimer’s. It doesn’t kill people, but complications can.”

In the car on our way home, I noticed children playing in a park, laughing. How could anyone be happy when our news was so sad? While we were going through a personal crisis, it was astounding to discover that the rest of the world was going on as usual. How dare it continue as if nothing had happened? After all, my personal world had flown off its axis.

I looked over at George, whose face showed no expression. I wanted to discuss the test results with him yet not be intrusive. I thought I should respect his need to process. Finally, I ventured, “How is this for you?”

My question hung in the air. George looked straight ahead and said, “She didn’t beat around the bush. She was very frank.”

“Yes, I’m glad she had the courage to tell us the truth. Now we know what we’re dealing with.”

George nodded, still showing no emotion. My heart-beat was rapid. I reminded myself to be calm, to drive

carefully. “I’m here for you, sweetheart,” I said as I reached for his hand. “I’ll be with you all the way.”

“Thank you,” he said. George was quiet. Finally, he asked, “When did this start?”

“About four years ago I saw some beginning signs,” I responded. “As the neurologist said, it’s more evident to the person closest to you than it is to you yourself. I noticed several behavior issues—and memory loss. Two years ago, you were diagnosed with mild cognitive impairment. Now that diagnosis has changed to Alzheimer’s.” I noticed that I didn’t like to say the word.

Neither did George. He said, “*Dementia* sounds better.”

In our silence, I recalled the words of author Faith Baldwin: “Time is a dressmaker, specializing in alterations.” We have been altered, all right—both the man I married and his wife.

We arrived home. George went immediately to lie down in the bedroom. I looked at the description of his new medication:

Memantine is used to treat moderate to severe confusion (dementia) related to Alzheimer’s disease. It does not cure Alzheimer’s disease, but it may improve memory, awareness, and the ability to perform daily functions. This medicine works by blocking the action of a certain natural substance in the brain (glutamate) that is believed to be linked to symptoms of Alzheimer’s disease.

Tears came easily. My strongest response was sadness. I was sad for George, sad for our children and grandchildren, sad for extended family and friends, and, yes, sad for myself.

My apprehension rose: what next? Am I going to be able to cope with this? Am I capable of being his daily caregiver? How many years do we have left? Will I live long enough to care for him? I was reminded of something I read, "Always carry a dream in your heart. It will keep you warm on cold days." On this emotionally chilly day, my dream was that we become other-focused as opposed to self-focused. With bad news, it is easy to become self-absorbed. Also, my dream was that we intentionally look for the beauty in little things so our souls would be blessed with inner peace. Was that too positive a spin? I needed it. That is how I cope.

In the midst of sadness and apprehension, life goes on. I glanced at our patio. A single yellow rose stood tall and gorgeous as it reached for the sun. Thank you, rose, for reminding me to look for the beauty in each day.

2. IS THIS MY MAN?

AWAKE AT NIGHT, I stared at the darkness, fear lapping at the edges of my heart. I told myself to be optimistic but also realistic. What did the future hold? Our marriage, this closest of relationships, was being invaded by an intruder. Was it an enemy?

As the days moved on and I tried to adjust to this unwanted news, I found that I had a few questions. Okay, maybe one hundred. I turned to Siri on my iPhone, my new best friend. “How can I help?” she asked. (Talk about an offer!) “Siri, what is the definition of *overwhelmed*?”

From her trove of information, that Library of Congress in her teeny-weeny head, she replied. “*Overwhelmed* is to bury or drown beneath a huge mass; inundate; have a strong emotional effect on.” (How does Siri do that?)

Why was I feeling overwhelmed—that is, buried, inundated, and yes, experiencing strong emotions? It was because I had so many questions and decisions to make in living with a beloved person who has Alzheimer’s. Questions loomed, ones that not even Siri could answer. In regard to my husband and some of his new behaviors,

I wondered, Who *are* you? What *are* you doing? How will we manage this? I realized that such questions were not dissimilar from those one may ask after the first year of marriage.

Let's start with "Who *are* you?" He looked pretty much the same. He was a six-footer with long arms and legs. He disliked his freckles, but I was fond of them as they lent a bit of "boy" to his appearance. I'd always liked his hands with long, slim fingers. When we were dating, I remember focusing on them, fascinated. He'd been balding for several years, but he joked that God made some heads so beautiful that they don't need hair to cover them. His appearance was very familiar to me, but other things had changed. Relationships are complicated. George had always been a bit of an enigma to me. (*I am a bit of an enigma to me.*) However, after almost sixty years of knowing and loving him, I thought I was close to figuring him out—until now.

It is important to say that George was still a person of intellect, especially in the subjects in which he had immersed himself throughout the years. He could talk theology and politics. He could express himself and ask intelligent—even brilliant—questions. Visitors said, "He seems fine, like his old self." A friend whose father had Alzheimer's wrote, "My father was very bright, as is your husband, and the neurologist said he probably had many coping strategies that hid the problem until Alzheimer's was more fully developed."

I experienced a new man. Our niece Amy said it well: “He is a different presentation of his former self.” He was a man I looked at daily and thought, Who *are* you? The present George was so pronounced that reaching back to recall the George of the past was difficult. Comments by other people helped me. Numerous people remembered that his speaking ability was outstanding; some claimed they recalled portions of his sermons from years ago. A former church member recently wrote, “We heard great sermons week after week after week.”

Others credited him with changing their life’s direction; his words and actions led them to move from selfish lives to lives given for others. Some worked for the resolution of world hunger. A man who now holds the position George formerly held as world hunger director for our church’s national organization recently wrote, “George has moved mountains and altered the pathways of history for good. He has changed hearts and minds and called people to courageously follow the journey of the Holy Spirit in the way of love and justice. He has spoken with authenticity and without hesitation.”

His sister Ruth wrote, “Brother, I so honor and respect your outstanding passion for social justice issues. Your books are written so well and they will be studied and learned from even after you get your wings.” Other words used to describe George were “relentless,” “indefatigable,” and “a burr under the saddle”—all true in my experience. “Focused and driven” was another description. Those

characteristics are precisely why he accomplished so much. He had the ability to be absorbed in a project, whether it be a sermon, a class, the planning of a conference, or, on a lighter note, a golf or tennis game. With his persuasive and persistent personality, he was able to network and, to the amazement of his colleagues, approach and secure big names to speak at any number of events. “It never hurts to ask” was his mantra.

Some of his characteristics that I knew so well were now changing. For example, one of his major characteristics—the essence of his personality—was his skill of asking questions. He often asked our children and grandchildren, “Did you ask a good question today?” In any social setting it was the same: questions, questions, questions. Surprisingly, he said to me, “I wish people would ask *me* questions at the dining table instead of me always being the one to ask questions.”

One evening we decided to have dinner alone in the dining room of the continuing-care facility where we lived—almost like we were on a date. I noticed that George enjoyed reminiscing, and I recalled his comment about wishing others would ask him questions. We’ll have some fun, I thought. I’ll ask him questions about one of his favorite topics: the churches he served as a pastor over the past fifty years.

During the salad course, between bites of crunchy greens, carrots, and cucumber, I said, “You worked with many organists throughout your ministry, honey. Did you

have some favorites?” He appeared to recall quite well, needing only minor help pulling up names.

While enjoying the entrée, I asked about his secretaries, “Who was the most efficient?” and then about the physical buildings, “Did you have a favorite church architecture?” While enjoying his helping of mashed potatoes and gravy, he seemed engaged in the conversation. I was pleased. In recalling the past, we were having a stimulating dinner hour.

That night in bed, George said, “Vivian, you made me uncomfortable at dinner tonight.”

“Really? Why?”

“I felt like you were interrogating me! You asked me all those questions.”

I was shocked. This from Mr. Questioner, the man who answered questions by asking questions? Go figure. Who *are* you?

In retrospect I realize that even though he wanted to be asked questions, he was more comfortable asking the questions. In being questioned, perhaps he felt inadequate, fearing that he couldn't recall the past. This made him ill at ease and agitated. As he reminded me, “I'm not the man I used to be.” I reminded myself that he had a disease, Alzheimer's.

Another of my husband's characteristics was patience. In fact, when he wanted to get his way, he would wait it out patiently until he succeeded. Now he became impatient, which showed up as irritability. At church one day,

George went to the technology booth where a young person graciously assisted hard-of-hearing people. Each Sunday, George would pick up a hearing device to better hear the church service. Suddenly, I heard my once-patient husband say in his loud preacher voice, “Where’s the hearing thing? It’s not here where it’s supposed to be!” His tone was less than kind, more like “you incompetent kid.” True, the device wasn’t where it usually is; it lay five inches to the left. Who *are* you?

I watched as the filters of speech and action and his inhibitions diminished. Sometimes the result was inappropriate behavior, which could be embarrassing. I attempted to learn how to interact with a dementia patient through various guidelines available in literature. I was told that I needed to embrace three tenets:

1. Don’t argue with the person.
2. Refrain from trying to reason.
3. Do not explain.

The first idea didn’t seem difficult, as arguing was not my usual method of interacting. However, refraining from reasoning and explaining was a different story. Reasoning and explaining were at the heart of how I thought and conversed, and they were the way I taught our children to interact. They were the way I operated with friends, and how I wrote and spoke. Surely, if I reasoned and explained, most situations could be worked through. I was told that

this was not the case when interacting with a person with dementia. I could explain and reason till the cows come home; it was not going to work. Instead, I was told to repeat, distract, or refocus the person.

One of our disagreements happened because George did not want me to lock the house or car. His reason was “it’s not necessary.” When I locked the door, he said, “What’s the matter with you anyway?” I learned not to argue, reason, or explain. Just do it.

Though the answer to “Who are you?” changed frequently, I didn’t question my love for this old new man. Somehow in George’s current vulnerability, he had endeared himself to me in a way that he couldn’t when he was young and physically, mentally, and emotionally strong.

He was still my man.