# What they are saying about *Who is God When We Hurt?*

What I love about Scibienski's memoir is that it's not primarily her own—through the interweaving stories of her late husband, her family, her community of faith, and her own vulnerable struggle as a pastor to know and trust God, we come face to face with our own questions, trials, challenges, and fears. It is a memoir that straddles the boundaries between narrative and devotional: inviting and enticing us through even the most painful of stories to know and trust that God is already and always a part of all our stories, too.

*Rev. Dr. Erin Raffety*
*Lecturer, Practical Theology*
*Princeton Theological Seminary*

Beth's book features compassion—both to those facing unspeakable heartache, and to Beth herself who lived with sometimes unbearable heartache. Beth points us to faith and shows us that God doesn't disappear during our difficulties. Instead, God shows up stronger to sit and stand with us. A must-read for anyone who questions how they will continue when life feels too difficult.

*Denise M. Brown*
*Founder*
*CareGiving.com*

In Who Is God When We Hurt?, Beth speaks directly from her heart to the heart of the reader. Although she is writing about her own experience in caring for her husband Pete she is speaking for so many other caregivers traveling that same path and facing those same challenges. Who Is Go When We Hurt? is a sweet, compelling, and honest telling of what it means to be a caregiver, the value of community, and how we all need each other. Thank you, Beth, for the courage to tell your story, including the challenges of caregiving and of faith.

*Elissa Lewin*

*Founder and Executive Director*
*Nancy's House: Caring for Caregivers*

Who is God when we hurt? Listen to the pastor, the caregiver. Listen to Beth—for this book reveals a completely human character on every page. A woman who is unafraid, or simply willing to be foolish enough to speak honestly, to ask impossible questions, to refuse to let go, and then to model for all of us how to let go. It's not Rev. Scibienski's bravery that most captures the reader—and there is much of that in this book—it's her quirky humanity—and that of her husband, her sons, her congregants, and friends—a humanity that lifts every reader into a conversation both pained and elegant. Reading this book, every single one of the fifty-plus essays and poems, is like sitting with a friend, a friend who remains through the trauma when everything feels fragile and things are out of control. She does not shout at us from the sidelines. An honest, healing book with human fingerprints all over it, a book that dares to follow the guidance of one's anger and to ask the unaskable questions. This book affords a healing therapy for anyone who is ready, or almost ready, to ask the questions.

*Dr. Virgnia Wiles*
*Professor of New Testament*
*New Brunswick Theological Seminary*

# WHO IS GOD WHEN WE HURT?

*A Pastor-Caregiver*
*wrestles with*
*grief, loss, faith,*
*& doubt*

BETH SCIBIENSKI

Open Door Publications

Who Is God When We Hurt?
A Pastor-Caregiver wrestles with grief, loss, faith & doubt

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*For Pete*
*and the Saints of*
*Grace Presbyterian Church*

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# PROLOGUE
# I PROMISE

EACH TIME I OFFICIATE A WEDDING, I find myself renewing my own wedding vows. Those of us who choose to live in a community such as a church experience life exponentially. We go to that many more weddings, that many more funerals; we witness that many more births, and that many more children growing up before our eyes. One year, our church community had seven funerals! On any given Sunday we pray for at least seven people who are severely ill! We live with an extended family of sorts—riding the wave of life's encounters together. Up and down, around we go.

When we experience the ups and downs of another person's life, we are invited to evaluate our own ups and downs. As the pastor of a church, I am always amazed at how much I have learned about grief and illness by being in relationship with so many others riding the waves of life. If I look back, I have learned many lessons about job loss, financial burdens, and the reimagining of one's future. I have witnessed many other couples learning how to love, how to commit, and watched people wrestle with their vows.

There is a moment in every wedding when a wave of emotion travels from my heart up through my spine and tries desperately to fill my eyes with tears. It is the moment when the happy couple says, "I promise to love you...in sickness and in health."

What do any of us know of the vows we take in marriage? In the same way we can't really be ready for the important things of life, we can't possibly know what "to love in sickness and in health" means. And the truth is—we don't need to. Sometimes I wonder about the people who wrote those traditional vows. What was going on in their lives? What had they witnessed that had them fashion those words as they are? If I were tasked with writing wedding vows in an official wedding book, would I include words like that? If not that, what would I write?

Pete and I did not use the traditional language in our vows. We wrote our vows after the prayer attributed to St. Francis entitled "Make me an instrument of thy peace." We vowed to sow love where there was hatred, hope where there was despair, light where there was darkness. We vowed to console, to understand, and to die to ourselves. We had no idea what we were talking about! And yet, the words fit us so very well. If I had to write an official book of vows now, having witnessed what I've witnessed, having officiated what I've officiated, I might include something like this:

*I, NAME, take you, NAME, to be my partner in life.*
*To share the happenings of life every day—*
*the mundane along with the profound.*
*I promise to spend my gifts and resources*
*to build a life together, physically, emotionally, and spiritually.*
*I promise to love my children, your children, our children.*
*And when we are poor,*
*or when we lose jobs,*
*or when we get sick,*
*or when the creek rises...*

Yeah, no one is gonna ask me to write an official book with vows in it anyway. What would you promise? What are we supposed to promise?

At this time in our relationship, I had begun to feel that the best promise I could make would be to remain. I will remain with Pete, my husband. I will remain with my family. I will remain with those under my care as a pastor. Sometimes I will be fully engaged. Sometimes I will be a depressed, raggedy woman. Sometimes I will have a great sense of humor, and sometimes my anxiety will be so palpable that I'm going to need you to help me breathe. I will remain and, in promising to remain, I promise that I will change. We will not be who we are the day we promised.

Pete and I changed so much. We made promises at one moment in time. Tangible, recordable, legal promises that also helped us evolve. Our promises weren't immutable. They rode the waves of life with us.

I remember standing before this lovestruck couple as they uttered the words, "in sickness and in health," and I wanted to say, "Are you sure? Do you really want to say that out loud? Because you're going to change. Everything that you experience together or apart is going to affect you, and how you think you'll keep this promise is not how you really will. And how you think this promise will be tested...well, you simply can't fathom." Of course, I didn't say that out loud. And it's not that I wanted to dissuade them from making that promise. In fact, what I was really thinking is, they can't possibly know the kind of wave that may hit them. None of us can.

# CONTROL

AS PART OF MY PREPARATION FOR BECOMING A PASTOR, I completed a field education assignment as a chaplain at an urban hospital. The hospital was designated a Trauma 1 Center. One of the first things I learned in the orientation for this assignment was the definition of "trauma." Trauma is damage by an external force. That's it. Trauma can be a car accident or a gunshot wound. Trauma can be a fist to the jaw or a head hitting the concrete driveway after falling off a ladder. When one thing strikes another there is trauma.

When someone comes to the hospital because of trauma it is called a Code 40. I was told it was called that because 40 personnel are called to the scene. One of the 40 is the chaplain. Over the loudspeaker we would hear the code announced, "Code 40—by ambulance," for example. That meant the person who had experienced a trauma is headed to the hospital by ambulance. Often, those words would follow with further instructions letting us know how many minutes they believed it would be before the patient arrived at the hospital.

One balmy spring night, I responded to a Code 40, an urban brawl that ended in a knife injury. The factions of the brawl followed the ambulance to the emergency room, the anger led the way. One sunny, Saturday afternoon, I responded to a young woman in a motorcycle accident. As the surgeons worked on her mangled body, I attended to her husband, a burly, tattooed hulk-of-a-guy who fell into my arms weeping. He had watched the trauma happen—his wife lost control of her motorcycle and slid onto the pavement going 50 miles per hour. One winter morning, I consoled an aging wife whose husband had climbed a ladder to affix Christmas lights to their home. Trauma by fall. And one spring evening, a trauma call over the loudspeaker woke me—Code 40 by ambulance, five minutes.

I opened my eyes, looked around my on-call bedroom. One bed, a television, and a small desk with a chair. I turned on the lamp by my bed, quickly dressed, and made my way to the trauma section of the emergency room. A few of my colleagues had already gathered: residents, patient advocates, security officer, surgeons. The trauma was a car accident. The driver of the vehicle, a teenager, was wheeled into the room where the frenzied trauma activity began, at least 12 people monitoring different things, each responsible for a unique part of this young man's care. The passenger of the car was dead on arrival. Neither of their families were present. The security officer began going through the young man's belongings, the patient advocate logged each item: $13, a driver's license, and then a note. The guard opened it up, began to read but then looked up for me, "Are you the chaplain?" "Mm-humm," nodding my head. He handed me the note.

I began to read a scratched out note that laid clear intentions of a suicide pact. I took a deep breath and looked up to find four residents standing over my shoulders reading the note. I stopped reading to notice the reactions of the physicians. I asked, "Hey, you ok?" At first they didn't say anything. They didn't even really want to look at me. As the chaplain, I represent all of the things that are out of their control. Physicians are taught and trained to repair life, to control bleeding, to help others escape death. When life isn't repaired, or bleeding persists, or death wins, the chaplain is called. Usually I didn't force myself into their world but I couldn't let it go this time.

"Seriously, are you okay?"

One finally spoke, "It pisses me off."

"Yes," I say, "I imagine it would."

Another spoke up, "Stupid kid, he writes the damn note and he survives while his friend dies. What's he gonna do now?"

Then another added, "Why should we save him? He wanted to die. Look at all that's going on to save him right now." We all looked up and into the trauma room.

After this pause, I returned to the note to read it again. I asked if anyone was calling his parents and arranged to be in the ER when they arrived. I folded up the note and handed it back to the officer on duty. “Thanks,” I said with closed lips and sad eyes.

*I take a moment for myself, go upstairs to the lobby where there is a water fountain and a gas fireplace with comfortable chairs. The lobby is empty in the middle of the night and I pick a good seat to catch my breath and gather my thoughts. What would I feel if this was my child? What would I think if this was my child? I try to imagine what will happen when he wakes. He will be greeted by a team of psychologists all wanting to help him find health. Will he want that? How will his parents convince him to want that? What relationship will his parents have with the grieving parents of the friend who died? Who will have to do this funeral? Thank God it’s not me. Of course that same clergy might eventually say, “Thank God I wasn’t the chaplain on call for this one.” What scripture might I use? Should I use scripture here? What can I pray if they ask me to pray? If they don’t ask, should I offer to pray?*

Those questions are typical and expected but not always helpful. Providing care for people happens in the moment, face to face, or voice to voice. I hadn’t yet met the parents. And often all those questions are not helpful because like this night, the psychologists and social workers got to the parents before me, and although physicians told them I was available, I didn’t meet them until 7 a.m. the next morning. By this time, their son was resting in a room in the Pediatric Emergency Unit. He would be transferred to a facility soon; he sustained few physical injuries.

I knocked lightly on the door and saw the parents on either side of the bed while a physician checked his vitals. The mother thanked me for coming. She asked if I had seen the note. I nodded.

“Do you have the note?” I asked.

“Yes.” And after a pause, she said, “We don’t understand.”

“I imagine you wouldn’t; be kind to yourself with this.”

She wiped tears from her eyes. I touched her shoulder and told her I had been thinking and praying for her all night. I had prayed for strength and wisdom, and now I would pray for kindness. She thanked me. I told her that I was about to go off call but there was always a chaplain on call and that I would pass on the information so that someone could check in with them later. I turned around and walked away. I returned to my bedroom, packed up my things, and after checking in with the pastoral care office, I went home.

It was not quite gray. The sun was shining through the wispy clouds here and there. There was a slight breeze. I watched as the world began to wake up—a woman walked on the sidewalk, a store owner put out a rack of shirts. When I arrived home, I made coffee and found a place on the couch to stare out the window for awhile. What had just happened? A person tried to take his own life; a person was unsuccessful in trying to take his own life. A person took a friend's life. Parents lost a son, whom they had spent endless energy keeping alive for over a decade—feeding, bathing, protecting, clothing, teaching, nurturing, loving, maybe even kissing and hugging. Another set of parents found a broken son. What was his childhood like? Did they take him to karate lessons, swimming lessons, piano lessons? Band concerts? Soccer games? Did they have to help with math homework? Starting that morning, those parents began a new chapter in their parenting journey. They were now raising a son who unsuccessfully tried to take his own life.

This traumatic experience lived with me amidst my class schedule and family activities. I didn't notice any signs of post trauma; I didn't appear to have any triggers from it. It's not that I could not stop thinking about it. But I would say I was reminded of it often. Three months later I came to understand why it was lingering beneath the surface of my mind: control. We fully lack control in this life. As I said before, as the chaplain (and possibly now as a pastor), I represented all of the things that are out of our control. The chaplain, the pastor, is available to talk about life when life is not making sense, when life is frightening, when life is—out of our control. As a pastor, I have a front row seat for all that is fragile in life; I am present when life is untenable. The majority of conversations that I have had with people, as a chaplain and as a pastor, dance around the truth that the world is unsafe.

Now trauma in the hospital is more obvious. We know when damage has been done by an external force. But trauma is not limited to car accidents and gunfire. Trauma is anything that disrupts. Trauma is anything that stops us in our tracks. In the parish, I have responded to trauma that comes in the form of divorce, diagnosis, death. We lack control. The world is indeed unsafe. We live in fear. I live in fear. I was living in some residual fear from this experience in the hospital with this young man who unsuccessfully tried to end his life.

And this unsuccessful attempt turned control on its head for me. Most of the trauma, the lack of control I was tending to, was about stopping bad from happening. But this young man tried to create bad—attempted to create a traumatic event that would result in death—and he was unsuccessful. That failed attempt at trauma was in itself traumatic for him. He was heading in a direction of destruction, and his plan was disrupted. My mind was wandering in and out of this experience, grappling with the reality that we are neither in control of saving our lives, nor are we in control of taking our lives.

Shortly after my stint as a chaplain I was ordained in the Presbyterian Church (USA) and began working with a small church in central New Jersey. Two years into this pastorate a beloved member of my congregation was diagnosed with ALS. Her good friend and I were sharing a bottle of wine in her kitchen.

*I sit across from this woman—she sports a stylish, short, platinum blonde haircut and she wears sandals way before Easter and well into the fall. She has been an elder for years; she has a deep passion for justice in our world and has developed a variety of opportunities for our congregation to serve hurting, broken people in our community. I have grown to trust her, her heart, and her ministry.*

*I ask, "How are you doing with your friend's illness?" She gathers tears in her eyes, finds a tissue, and says, "I don't know why I bother with mascara anymore," as it runs down her face. After a pause and bite of shrimp, she starts again, "It's hard, it's really hard. She had already suffered with the breast cancer."*

*She sniffs, blinks and finds her forceful voice to say, "And she fought hard, she won that battle with cancer. And now look; I can't bear to see her suffer like this."*

*I finish chewing and say, "How can I help you through this?"*

This woman has lived through more loss than anyone I have known. She buried three husbands. She lost her mother to Alzheimer's and a close friend to lymphoma. She has quilted together an incredible family from the broken pieces of three families. She loves them, and they love her. She is grandma in her own unique way while always honoring the other grandmothers involved. When she cries, her tears come in every color of grief.

Therein lies the beauty of grief: It is colorful. The tears she shed for her friend that afternoon leaked into tears shed for her husbands, that then leaked into tears for her mother. She said, "I thought Alzheimer's was the worst until I came face to face with ALS. This is worse."

"Yes, I believe so," I said.

"I don't ever want to go through this. And I won't. I don't think I've told you this yet but I'm going to take my life if I ever get Alzheimer's disease."

Looking up from my glass of wine, I say, "I'm sorry; what?"

"I might as well tell you now, Jean (her friend with ALS) and I have spoken about suicide at length. We've even purchased this book. I will lend it to you when I finish. It's all about how to kill yourself...and did you know that none of the options are ever really fool-proof? The author suggests that you always put a bag over your head just in case your first choice doesn't work."

I have no idea what facial expression I had at that moment. I remember taking a deep breath, putting a smile on my face, stopping to pour another glass of wine, and if I remember correctly, I said, "Stop, just for a second." She laughed with her wonderful chuckle, shaking her head at me, a youngster pastor whom she had grown to love and need. "Start over," I ask. "The two of you are talking about suicide?"

"Well, we've talked about it but I don't think she'll be able to do it. She’s always been such a good, Christian girl. But we’ve been looking into which pills she is taking and how she could collect some on the side.”

After a sip of wine she continued, “The thing that makes me most mad is that there isn’t assisted suicide in New Jersey. I told her, ‘I love you but I’m not going to jail. You’re going to have to do this on your own. I’ll be there with you, but I can’t help you do it.’”

“What did she say to that?” I asked.

“She agreed and also laments that there is no assisted suicide in New Jersey. If there was, this would not be an issue. She would be able to talk to her physician about her wishes. The problem with ALS is that by the time it’s too much for her to handle, she won’t be able to do it herself. She’ll be too weak or she’ll have lost the use of her arms or even her voice.” We paused and looked at one another.

Now my mind was spinning—I certainly didn’t want someone in my church to have thoughts of suicide. While I had personal preferences and political beliefs about it, I had not anticipated this conversation. My pastoral training certainly didn’t cover this. Any psychological training I had told me that thoughts of suicide are signs of disease, severe signs of an unhealthy mind. In the abstract, this conversation needed to be shared with a professional. But then I realized she *was* sharing this with a professional. I was that professional. I knew my role as a pastor, and this conversation was most certainly meant for her pastor. I was her pastor. So the words I chose had nothing to do with my personal preference or political beliefs about assisted suicide. The words I found had to do with relationship. I said, “Well, I don’t think anyone should die alone. So, if the day comes, I want to be there.”

She responded with concerns for me professionally. “I don’t think you can. You’d be committing professional suicide. You would get into a lot of trouble for this, don’t you think?” We went on to talk about how much involvement I could have if a congregant decided to end his or her life. Here we were, trying to control what is out of our control. A meandering conversation about life and death, illness and friendship, all of it trying to manage, or control, that which is out of our control. The conversation in my mind, however, was less about suicide and more about wondering how much control we have in the first place. Would her friend have enough control to end her life before her ALS progressed? Would she be able to control whether or not she lived with Alzheimer's disease?

What about the guy who ended up with a knife wound on that spring night? How much control did he think he had? Or what of the woman in the motorcycle accident or her husband who tried to warn her of the danger ahead? Did they have control? How much control? Sometimes it appears we are successful in saving a life through machinery or medicine. Other times we are unsuccessful when we try to destroy life with a moving car and a note to our parents. Life is filled with trauma, and we are not in control.

# CASTING OUT A LINE

MY HUSBAND PETE AND I WERE WALKING BACK to our car after attending a Bonnie Raitt concert at the State Theater in downtown New Brunswick, New Jersey. Pete first saw Bonnie Raitt in concert when he only 18. She was about the same age at the time, not yet famous. He had had a little crush on her ever since. Midway through the concert that evening, she surprised us by inviting Rock and Roll hall of famer, Grammy winner and beloved session musician, Dr. John, onto the stage. Although Pete didn't show it, I knew he was thrilled.

I had been listening to her music in preparation for the concert. One song I had been stuck on was "God Was in the Water." She played it that evening. The tune has a haunting melody. With her low, slow drawl she sang these words that rested like steam over the music, *Castin' out a line, Castin' out a line to the shadows, Castin' out a line but no one's biting.*

As we walked back to the car, I noticed that Pete was dragging his feet. "Pick up your feet," I said. Nag, nag, nag. He seemed to be a little slower than usual. Normally, Pete ambled. He really belonged in South Carolina, but the stork dropped him in central New Jersey. Pete spoke with a drawl. Maybe that's why he liked Bonnie Raitt. I nagged again, "Pick up your feet. Do you see that you're dragging a foot? Are you okay?" He replied, "Yeah, just a little tired, I guess." I wasn't ready for him to be tired. I was 18 years younger than Pete. I wasn't ready to slow down. But there I was on Livingston Avenue, slowing down to see what was wrong with Pete and his dragging foot.

We had turned the corner and settled into our white Honda Accord when I asked the oddest thing of him. "Honey, try something for me. Lift your right knee. Now your left. And your right again." By the third round, he was unable to lift his right leg. He looked at me, "Well, that's odd." "Yeah," I said.

I turned the key and headed home. We didn't speak but Bonnie Raitt was ringing in my head, *Castin' out a line, Castin' out a line to the shadows, Castin' out a line but no one's biting.*

We made an appointment to see our primary care doctor/internist, thinking that he probably had pulled something or overexerted a muscle in his back. Physical therapy was going to be the answer, we were sure. I had been going to this doctor's office since I was a teenager. Our physician is Asian American, with a great smile and an even better laugh. She listens with her eyes. She agreed about sending Pete to physical therapy. We seemed content. But then something other than my logical mind spoke up and said, "But I hear a change in his speech pattern, too." Full stop. "You do?" she asked. "Yes, I do. I think something else might be going on with him?" I said, not knowing where it was coming from. Was I making it up? Why? What data did I have to support a theory other than a pulled muscle?

I don't have an answer to that question. Sometimes I think my subconscious simply overcame my conscious. A knowing within me took over and acted on my behalf. My subconscious had cast out a line and caught a script for an MRI and a referral to a neurologist.

Nonspecific white matter. There was *nonspecific white matter* in Pete's brain and spinal cord. We wanted our internist to read the MRI to us first. We would go to a neurologist but, wanted to hear her voice first. We trusted her. She knew us. "I'm sorry. It reads like multiple sclerosis. Go see the neurologist. There is treatment. He will know what to do now."

The first neurologist spoke to us as if he was unaware that he was making human contact. It wasn't just the medical terms that we didn't understand. He talked to us as if we were in the same science lab, doing an experiment together and preparing to write up a report. He didn't understand the basic definition of trauma. He didn't understand that the information he was reading on Pete's MRI was an external source, and it was hitting us—physically, emotionally, spiritually, mentally, relationally. He was delivering trauma. When I started to cry, he honestly looked surprised by my reaction. He seemed to take note of it as if he was keeping a file on "odd human behavior." After staring at me in confusion, he excused himself "to give us some privacy."

Pete looked like he had been kicked in the chest, the wind knocked out of him. I sat in the corner of the exam room trying unsuccessfully to stop crying. The doctor returned, and he said things. Non-specific white matter. Multiple sclerosis. Interferon injection treatment. Chronic, progressive disease.

We tried to listen but honestly, we needed to get out of there as fast as we could. *Castin' out a line, Castin' out a line to the shadows, Castin' out a line but no one's biting.*

He wrote a script, we made a follow-up appointment, and then we headed for our car with Pete's foot dragging behind.

Doctors and specialty pharmacies became part of our lives. Medication began to arrive at our back door in a cooler marked "refrigerate upon arrival." Pete began to take medicine that created false targets for his body to attack rather than his body attacking itself. *Castin' out a line, Castin' out a line to the shadows, Castin' out a line but no one's biting.*

One test led to another test that led to seeing another doctor that necessitated more tests, more medication, and more follow-up visits. We had experienced trauma; we were hit by an external force. With each test, pill, and physician, we were casting out a line. We were looking for something that would bring control back to the chaos. We were searching for the right treatment that would bring order and understanding to the diagnosis. We were trying to organize, manage, or control the trauma. Sometimes some piece of information would surface that made us feel as though we had "caught" some form of control on the line we had cast. Sometimes medicine would feel as if we had caught some relief. Pete would walk lighter…but still drag his foot.

People sent us articles and websites to read. Everyone else had more energy to attack Pete's diagnosis than either of us did. We hadn't recovered from the first kick in the chest. We moved very slowly into this reality, barely walking, really. We simply didn't want to create a relationship with multiple sclerosis (MS). Although working on treatments and thinking about alternative medicine or diet were needed, it felt as if we were giving away our life to MS. And no matter how we tried to engage with medicine and doctors and articles, we felt as if MS always had the upper hand. MS was in control; we were not.

Each time I surfed the internet for information about MS or treatment options, I was met with suffocating trauma. MS was hitting me over and over. I cried. All the time. My tears were casting out a line. Nothing, no one was biting.