

Our Journey With Alzheimer's

Two women religious reflect on how the disease has affected their lives

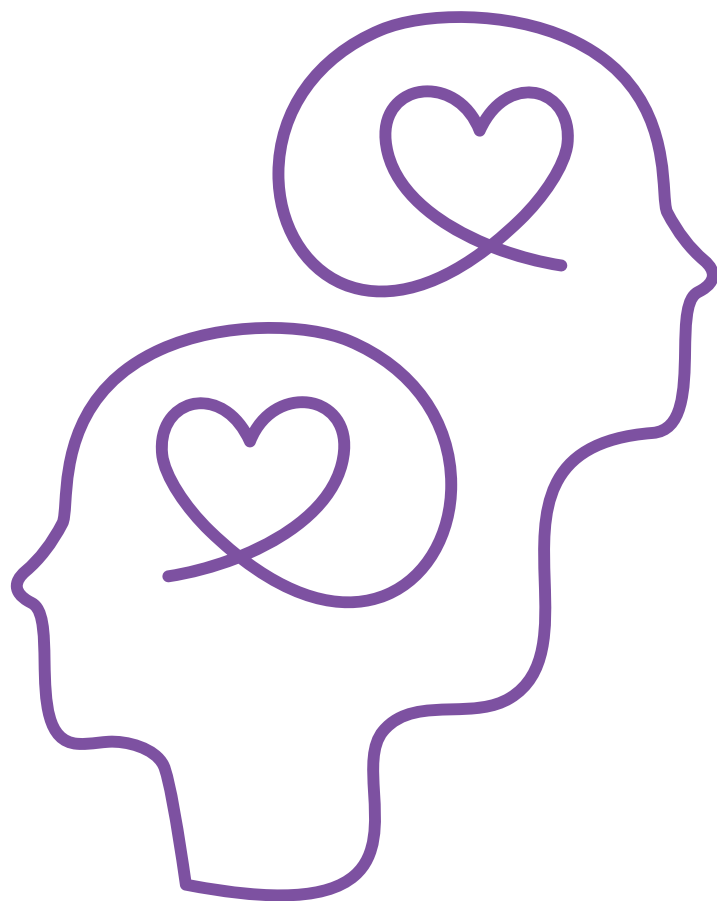
By Sheral Marshall and Maureen Sinnott

Sister Sheral: I write now with a sense of urgency. During the past few months, I have become more and more aware of how Alzheimer's has affected my behaviors and attitudes. I share my experience as a 77-year-old Franciscan sister looking forward to celebrating my 60th jubilee soon. At the same time, I am becoming more aware of my vulnerability and dreading my decline.

I was diagnosed with Alzheimer's in 2018, after four years of resisting, excusing and denying the major changes in too many of my everyday decisions and behaviors. Fortunately, Maureen Sinnott, O.S.F., the sister with whom I have been living for a long time, is a recently retired clinical psychologist. She refused to give up on her efforts to alert me to these constant behaviors that have indicated the presence of Alzheimer's since 2014.

Sister Maureen: Sister Sheral and I have been good friends for many years. She is still very articulate, joyous, positive and outgoing. She has a global heart that worries about and prays for all who live on the margins. Those who have been touched by her compassion and loving kindness include a very wide-open circle of multicultural friends. She has been a leader in our St. Francis Province of sisters and has been elected to our province leadership team, served as our vocation director for women interested in joining our community and been a member of our Marian Regional Medical Center hospital board. She has been coordinator of educational and outreach ministries for three multicultural parishes in the San Francisco Bay Area for decades and has served as leader of the vocations offices in the Sacramento and San Francisco dioceses. She has been to our border with Mexico to better understand and serve those crossing over. After Hurricane Katrina, she went to Louisiana to help the survivors find temporary housing and other assistance.

We are blessed that Sister Sheral is still able to write about the vulnerability of living with Alzheimer's and ad-



vocate for others. But there is no cure. She is experiencing a decline, which we are facing together.

Sister Sheral: I am deeply aware of the constant gift my faith in our loving God provides for me—and everyone blessed with a spiritual foundation of whatever source—as we try to navigate the everyday reminders of our diminishing awareness and abilities. I can't imagine living with the very real limitations this disease imposes on me, as well as the anguish borne by all those caring for me, without a sense of God's support and guidance through it all.

After all these years, I am finally learning to accept and live with Alzheimer's in as healthy a way as possible. We walk for 40 minutes twice a day, eat healthily, sleep well and try to avoid stress as much as possible. I have no medical background, but I know that each person's experience with this disease will differ. And each person with Alzheimer's may, of course, identify various aspects of their diminishment as particularly difficult.

Sister Maureen: We both retired from full-time ministries three years ago and moved from the Bay Area to Arroyo Grande, Calif. In truth, Sisters of St. Francis never really retire; we continue to advocate and pray for people who are underserved, disenfranchised and on the margins until our last breath—and then, God willing, in heaven. As retirees, we are blessed to have abundant time to pray, jour-

nal, share our reflections on the Gospel at a deep-down, feeling-and-healing level, and continue trying to be bearers of hope, peace, joy and loving kindness.

It took me several years to get Sister Sheral to a neurologist. Who wants to hear that they may have Alzheimer's? As a clinical psychologist, I noticed changes in Sister Sheral and started documenting them a decade ago. She was slowly declining, but because she was so articulate, she hid the signs from many others. She resisted, delayed, denied and kept repeating and minimizing my concerns by saying, "You worry too much." It was her way of focusing on me rather than focusing on the changes we both were seeing in her behavior. I was more stressed and worried about her than she was worrying about herself. And that is the beginning of the story of most caregivers: getting through the hurdles of denial, resisting, delaying and getting your loved one to agree to the care they need.

Sister Sheral: St. Ignatius' famous Suscipe prayer reads, in part: "Take, Lord, receive all my liberty, my memory, understanding, and my entire will.... Give me only your love and your grace. That is enough for me."

When I was young, it was easy to pray this prayer, but it is much more difficult for me to pray it now. I am grieving, losing so many examples of "my liberty": driving, walking without wearing an emergency call button, taking my medications by myself, using credit cards or my computer, or serving as a delegate at our provincial meeting. All of these new limitations are unchosen experiences for me. The helplessness I feel is intensified after being independent and a leader all my adult life; so many of my ordinary abilities have vanished, never to be regained. My life will continue for as long as God gives me, and the blessing of still being able to write and speak can hopefully help the many others experiencing this.

Losing "my memory" means that I have no choice over what I remember or forget. Names of people I dearly love and have spent great times with long ago are gone. Other times, I can see a recent friend's face, but the name will not come, nor will the particulars of our relationship. Someone will relate a significant conversation or experience of which I was a part, and I have no recollection of it or the other persons involved. Major community events or decisions, even if I have participated in them actively and/or recently read about them, have disappeared forever.

Lately, it feels frightening and scary to me that my memory has been so fleeting and fragile, words I have never used in this regard. I find myself hoping these moments will be rare, rather than the new normal. I wish it were the former. What I am sure of is that God will be with me, either way, as God has always been.



Sheral Marshall, O.S.F., left, who has Alzheimer's, and Maureen Sinnott, O.S.F., who serves as her caregiver, have become advocates for others who are affected by the disease.

The ability to process and gain understanding—being able to think something through completely—is also vanishing. I often need to ask someone to repeat something she or he has expressed very clearly, since I have difficulty following even a simple, logical conversation. It may seem as if I am distracted or simply not paying attention, but the reality is that my mind simply cannot take in what is being presented, no matter how clearly. We all realize that regular, significant conversations and memorable, shared experiences are vital to sustaining and deepening valued relationships. What a challenge it is and always will be to build meaningful relationships without such a foundation.

I have trouble understanding visual images and spatial relationships, which is one of the 10 warning signs of Alzheimer's, and I am experiencing it worsening. This means that my visual perception is off. I can place something of any size or shape on a flat surface and it falls off, since though my eyes see it correctly, my mind cannot process it accurately. This is embarrassing; people who are unaware of my disability could understandably wonder why I am so clumsy. I regularly run into obvious, often large objects for the same reason, often resulting in bruising on my forearms and legs. As I'm typing this article, it is evident that this limitation also causes my fingers to hit the wrong keys, thus creating a need for many corrections to the spelling

The first hurdle for most caregivers is getting your loved one to agree to the care they need.

of the simplest words. The bottom line for me is that, with this condition, I must allot extra time to accomplish almost anything I need to do.

Sister Maureen: Some of the warning signs that Sister Sheral had Alzheimer's were when she began forgetting how to do everyday, common activities. She would leave the stovetop on and burn pots and pans, forget to lock the garage or house door, and have problems paying with credit cards. She was having difficulty completing familiar tasks like how to use the TV remote, turn on the dishwasher or use her computer. She also frequently misplaced house keys, car keys and sunglasses, and was sometimes unable to retrace her steps to find them, which is another warning sign. I am now careful not to leave anything around the house that she might misplace. She is a creative cook who loves to change up recipes but has challenges planning and solving problems, and sometimes supper is an hour later than expected because she is slowing down. Of course, by then we are both hungry, and I try to pause and thank God that she can still take her turn preparing supper. Sometimes, when she repeats a story, I pause and try to listen even more closely, and I thank God that she can still tell me a story.

Driving became extremely challenging for Sister Sheral. She began having trouble understanding visual images and spatial relationships, which is another warning sign. When cars would enter our lane, she did not slow down; she saw the car enter, but her brain was unable to process that she needed to slow down. She would wait until the last minute to change lanes to leave the freeway. Of course, other drivers honked their horns, but she insisted it was their fault, which told me her previous good judgment was fading. When I would ask her to stop driving, she would respond: "It is too much for me to process now," and "I don't have enough information yet to make the decision to not drive." Eventually, we made the decision that Sister Sheral would no longer drive. Anyone who has had to get the car keys from a loved one knows that this may be the most stressful negotiation ever, be-



Sheral Marshall, O.S.F., left, and Maureen Sinnott, O.S.F., participate in an annual Walk to End Alzheimer's.

cause they are surrendering a key aspect of their identity and independence.

Sister Sheral: After much reflection and prayer, I've also experienced what I honestly consider to be gifts from living with Alzheimer's. Through many decades of work in parishes and dioceses, I've facilitated Scripture studies, given retreats and served as a spiritual director for adults, as well as helping to design and coordinate formation programs for deacon candidates and spouses. I realize now that my ongoing interaction with these committed people has taught me to share my own journey of faith and struggles, and to share the changes living with Alzheimer's have brought about and are continuing to develop within me.

I have a greater realization of the importance of each relationship, each day and each situation, since I don't know how long I will be able to enjoy these gifts. I feel gratitude for the many abilities I still have, which in the past I often took for granted, and for the energy and commitment to share them now. I also feel a deeper understanding and acceptance of the limitations of others, a sense of the whole human family as one, each with our own gifts and challenges.

Though I am an optimistic extrovert by nature, I have tended to be very private about my deeper feelings and to share them with only a very few. Now I am much more in touch with my sense of vulnerability and moments of depression and grief and am able to express them, which is deepening my relationships. Recently, I had a brief experience of depression. My feelings were connected with the recognition that we all are going to die, and that Alz-



Maureen Sinnott, O.S.F., left, and Sheral Marshall, O.S.F., in back, attend a demonstration against climate change in San Francisco.



Maureen Sinnott, O.S.F., left, and Sheral Marshall, O.S.F., cook supper for friends.

heimer's really is a fatal disease. I don't know why this occurred to me then, but it caused me to cry as I shared my feelings with Sister Maureen. I told her that I was depressed and wondering how long I might live, and then we had a comforting and fruitful conversation.

I continue to reflect and to write in my journal, as has been my daily custom. I'm grateful to still be able to write (thankfully, I was an English major) and to share my story with Sister Maureen through presentations to Alzheimer's groups. For many years we have been advocates for local and global issues by donating, going to demonstrations, and calling and writing letters to senators and representatives. Hopefully, our sharing may encourage those who read this or hear us to deepen and rely on their own faith in the One they believe in and through whose embrace they are being held and sustained.

Sister Maureen and I hold a shared commitment from our different perspectives to continue speaking and writing opportunities through the Alzheimer's Association, while I can still speak to my experience. I feel gratitude to God for my community, the Sisters of St. Francis, whose values, openness to change, continual support and work for justice and peace have shaped and guide me still. My prayer is for all of us to know the presence of the One who loves us each day until we enter the life which never ends.

Sister Maureen: I want to be a companion to Sister Sheral on this journey for as long as I have breath. She is 77, and I am 83, so God only knows which one of us will get to heaven first. Sister Sheral has given her whole life in ser-

vice to others and has even decided to donate her brain for research when the time comes. But until then, we are trying to live in the present moment, grateful to be living together, and for all our blessings of still being mobile, reasonably healthy and able to advocate for others, trusting that God will provide!

Editors' note: If you have any concerns about yourself or a loved one, find out more at the Alzheimer's Association, www.alz.org.

Sheral Marshall, O.S.F., is committed to sharing her experience of Alzheimer's through speaking and advocating for those living with the disease and the family members and caregivers who love them. She earned a master's degree in theology from University of San Francisco.

Maureen Sinnott, O.S.F., is a retired clinical psychologist and worked as a nurse-midwife in Ireland, Taiwan and Tanzania. She is currently an advocate with the Alzheimer's Association.

