

CHAPTER ONE

Then Sings My Soul



Listen to me, O house of Jacob,
 all the remnant of the house of Israel,
who have been borne by me from your birth,
 carried from the womb;
even to your old age I am he,
 even when you turn gray I will carry you.
I have made, and I will bear;
 I will carry and will save. (Isaiah 46:3–4)

The first time it happened I cried, then laughed, then asked myself, “What just happened?” The first time a patient with Alzheimer’s made a spiritual connection in my presence—moving out of darkness into light, moving out of loneliness into togetherness, moving out of despair into calm—I knew I had witnessed something miraculous, and I was hooked. Thus

began a journey to learn how to provide spiritual care to those with Alzheimer's and dementia. God was "still there" for them and I was determined to find ways to help them "remember" the One who calls them beloved. These are some of my first teachers, through whom God spoke. God said, "Pay attention, they have much to teach." And so I listened.

Meet Frank

It was the week before Christmas and all through the nursing home . . . it was very depressing.

I sat with Frank in a small, outdated common room. Another resident slept soundly in a chair across the room by a window. The hallways were lined with wheelchairs, the air was warm and stale, and a TV in the corner was on but the sound mute. Attempts to decorate the room to look festive had been tried, but the plastic poinsettias struck me as tacky. They were old with branches bent out of shape from being stuffed in a box since last year. There was a Christmas tree in a corner whose lights blinked on and off. I pulled up a chair next to Frank. He looked as though someone had stuffed him in the wheelchair. Food stains covered the front of his shirt; his head was wedged between two pillows. He barely responded when I said, "Hi."

Frank had advanced dementia. A year ago when I visited him, he could recite the Lord's Prayer, take Communion, and tell brief stories about his family and his career as a police officer. So much had changed since then. The times of praying "Our Father" had ceased. No longer at home with his wife of some sixty years, Frank was in this facility where he mostly slept, which was what he was doing that day.

As is so common attempting a pastoral visit with someone with dementia, I had a heavy feeling in my stomach of not knowing what to do with Frank. I felt helpless and even questioned my efforts. Maybe some of the nurses here were right; they would always say to me, "He has no idea what is going on." I always felt like they were discouraging my visits, and today I was feeling that maybe I had been too idealistic about this, maybe all really was lost by now for Frank. The nurses, after all, must know so much more than I do. As I thought about leaving, the lights of the Christmas tree were flickering in colorful patterns with a kind of urgency that nudged me to think differently and seemed to be asking me to hang in. I tried the Lord's Prayer, and finished it alone without response. I sat for some time and held his hand. I sat some more. It was three days before Christmas; I wondered what he was missing out on at home. What did the family do for traditions? Is he missing his favorite warm pumpkin bread? What toy trains had he put together as a young father? Did he teach the kids to ride a bike, "Look Dad, no hands!" Did he dance in the kitchen with his wife?

Today he just slept. And I sat. And then the Christmas tree nudged me again with its insistent lights. So I began to sing. (I will only sing with dementia patients, because I sing very badly, but they never tell anyone.) So I began, "*Silent Night . . . Holy Night . . . All is calm*" . . . and a voice joined me, slow and weak, but precise . . . "*all is bright, round yon virgin, mother and child.*" It was Frank and he finished every line of "Silent Night." Though everything else had failed him, his faith remained. "*Sleep in heavenly peace . . . sleep in heavenly peace,*" Frank concluded that day.

Frank died just days after Christmas surrounded by his family. While it might have been easy to imagine that everything had been

erased from his memory, in the days before his death it appears “Silent Night” had remained loud and clear.

Meet Dotty

Dotty rambled on like no one else I had ever visited: short quick sets of words like “mother came,” “garden water,” “go, go, get.” Her nursing home room was cheerful and sun splashed; her family had taken obvious efforts to make her comfortable. Along with family pictures, her room was decorated with numerous crucifixes, statuary, and rosary beads. Fresh flowers were on the windowsill, and they had placed her chair so that she could look out the window onto the nursing home’s beautifully landscaped grounds.

On my visit that day, I took down the rosary beads and, placing them along Dotty’s hands, attempted to say the Hail Mary, but it didn’t work. Though I am mostly a stranger to her, just the friendly hospice chaplain, she seemed to only want to hold my hand and, well, sometimes hand-holding is enough. So I held her hand, looking at all the old black-and-white photos on her nightstand. After a while though, I began wishing for something to do with her and I remembered that I had my communion kit with me, having just visited another patient who generally takes communion. For lack of anything else to do, I started to unpack the kit.

I used her bedside tray as a “mock altar” and slowly and quietly “set the table” as I would the altar in church. I laid out my beautiful white linen, my battery-operated candle, a small cross, and a miniature silver chalice and paten. I didn’t say anything as I set the altar, just moved slowly, deliberately. She watched me through the corner of her eye. Then suddenly, midway through a ramble about her mother, Dotty stopped talking and got quiet. Dotty was never

quiet, so I didn't know what was happening, but then she looked at my altar, took the small chalice in both her hands, lifted it to heaven, and said, very clearly, "Remember me."

Remember indeed!

Meet Allie

I visited Allie at the nursing home one afternoon when I was researching how those with memory impairment responded to visual cues of faith. Allie was a cheerful woman in her nineties and couldn't have weighed more than eighty pounds. Her family had said she was a woman of deep faith and would probably enjoy saying some prayers.

To visit with Allie, I had brought colorful pictures of Jesus, several kinds of crosses, candles, even a Russian stacking doll of the Holy Family. I had church hymns playing on a CD player I had brought in . . . *"Amazing Grace, how sweet the sound . . ."* I showed Allie a child's picture book of Bible stories with bright colors of Noah's Ark, sheep and the Good Shepherd, angels on high. She didn't respond much to the pictures. I tried to begin prayer, making the sign of the cross: *"In the name of the Father, and of the Son . . ."* but Allie didn't follow along and was more interested in the hem of her sweatshirt.

I then took out a beautiful silver cross to show Allie. I didn't say anything; I just let Allie touch it. It was cold from having been out in my car trunk all night. After turning the cross this way and that, Allie paused. A strange look came over her face that turned into a silly, somewhat coy, smile. It seemed to me she was remembering something very pleasant. And suddenly Allie exclaimed excitedly, looking at the cross, "Yes, all that and regular sex too!"

Well, I will never know (and perhaps don't want to know) what Allie remembered that day, but by the look on her face it was a very happy and pleasant memory. When I relayed this story to a colleague, she reminded me that in pious Catholic families of Allie's era, they would have had a crucifix hanging over their bed. They would have knelt by the bedside to say bedtime prayers and probably blessed themselves before getting into bed. Hmmm? God's grace is indeed amazing.

God Does Not Forget

What I learned from Frank, Dotty, Allie, and the numerous other adults with memory loss I've had the privilege to care for, is that for people of faith, Alzheimer's and dementia cannot erase God's imprint. When everything else is crumbling around them, God remains intact and is very present. This makes complete sense because faith has always been something only understood with the heart and not the head. Faith has never made sense on an intellectual level and has never been something to be reasoned or explained with words. Faith is etched in the heart and spirit, so it only stands to reason that dementia cannot rob people of God and their faith. While the disease steals many things, I am convinced that the presence of a loving, healing God is "remembered" and is very real to those with memory loss. After all, one does not need words to know God.

As people of faith, as spiritual caregivers, and as family members who care about our loved ones, providing a space for spirituality and religious practices during the phases of Alzheimer's and dementia is more than just a nice thing to do. As Christians and followers of Jesus, are we not led by his longing to care for "the least

of these”? In Jesus’s time, the least of these were the poor, the outcasts, and the widows. In our time, those living with memory loss are the new “least of these” that we are called to serve. Throughout the Bible we meet a God who has a special concern for those who were forgotten and suffering. For our generation, in a time, world, and culture that places so much value on youthfulness and productivity, those of older years and limited ability can be easily forgotten. But we must not forget them or we lose the very essence of what it means to be a people of hope and healing.

Teepa Snow is a dementia-care specialist, educator, and occupational therapist who has been working with and studying the field of dementia care for over thirty years. She is founder of Positive Approach¹ and travels nationally and internationally teaching families and nursing home staff how to effectively work with this population in a way that is nurturing. As spiritual caregivers, Teepa says we have an opportunity to help people address their feelings and deal with the challenges of dementia by reconnecting them with their faith. Through worship and prayer, which naturally draws out emotions, she says spiritual care offers them a place to remember who they still are inside.

For years, she says, people, including clergy, have assumed there was nothing they could do to connect with and reach people with dementia, but her research has proven that wrong. There is always what she calls a “spirit part” inside every person: no matter how far the disease has progressed, there lives a flame that if we can touch will bloom. As providers of spiritual care, according to Teepa, we become not care *givers* but care *partners*, which can enfold them into a larger sense of community and wholeness. She believes

1. www.teepasnow.com

people can be trained to work with dementia patients in a way that is positive, focusing not on their losses but on their abilities. In other words, what can they still do? How can they still be in relationship with people they love? How can their lives be improved through the right kind of care? And so what we have learned is that what they *can* still do is pray, sing, and worship.

Some research on Alzheimer's suggests that people living with dementia often know what they want to communicate but can't use words, especially in the early stages of the disease. So while their "intake" works, their "output" does not: they cannot find the words to communicate back, so we assume "they are gone." I think of all the times in the early stages of my dad's disease that he would word search for a long time and then finally give up. Sometimes he would laugh at himself and point to his head, indicating something wasn't working; it was kind of cute and funny. But sometimes he would get mad and sad. Realizing that *he* knew what was happening to him was heartbreaking for us, his family.

When I think about this, I try to imagine what it would be like to be trapped in a body and mind that knows what it needs, wants, and longs for, but can't ask for. And then I imagine the chaplain, my parish priest, my friend, or my spouse coming in, treating me as though I *am* still there, praying out loud words I ache to speak myself, letting there be a quiet moment where I can ask God for help too, and then singing "*Joyful, joyful, we adore thee.*" What a difference this would make in my life when others are merely rolling me over in bed to change my Depends, forcing me to sit in chairs I don't want to sit in, and talking to me like I am a child. It is amazing care to give. Whether in the form of a prayer, a song, or a shared moment of tears, this ministry validates that those with dementia are still alive inside.

I was once invited to attend an Alzheimer's caregiver support group at the agency where I was working as the hospice chaplain. Some of those gathered were family of patients I'd been visiting. After I demonstrated some of the things that I do with patients, I noticed one of the women at the far end of the table was crying. I stopped and said, "Would it be ok if I asked what has triggered your tears?" She said, "Thank you for doing this, everyone else has given up on them."

When I play the hymn "How Great Thou Art" during my service of "Prayers and Song" in the memory care unit, I notice that people with otherwise few words will suddenly sing very loud and clear the refrain, "*Then sings my soul, my savior Lord to thee, how great thou art.*" The souls of those with Alzheimer's and dementia indeed do still sing. No matter how advanced the disease, faith is not lost and we will do well to "Do This, Remembering Me."

Interlude

My Huckleberry Friend

It might have been his last “professional” appearance.

I had come for a visit to his memory care unit and as I walked down the hall past Dad’s room (he was never in his room), I noticed he was sitting next to Mary, and Mary was clearly in the midst of a good cry. As she sobbed, overwhelmed by some sadness she couldn’t speak, Mary sniffled loudly and big tears ran down her red face.

Dad had one hand on Mary’s arm and in the other he held a clipboard. In language only dementia patients share, it appeared he was giving her some advice, some council. Most likely it was legal advice, which he had spent his lifetime giving people as a lawyer and city councillor. As Dad sat with Mary, he was being intentional with his words and looked very much the part of “attorney extraordinaire”—serious, compassionate, and ready to take notes with his clipboard. He had that “leaning forward, making a point” body language I had seen in his younger years when he tried to explain the legal ramifications of some thing. This is the man who dealt with racial riots and urban growth, defended a family whose daughter had been burned by flammable pajamas, and stood by fishermen trying to make a living in our hometown of New Bedford, Massachusetts, a city known for its once vibrant fishing industry.

That morning in the memory care unit, it was easy, for a moment, to see Dad as he used to be; to imagine him not a patient here, but

rather, the facility's legal expert come to help. It was easy, for a moment, to see him as he had once been: well dressed, gentle and gentleman, wise attorney and confidant who could ease whatever your worry.

It *would* have been easy to imagine all these things . . . except . . . he was wearing a straw hat decorated with huge colorful silk flowers.

An aide finally came over to assist Mary in her despair, so I tried to distract Dad. "Nice hat," I said, but he didn't connect my words with the cartoon-like thing on his head—the hat in complete opposition to his very serious face.

We were lucky; Dad's dementia never took away his ability to recognize family. Sometimes he confused us, like calling his son his brother's name, but for the most part, he knew who we were and was always happy to see us.

After the aide took Mary away, Dad and I walked down the hall. He was a walker, always pacing—I think that is how he and Mary became friends; she was a walker too. After lap two around the unit, I asked if he wanted to take the straw hat off. He said he would keep it on. (There are some things you don't argue over with dementia patients, colorful straw hats being one of them.)

As we headed to the music room where I knew a singer was performing, I had Dad stop in the bathroom, "Hey, look how cute you are in the hat," I told him steering him in the direction of the mirror.

He looked at himself, laughed, and then made the silly face that had become his trademark since dementia freed him from his otherwise serious self. His goofy face made me laugh too, and when I laughed he said, “Hey, don’t laugh at me, I’m your father.”

When those very “clear” full sentences came out, it was always bittersweet. Bitter because as family it made me worry he knew more and understood more than we thought; but then sweet too, because I knew he remembered I was daddy’s little girl. It was always nice to have a little of him back, even if for a short time.

We walked into the room where an entertainer was singing, “*I did it my way.*” Heads of the aides turned as Dad walked in the room still in the straw hat. We took a seat side by side. He was his usual self for the next few songs, listening to the music one moment, tapping his knees and clapping, then, in the next moment, asking questions about things I couldn’t piece together, and so to which I offered, “I’m not really sure.” This had become a customary answer to questions that didn’t make sense. Other responses I had learned were things like, “I’ll have to check on that” or “I’ll look into it.” These usually worked well, especially when he seemed exceptionally worried or concerned about something.

As we sat listening, I was thinking to myself that I wanted to remember to write down the scene I had just witnessed with Dad and Mary in the notebook of “cute stories” I’d been keeping about him and other dementia patients. For over a year I had been jotting down sayings, stories, and observations I wanted to remember. “The encounter with Mary would be a good addition,” I was thinking to myself as the singer moved into a rather nice version

of “Moon River” . . . “*Waiting round the bend, my huckleberry friend, Moon River and me.*”

Huckleberry friend . . . I repeated the phrase to myself, thinking it would be a perfect title for the piece about Dad and Mary. He was always such a good friend to her, in his own way, and right now in the hat, he looked like a “huckleberry friend.”

Songwriter Johnny Mercer coined the phrase “huckleberry friend” for a song in the old movie *Breakfast at Tiffany’s*. Mercer grew up in Savannah, Georgia, and wrote “Moon River” thinking about the waterways of his youth, the huckleberries he picked as a kid, and the connection he found between them and his carefree boyhood of which the character Huckleberry Finn was a hero. Over the years the term has come to evoke a sense of lifelong friendship. Huckleberry friend?

I suddenly felt emotional about the way dad had become my huckleberry friend too. Over the last years in his dementia, I’d gotten to know him in a way I otherwise wouldn’t have. Growing up he was the consummate 1960s, 1970s dad, working two jobs, involved in church and civic life, who loved sports on Sunday afternoons and was always home for dinner. But dads of his generation weren’t hands-on like modern dads; we didn’t spend a lot of time together outside of family time, but his dementia brought something new. We got to spend a lot of time together. I got to know him in helping to care for him, differently, tenderly, simply—quiet cups of coffee, silent walks, hand-holding, looking over old photos, and from time to time, hearing pieces from stories of long, long ago. Sometimes I got the sense he trusted me, but with what and about what I don’t

know. He didn't get agitated when I was around, and when it was just the two of us, he was calm and peaceful.

Listening to "Moon River," I rubbed the back of his neck and noticed how he smelled, clean but somehow institutional, like disinfectant or something. I wondered if everyone in the room smelled the same way. I had to fight back the pit in my stomach where the sadness lived, sadness that Dad had to be here and not home with us. As I was thinking all these things, he suddenly started to fidget with something in his pocket and pulled out a stack of white napkins, clean and neatly folded. He looked through them gently, stacking them and then fanning them as one would if looking through pages of a book.

Then he leaned over to me, and taking the napkins as if he was indeed opening a book, he said, very clearly, "Another writing by Colette Bachand."

How could he have known I was thinking about writing about him and Mary? He couldn't have known, I'd never said anything to him about it, ever. But there it was, he *had* said it.

I didn't know at the time, but this would be our last visit where it was just the two of us. It was the last time we would walk down the hall together, giggle in a mirror, talk nonsense, and clap to old songs. In just a few weeks he would be gone, and so would these moments

Change was indeed just around the bend for my huckleberry friend . . . and me.