



Accompanying Dementia

Celia McBride

“Oh, I’ve had such a wonderful life,” says Doris, a grand lady in her early nineties whose family was part of the British aristocracy. I am sitting beside her on a pale green, silk couch in her assisted-living apartment, and we are surrounded by sophisticated art and unusual sculpture from around the world.

Doris’s eighty-three-year-old boyfriend, Ben, whose family has hired me to accompany him for several hours a week, sits across from us. Often when I arrive to see Ben in his humble apartment

on the ground floor of the building, he and Doris are spending time together at her more lavish place upstairs, and I end up accompanying the two of them.


“I was a spy for the British army, you know,” Doris continues.

I do know. Doris has told me that particular detail of her life many, many times.

“That’s amazing, Doris,” I say.

“Oh, yes. It’s been a wonderful life, just wonderful.”

“Until you met me,” says Ben.



“Oh, be quiet, you dumb cluck.” Ben cracks up laughing. Doris turns to me and says, “I love calling Ben a dumb cluck,” and I laugh along with them.

“Did you know I was a spy in the British army?” Doris asks me after our laughter has died down.

“Really?” I say.

“Oh, yes. I’ve had a really wonderful life.”

“Until you met me,” says Ben.

“Oh, do be quiet you dumb cluck.” They laugh again. “I just love calling Ben a dumb cluck.” Another few moments pass. I wait for it.

“When I was young I was a spy during the war,” Doris tells me.

“Is that right?” I ask.

Both Ben and Doris are living with dementia and we will go on like this, with some variation, for almost as long as I am with them. This loop, and others of a similar nature, make up the majority of our conversations. When Ben and I are alone, he tells me the same stories again and again, and we look at the same photographs nearly every time I come. He shows them to me as if I have never seen them before.

“Here’s my cat, Ollie,” he says, passing me a photo of a black-and-white cat playing with an electric toothbrush. He then places the photograph of Ollie behind another one of him and his children.

“There’s me and the kids,” he says, showing me the photo briefly and then tucking it behind the one of Ollie and the toothbrush.

“And here’s my cat, Ollie,” he says, handing me the same photograph. “He loved that toothbrush.”

Ben is not the only person living with dementia whom I accompany but he is the only private client I have. The others—and there are many—all live in a long-term care facility where I am contracted as a “spiritual care worker.” When the administrator hired me and we discussed what my official title would be, I suggested “spiritual director,” since that is what I am.

“It’s a little too formal,” he said, so we agreed on “spiritual care worker.” It is humble, which is right for the job.

Although I am accompanying people living with dementia, I often feel like I am accompanying dementia itself.

*Although
I am accompanying
people living
with dementia,
I often feel like
I am accompanying
dementia itself.*

Dementia is like a scene from *Invasion of the Body Snatchers*, only it is the mind that has been snatched. Dementia can take over an entire person, changing them irrevocably, making them a stranger to themselves and to their friends and families. Dementia can create entire realities—fascinating, perplexing realities—perceived only by the sufferer.

“My neighbors kept me up all night,” Celine says, her head shaking with fierce disapproval. Celine is a strong-willed, deeply Catholic woman who is, in my view, still traumatized by the sudden death of her husband when she was a young woman, leaving her with two small children to raise.

“Oh, Celine. I’m so sorry to hear that.”



“They couldn’t care less! I’m telling you, I just can’t take it any more.”

There are, in fact, no “neighbors.” Well, there is one: Alice, a woman living with multiple sclerosis, who occupies the adjacent room and shares the bathroom with Celine. But the neighbors Celine is referring to exist only in her mind. She believes they are Alice’s five children, but Alice has just one daughter who rarely visits. Not only is the “gang” (as Celine calls them) noisy, keeping her awake at all hours of the night with their loud music and partying, they also come into Celine’s room when she goes out, rearranging her things and stealing her stuff. Some of the staff tell Celine that the neighbors do not exist. Some of them reassure her by saying they will take care of the situation and not to worry.

“But they do nothing,” says Celine. “Nothing!”

As a spiritual director, I neither deny the existence of the neighbors nor offer to fix the situation. It is not my role to improve or change anyone or anything. Just as in spiritual direction for the mentally sound, offering my presence through deep listening remains the primary intention. Celine needs to be heard, supported, and validated, and the simple act of “being with” is the cornerstone of this practice. That said, no one benefits from dwelling in negativity, and if the complaining goes on too long or if Celine is getting too riled up, I will redirect the conversation.

“Did you get a new book?” I ask her. Celine’s spiritual books are her lifeline, and she likes it when I read passages to her. She gets stone still, listening to every word with razor-sharp attention. By the time I leave her, she is relaxed.

“Thank you for coming,” she says, giving me a hug. “It helps me.”

As I pass by the lounge, I hear Helen, Gladys’s daughter, pleading with her ninety-seven-year-old mother.

“I come and see you almost every other day, but it’s still not enough for you. I’ve only just arrived and you’re already criticizing me.”

They are both crying. Gladys does not remember Helen’s visits and thinks her daughter has abandoned her. When Helen does come, Gladys makes her feel guilty. Both of them need to be

heard and validated. Both of them need support.

After saying hello, I kneel down beside Gladys’s wheelchair and take her hand. The two of them go back and forth for a little while longer, trying to understand each other but not really getting anywhere.

“What’s so hard, Gladys, is that you don’t remember Helen’s visits. You’ve got short-term memory loss, and you forget when she comes.”


“Is that what’s happening to me?” she asks, meeting my gaze directly. I nod.

“I’m sorry I don’t remember,” Gladys says to Helen.

“It’s okay, Mum.”

A staff member wheels Gladys away for an

*Just as
in spiritual direction
for the mentally sound,
offering my presence
through deep listening
remains the primary
intention.*



Family members and friends who have witnessed their beloved's younger days often struggle to meet the whole person where they are now without judgment.

appointment, and I take the opportunity to talk further with Helen. Sometimes accompaniment involves making suggestions, and I ask Helen if she is open to receiving one.

"Please," she says.

"She's your mother, so of course it's not easy to do this, but if you can find a way to remember that her criticism is not personal, you will spare yourself a lot of grief."

"I try not to take it personally," Helen says, tearing up again, "but today it just got to me and I had to defend myself."

Because I have no attachment to any past version of Gladys it is easier for me to accept her as she is now than it is for Helen. Family members and friends who have witnessed their beloved's younger days often struggle to meet the whole person where they are now without judgment. They defend themselves or correct the person, trying to get them to see things as they do. Dementia almost begs for these kinds of reactions, but they are futile. One cannot win an argument with dementia. Gladys is Gladys now and I must encounter her where she is, taking all of her at face value, accepting her completely and allowing her to be just as she is.

Later, when I pass Gladys in the lounge, she is still weepy.

"My daughter never comes to see me anymore,"

she says, rifling around in the sleeves of her cardigan where she has shoved a mountain of tissues. "She puts me in this place so I can be nearby and then I never see her."

Rather than try and convince Gladys that Helen was just here, I take a different approach. "I know it's hard, Gladys," I say, holding her hand in mine. "You've lost your independence, and that has been very difficult for you."

"It has. I used to be so active."

"I know."

"I just don't understand why God would do this to me. What did I do wrong? What did I ever do to deserve having to live like this?"

Gladys is not the only one to ask me this question. It is a common refrain: "How have I ended up alone, in an unfamiliar place, surrounded by sick and dying people after a lifetime of hard work, raising families, and helping others? I did everything right and now this?"

Taking a moment to breathe gives me time to discern how to proceed: Do I remain silent or offer more encouragement and reassurance? I have done both, and both are appropriate. Either way, she will soon forget. I decide to engage with her.

"You didn't do anything wrong, Gladys. Old age is not a punishment."

"No, I guess not," she says, quietly. "But I don't understand why God is keeping me alive when all



*Accompanying
dementia means accompanying
so much suffering.*

I want to do is die.”

“Your time will come, Gladys.” She looks hopeful. “It will.” She nods. A moment of peace. Seconds pass, she shakes her head and begins to cry again.

“I just want to see my daughter, and she never comes to see me.” This time, I squeeze her hand and let her cry. She will die a week later.

Didi has been deteriorating mentally over the last number of weeks, changing from a fun-loving jokester to a paranoid, high-maintenance challenge for the staff. The photographs on her wall tell the story of a woman who loved to party. There she is at her seventy-fifth birthday party, shaking her tail-feather in the middle of the dance floor and singing along with the music, probably Elvis, whose face, painted on a large canvas by Didi’s grandson, takes up an entire wall in her small room. Music makes Didi feel better. Sometimes there are classics like “Wake Up Little Susie” playing from a CD player on her dresser. Sometimes she is listening to her iPod and singing along. Today, she is in her big, colorful armchair, tearfully pleading for salvation.

“Help me, Lord. Please help me, please, please help me, Lord.”

“Didi!” I exclaim joyfully, knocking on her door frame and entering, holding out my arms and smiling into her eyes.

“Please help me,” she says, looking up, lips quivering, hands reaching toward me. I take her hands and sit in her walker, which is parked in front of her chair.

“I’m here,” I say. “What’s wrong?” Looking directly into her eyes, I smile again, compassionately, giving her all my attention.

“They don’t want me to go, they’re gonna get me in trouble, I can’t... I gotta get my stuff and move it over there and they ... they won’t let me.” At that moment, we hear a fellow resident call out from across the hall. “See?” Didi says, her eyes widening, “That’s them.”

“I can help you,” I say, continuing to smile, pressing my hands into hers.

“No, you’ll get in trouble.”

“I’m not afraid.” This seems to relax her. “It’s so good to see you, Didi! I haven’t seen you for a long time.”

“Where you been?” she asks, brightening.

“I’ve been up and down and all around,” I say, “You know how it is.” She gives a little laugh, the twinkle returning. “Shall we listen to some music?”

“They don’t want me to. I’m gonna get in trouble.”

“This is your room, Didi, and you’re allowed to do whatever you want.”

“Oh, yeah?” she asks.

I put on “Hound Dog” and dance in front of her



chair, taking her hands so she can dance with me. She immediately starts singing and swinging. She knows all the words, even the background vocals, and she bops and doo-wops along, her fears temporarily lifted by the King. We get through most of the album, and Didi is happy and relaxed. I tell her I have to go and she darkens.

“Stay with me,” she says. I give her a hug and tell her I will come again, smiling and dancing my way out the door. I can hear her continuing to sing, the words taking her forward, keeping her fear at bay for the time being.

How hard it is to leave the ones who are suffering, who do not want to be alone. Accompanying dementia means accompanying so much suffering. This takes its toll on everyone who is providing care in the long-term sector. Personal support workers (PSWs) tell me their main stress factor is their inability to provide relief for the mental and emotional suffering of the residents. As a spiritual director, I feel the same kind of stress, but I have dedicated spiritual practices that address my feelings of powerlessness and despair. In my view, most staff and families on the front lines do not have these practices, and their grief goes unmet.

Spiritual practices, for me personally, include respite, both “on the floor” and off, and supervision. Supervision obliges me to do the inner work and be accountable. Respite means taking time to attend to the parts of myself that are in need of my attention.

With my supervisor, I have been able to identify

my attachment to outcomes and where my desire to fix shows up. We have exposed shortcomings and pinpointed triggers. One trigger is self-pity. For example, when Gladys feels sorry for herself, irritability can rise up within me. Irritability is really powerlessness in disguise. Being powerless renders me vulnerable, and vulnerability then creates the intolerant defenses. My supervisor has gently directed me toward self-acceptance.

*Respite
means taking time
to attend to the parts
of myself that are in need
of my attention.*

Accepting my human foibles means watching my reactions rather than getting hooked by them, and becoming curious about what is happening internally rather than engaging in self-blame. In order to allow Gladys to be Gladys (without judgment), I must accept my own humanness as well. An irritable response is natural. It is okay.

Another human response is the “tune-out.” I check out of the moment and disappear into the shopping list or the next day’s activities or the next meal. Deep listening goes out the window. I am “listening-lite,” nodding at the appropriate times and saying “yes” and “oh,” but I am mentally absent. I can also get sleepy, that kind of tiredness where the eyelids get heavy and sleep is just a blink away. My supervisor has helped me to understand that when I tune out or start to fall asleep, I have perhaps reached my capacity for listening. There is no more room to take anything in.

We all have limits. Knowing mine has been a learning process. On-the-floor respite is indispensable. Moment-to-moment self-regulation is



an essential element when continually encountering people in despair or listening for hours at a stretch. The brief walk from room to room provides an opportunity to check in with my emotions, reconnect to breath, and say a mindful prayer. When I have succumbed to “listening lite,” I trust that my physical presence is enough. At all times, I am doing my best. When my best falls short, it is still enough. I accept imperfect reality.

“Are these your sisters, Mildred?” Mildred has been telling me about growing up on a farm for the 346th time, and I am feeling very sleepy. On-the-floor respite: get up and move around. I walk to the other side of her room and shake out the cobwebs.

“They must be. I grew up on a farm.”

“Did you?”

“Yup. Worked hard. There were no boys, so we had to do all the chores. I did everything—you name it.”

The familiar refrain suddenly sounds different as I look at the photo of Mildred in her twenties, more than seventy years ago. Every few minutes, Mildred, locked in the ever-present present, remembers that young time of her life and then tells me about it as if she has never mentioned it before.

“Good for you, Mildred.”

This is where “off-the-floor” respite comes in. To continue meeting Mildred where she is and hearing the same stories as if I have never heard them before, I need to take care of myself and

tend to my inner life outside the facility. If I do not, frustration will mount and impatience will grow. I must cultivate an open mind and an open heart through daily prayer and meditation, weekly rest and relaxation, and regular fun and fitness.


Detaching from my limited idea of the way things should be and releasing my grip on linear time are nearly impossible actions without prayer and meditation. Prayer builds humility and grati-

tude, and meditation is what enables me to simply return to the here and now every time I realize I have disappeared. Regular rest and relaxation calm my often-frayed nervous system and allow me to release the strain that can build up without my realizing it. Enjoying life and keeping fit, even if it is a walk around the block to breathe the air and watch the birds, ever reminds

me that there is a bigger picture and I am just a speck in a single frame.

Deepening my own spiritual life is what finally empowers me to make the necessary surrender to my own human frailty and to keep letting go of any built-in expectations and preconceived notions. Building trust in the life-force-energy that is vitally and wondrously dwelling within every suffering person is a process that requires my ongoing attention. Without these practices, I flounder in the darkness that dementia can breed, sucked into the negative energies of “disruptive neighbors” and nefarious “theys,” wailing “whys,” and punishing gods. Some dementia sufferers are consumed by negativity, and some are happy as

*When my best
falls short,
it is still enough.
I accept
imperfect reality.*



clams. None of it makes sense to me. The good news is, I do not need it to. So while I still have mental acuity, the cornerstone of my work will be to keep shining the light into the darker corners.

“Are you married?” Paul asks me. His six-foot-plus frame is stretched out on his reclining chair and I am across from him, sitting on the edge of his bed. He has asked me this question before; he has been sexually inappropriate with a number of the support and nursing staff, but he has never crossed the line with me. He thinks I am with “the church” and that may explain why. Although Paul is not a religious man in the strict sense of the word, he and I have meaningful spiritual discussions about “the Lord” and what “his” will is for us wee, little humans.

“No, I’ve never been married.”

“No?” he asks, surprised. I can see him formulating his response. He shakes his head. “I don’t know. I don’t know what the Lord has in store for me, really. I’m ready to die, but he’s keeping me here. He has his reasons. But I’m not much use to anybody now, so I just don’t know.”

“You are giving me something, Paul.”

“Am I?”

“Of course! I’ve learned so much from you.”

“Is that right?” He smiles. “Well, these conversations have been very helpful to me. I feel I can be myself with you and talk about things I can’t say to anyone else.”

“Then we’re of use to each other.”

“Yes, yes, that’s true. That’s very true.”

The photo above me on the wall shows Paul at nineteen, a handsome British soldier, serious-looking and determined. Even though it is only a headshot, one can see that he was a very big lad. He is still a big man, but much reduced. He hunches over his walker and drags his feet. Time has changed him.

I was once nineteen. Now I am forty-seven. Paul was also forty-seven. Now he is ninety-four. Will I get to see ninety-four? Will I, too, lose my memory? I see the span of Paul’s life in its entirety. I see the span of my own. I recognize the elastic nature of time, its slow-burn-ninety-long-years quality and its fleeting, where-did-the-years-go quality. Before me and before Paul, there were others, millions and millions of others, all gone now. After us, there will be countless more.

He is quiet. I am quiet.

“Do you know that quote from James about our lives being but a vapor, Paul?”

“I’ve never really been one for scripture,” he answers, “That’s more your territory, I’m sure.”

“Well, not really. This quote came to me in a comic when I was a kid and I’ve never forgotten it. It says, ‘For what is your life? It is even a vapor, that appears for a little time, and then vanishes away.’” Paul nods, closing his eyes.

“That’s good,” he says.

His enormous hand takes my own as I get up to leave.

“God bless you,” I say.

“And you,” he says, “You’ve really given me a lift.”

I close his door, knowing that the “lift” will not last very long. He will forget quite soon that I was there, and when I come to see him again I will have to remind him of who I am.

I move along the hallway, passing Lily shuffling her feet to move herself down the long corridor in her wheelchair. She winks at me. I wink back. Then I knock on Beverley’s door. It has been a while since I have seen her. ■

All names have been changed in this article to protect each individual’s privacy.



ABOUT OUR AUTHORS



CELIA MCBRIDE is a spiritual director who leads healing retreats and provides spiritual care to residents in long-term care. She completed the Pacific Jubilee SoulGuiding program and the Pacific Jubilee SoulMentoring program. Celia accompanies people from all traditions and no tradition. She lives in Port Hope, Ontario, Canada. She can be reached at celiajanemcbride@gmail.com.