Alzheimer's & Dementia International

Perspective
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Sentio, Ergo Sum*

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Perspective

I have no words of wisdom to comfort those whose loved one has Alzheimer's. Of all the diseases, there is none obscener: It's the only disease that as it progresses, the person with the disease suffers progressively less and less, and the loved ones suffer more until their suffering becomes almost too great to endure.

Many relatives of the Alzheimer's patient don't visit them. It might be just too painful for them to witness the decline of the once-disease-free and functioning person. What I've witnessed is these patients sitting and staring at the walls or at staff passing by, but as for hand-holding or hugging or kissing or smiling, these acts of kindness have disappeared along with the patients' memories.

My 78-year-old sister (let's call her Rosie) is now in the advanced stages of Alzheimer's. When she was first admitted on an emergency basis to the long-term care facility seven years ago (her husband was very ill and was hospitalized on an emergency basis), Rosie was able to dress herself, walk quickly through the halls, eat on her own, use the bathroom, talk with me and with those around her, sing and play the piano (she was very gifted musically), and watch and sing along to the hundreds of music videos I had downloaded for her. Of course, she demanded of me that I bring her to her husband, which I did. Seeing her husband calmed her down, and shortly after we returned to her care facility, she pleaded with me to visit her husband (having forgotten that we had returned an hour before). A month after she was admitted, her husband died. Her five children, four of whom lived outside Canada, attended the funeral.

(A note about destiny. Within an hour of Rosie's arrival at the facility, her primary nurse's aide came to introduce herself. Her name was Ann, the same name as that of my dearest younger sister who had died 19 years ago, while in in her mid-fifties, of breast cancer. Genuine warmth and good humour radiated from this nurse's aide, and I thought, "This is without doubt destiny." Throughout Rosie's seven-year stay on that floor, Ann was a beacon of hope and love and laughter to Rosie and to me.)

By this time, my sister's condition had deteriorated to the point where she no longer recognized her own children or anyone else although she was still able to talk and walk and eat on her own.

The son who lived in the suburbs of Montreal would visit her, even if only sporadically, and then his visits ceased completely. Why, I wondered? His answer: "There's no point in going because she doesn't even know who I am!" A bizarre reply because he had made the frightful situation about himself, with no regard for the wellbeing of his mother! It was as if his ego were at stake and needed to be protected at all costs.

So, I learned first-hand one of my first significant lessons then about Alzheimer's: When one visits an Alzheimer's patient, leave your ego at the door. It's not about you any longer; it's what you can do for your loved one.

My sister was highly educated, independent and gifted in so many ways. She used to be a teacher, and at one point, she became a school principal. She composed music to songs from the prayer book and had a CD of her songs professionally produced.

Several years ago, when Rosie was still able to speak and sing, there was a pianist and singer who came once a week to the floor where Rosie lived. The pianist was late in arriving, so the staff asked Rosie to play the piano! The staff mentioned which songs she should play, and Rosie played them perfectly, with the staff and many of the residents singing along.

I had a friend many years ago who was a professor of English; specifically, a Shakespeare expert. I sat in on one of his classes and could vouch for the fact that he knew most of Shakespeare's works by heart. At one point, he found himself forgetting what he had known for decades and had to write notes. Knowing something was very wrong, he went to a specialist, who diagnosed his disease:

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The Latin "Cogito, ergo sum" ("I think, therefore I am") is a famous principle of the 17th-century philosopher René Descartes. Even without the ability to think clearly, people with Alzheimer's still have feelings. That is why the title says "Sentio."

early onset Alzheimer's. He was institutionalized, and I visited him only once. He was sitting in a wheelchair, absolutely still and not recognizing me or even recognizing that a human being was standing near him. In his case, the disease progressed so quickly that within a year, he was dead.

Of course, not all Alzheimer's patients are gifted. They are just "regular people," living their lives until the dread disease alters them fundamentally. Many of these people, who in health were placid and pleasant, turn violent and abusive: another dreadful sign of the power of Alzheimer's to destroy. Furthermore, Alzheimer's does not discriminate. The disease strikes all races and all people, regardless of their differing political and religious values and lifestyles. It is an indiscriminate and vicious killer.

Now, Rosie can no longer speak or play the piano. About a half year ago, I brought Rosie to the piano, hoping against hope that she would still be able to play it, but she sat there motionless in front of the piano, which had now become a foreign object. My sadness was overwhelming, but I just brought her back to her room and played more music videos for her. Astonishingly, even though Rosie had ceased speaking in a language intelligible to listeners, at that time she sang each word perfectly to every video! At this stage now, Rosie doesn't recognize the two-dimensional people on the laptop. She has stopped looking at it or showing any interest in the music or the singers. More overwhelming sadness for me, but none for Rosie. She is now like a four- or five-month-old child in a 78-year-old body.

For many years, I would visit Rosie daily and then return home and disintegrate emotionally. It felt as if I had nothing within me except this profound sadness. I ended up hiring a caregiver, paid through Rosie's pension, and I began going only twice a week. Now I go once a week to feed her and hold her hand and talk to her and smile at her and brush her hair and kiss her and put cream on her arms and face. Occasionally I go another day as well, but only to feed her lunch, and I leave shortly after the caregiver arrives. The paucity of my emotional strength is, to say the least, profoundly disturbing.

At one point, I came home after having visited Rosie, and I burst out crying. Now, I am a person who rarely cries, but I was devastated; thus, the outburst. I phoned 811, which is a free service, offering nursing or social work advice. I spoke for quite a while to a social worker, who referred me to a website. It happened to be an Alzheimer's site, but I learned there that there's a term for what I was experiencing: ambiguous grief.

People experience ambiguous grief when they have profound feelings of loss without the death of a loved one. My Rosie is "dead" in that her self-awareness and speech and other attributes have disappeared. But she is still human and, as such, is enriched by essentials, much like those that one gives to a new born to help him or her survive: holding, touching, smiling, feeding, and speaking comforting words in a soothing voice. The words will most probably not be understood, but the calming essence of those words will be transmitted.

Rosie is now in her seventh year of living in the institution. As she has lost her mobility, she was transferred several months ago to another much larger section with many more patients and a corresponding increase in the number of staff. Unlike the staff in the first section when she was admitted, the great majority of whom were warm and caring and often funny, the great majority of the staff in the new section do not show an iota of warmth to the residents. Other than three of the staff, who show warmth and their humanity, I have yet to see any other staff person touch or smile or speak to a resident although among themselves, the staff are always engaged in talking to one another and often laughing. The residents sit in front of a wall-mounted TV, and that's where they spend the majority of the day: They are treated as objects: a travesty and a tragedy.

What is it to be human? It's a multifaceted experience that includes consciousness, empathy and emotional depth, among other attributes. In the case of those with Alzheimer's, being human involves the intrinsic value and emotional capacity of the person without the cognition and memory retention of those free of the disease.

So what do we say to the relatives and friends who have ceased visiting the Alzheimer's patient? Jane Goodall, the British anthropologist, noted that "if chimps meet after a separation, they hold hands, they embrace, they kiss...." If these actions are to be found among non-human primates, how much more so must they apply to higher-functioning humans! Yet those Alzheimer's patients are denied their God-given humanity by what seems like hard-hearted relatives, friends or staff, the last group having no right to be working where they are.

Hillel, one of the most influential rabbis in Jewish history, who lived in the 1st century BCE, wrote in Ethics of the Fathers (Pirkei Avot in Hebrew) the following: "If I am not for myself, then who will be for me? And if I am only for myself, then what am I? And if not now, when?" Words for everyone to live by, but especially for those who hesitate to visit their loved one who is being decimated by Alzheimer's.