

Chapter One

Uncertainty

Diving into the Unknown

On either side of narrow line
on which you walk, run, or drive along,
there is acute disappearance of all
that is known, and you're reminded
of a fresco painting from
The Tomb of The Diver in Paestum,
once the Greek City of Poseidonia,
where a young man,
not unlike your son, at least in age,
may be seen perpetually leaping from
formidable, rough stone walls
into uncharted seas,
his head held high as he stares
straight into light-blue waters,
the dropping off like looking out
over mountain roads—nothing to stop
a precipitous descent.
But you hug an imaginary line
as if it is the last entity
you will embrace.

For a long time—during the period of my mother’s illness—I felt uncertain of nearly everything. That tension produced by these questions—What was wrong? Why was it happening?—was almost unbearable. Like my father, I refused to accept the evidence in front of my eyes, evidence that suggested there was no logical explanation and no cure. The mother I knew was not returning.

There is a haunting poem by Howard Nemerov titled “The Human Condition,” in which a man waits in a motel room wherein he, “pace[s] the day in doubt / Between my looking in and looking out,”¹ the uncertainty of his ambivalent condition agonizingly transparent. The man exists in a domain—or between these expanses—of which he is unsure, the reality and unreality. This feels like the domain of experiencing Alzheimer’s. For me, it was as if I was trapped and waiting for someone or something.

There is an awful, uncertain air that AD sufferers inhabit for part of their lives near the end, and it is intermittently the realm entered into by family members of those suffering from Alzheimer’s. Unlike the certainty I feel about my father’s tragic fall and death, there was little certainty about my mother’s terrible malady.

I could not write the title of this chapter without thinking about numerous works of literature in which uncertainty is a theme, perhaps because the concept points so accurately to our human existence. Uncertainty is particularly fitting terrain for those dealing with Alzheimer’s because that ground keeps moving from under us. All of those touchstones defined by memory begin first to appear opaque, and we are unnerved before they disappear altogether for the person suffering from this disease.

After I discovered that my mother had Alzheimer’s, I found myself wondering what she knew or didn’t know during that period in which bewilderment was the starting point in a daily battle. She masked her confusion as best she could. It was only

later, when we began to find items in strange places that our questions started to multiply. A glove in a shoe, a sock in a box of cereal—no item was too strange, no location too weird in terms of places common items were discovered.

She also began throwing away items of value, some of which we never recovered, finding out too late that she had tossed a necklace or a ring away. Initially, it must have caused her agonizing stress to realize that she did not know where items were, at points even what the objects represented. Far more disconcerting, however, are the misplaced emotions, substituting what appeared to be anger for some other more appropriate affect. Frustration and confusion deeply held look like anger, and it seemed to be the place she fell into when her fear was most deeply rooted.

On a distant Saturday afternoon, I arrived at my parents' home with a bag of cookies purchased from a local bakery. At that point, my father was struggling for his life in the hospital, slipping in and out of consciousness and unable to talk. My mother was wandering in their rather massive house with a home health care aide nervously watching her movements.

The cookies were my mom's favorite kind, but when I offered them to her, she took the bag and threw it at me, cookies flung out across the kitchen, a broken piece hitting me in the cheek. Initially, I was upset with her for her irrationality. Already exhausted (I had just come from the hospital and was more worried about my father at that particular juncture), I wondered how much more I could take. Of course, I would learn that I had to take so much more. Only later, did I try to go back and consider what might have triggered her peculiar response. I knew so little about Alzheimer's then.

When it comes to Alzheimer's, certainties are still few. Even the estimate of the number of people with this type of

dementia's diagnosis varies, with National Institute on Aging's statistics suggesting upward of 5.1 million Americans currently affected with Alzheimer's.² This site states that, "unless the disease can be effectively treated or prevented, the number of people with it will increase significantly if current population trends continue."³ That is, indeed, a frightening pronouncement.

The nature of the disorder makes for the predicament of dealing with it by families and even medical practitioners. It was a surprise for me to learn through personal experience that this type of dementia is infrequently diagnosed early. It is particularly difficult to consider this type of memory loss in a loved one, and it is often easier to come up with alternative explanations for odd actions, misplaced items, and examples of memory loss and confusion.

Although physicians know the proper medications to prescribe to manage the psychotic episodes associated with this disease, it is not really their job to manage the emotional fallout of this diagnosis, and that burden falls to the most immediate caregivers. While there are health care professionals prepared to help families, as well as the person with Alzheimer's, the family first has to seek out those professionals, know where to go and what to ask. Yet some of the best ways of coping with AD in the family appear to be counterintuitive, but it is up to the patient's families to advocate for their loved ones and themselves. Neither my father nor I knew how to go about being advocates for my mother or for the type of care she needed. It took us far too long to get to that point.

"Your mother had an accident."

"What? Is she okay?" I looked around the room and saw Mom standing near the doorway. She appeared to be fine, except she looked suspiciously at us.

Dad nodded his head but in a way that indicated nothing was fine. “She hit a woman with kids in her car.”

Mom turned with an angry expression on her face. “I did not hit her. She hit me.”

“She hit your car? Where?”

“She ran right into me. Driving like a crazy person.”

“Was she ticketed?”

“I didn’t get a ticket!”

“Nobody was ticketed,” said Emerson Sr. I still do not know if my father was telling me the truth in that situation. He was far more concerned with my mother’s feelings than the collision of vehicles.

“The policeman said it was that woman’s fault.” Mom was becoming increasingly agitated and yelling at that point.

“No,” said Dad, shaking his head with sorrow rather than disagreement. “No, he didn’t, Phyllis.”

“Don’t you tell me; you weren’t there!” At that point, Mom’s voice was strained, nearly hysterical. She was almost shaking with what appeared to be anger.

“Mom, don’t worry about it. It’s over, and you’re not hurt. She wasn’t hurt; the kids and their mother weren’t hurt, right?”

“They could have been,” said my father.

“Don’t you say that,” yelled Phyllis Marie, walking out of the room and then turning around and standing there near the doorway.

“Dad, you can’t let her drive anymore,” I almost whispered.

“I can’t,” said Dad.

“Hide her keys,” I suggested.

“I can’t do that to her,” he said, looking defeated.

Eventually, my father did hide my mother’s keys, but it was not really necessary since she was beyond the ability to recall

what to do with them even if or when she came across a set of car keys. I watched her take house keys and try to open the door of her car one afternoon.

Years before we recognized her condition, she had begun exhorting a promise from my father to never put her in a nursing home. She had an irrational fear of nursing homes based on misconceptions. I wonder now whether or not she was already experiencing early manifestations of the disease at that particular point? I suspect that she was, that the fear was driving her angry demand.

Recurrently, when my husband and I were in the front seats driving my parents to an event, my mother would lean over to my father and whisper conspiratorially, implying that my husband and I wanted to get rid of her, to put her in a home. We could barely hear her, but we always heard my father say, "I'll never let them do that to you." And he kept his promise, while he was alive.

It was only years later that I saw how helpful breaking that promise could have been. It might have saved my father's life. My mother's care in both the assisted living facility and the nursing home allowed her to be comfortable and her care well-managed, in a safe environment, far better than my father could create for her in their home once her disease progressed.

Of course, Dad's comment in the car was also hurtful to me, even though neither of them meant their words to be vexatious. Initially, I did not want my mother in a nursing home, either. If I could have had my preference, they would both be alive and living happily and independently. However, I also did not want them to be injured because they could not care for each other at home.

This dilemma is familiar to nearly everyone with aging parents, particularly those with some form of dementia, in some

manner. Few people have the good fortune to remain completely independent their whole lives and die peacefully in their own beds.

Would all of the events and their consequences have been less tragic if my father had not been so protective of my mother and so vigilant in his promise to her? Even when I did not know what clock was ticking, I deduced the pressure of the inevitable, of tragic conditions weighing down on us. His secretiveness and morose qualities were particularly unsettling because my father had always carried an air of optimism about him. He was fighting with himself as well as with his wife. Then he felt he had to fight his children.

Phyllis had always been more of a realist than Emerson, but she was not as prescient as she tried to project. On several occasions, she declared that she was going to die young like her mother and father had. That early loss may have made her feel lonely and isolated even in a room filled with family. Increasingly, you could see it in her eyes—the fact that she was in the room with you and not in the room at all. Phyllis did not die young, however; she lived until she was nearly eighty-three.

I recall standing in the dining room at the assisted living facility where my mother stayed for three years after my father's death, and suddenly becoming aware of the detached threads of familiarity around me. What initially was discerned as an illness that alienates on so many levels—the mind from the body, the members of the family from one another, the debilitated person from family and friends, and the family dealing with Alzheimer's from the rest of the community—began to reveal itself as remarkably patterned.

Inadvertently at first, then deliberately, I heard the same conversations about various incidents in people's lives around me that my family had experienced with this pathos as the

silent, angry member. The irony is that most likely each of the individuals in those family groups presumed that he or she was going through this terrible battle in isolation. There were middle-aged daughters and sons speaking softly and then sharply to their aging parents, confused about what to make of their parent's lack of responses or inappropriate statements. There were the inevitable embarrassments as out of context comments punctuated the air, the insults that flowed like acid in a sour room. There was anguish, of course, but it was masked by so many other conflicting emotions.

Family members of those with Alzheimer's often look like they are sitting in a dark room alone although the common room full of people is brightly lit. The strangeness of it is that we don't recognize these isolating actions and circumstances right away or we simply have no appropriate manner in which to deal with the strangeness of the experience. Then again, with uncertainty at the heart of this, we are not really sure what we are seeing and how we are interpreting the odd gesture, the disconnected phrase, the random pair of knitting needles in your mother's purse that is ready to be passed through an airport scanner.

Because of the nature of the Alzheimer's, it is one that many families do not recognize immediately, and then commonly deny, simply cannot believe, making excuses for the early indications that are perhaps missed or misunderstood. That was our family. We covered for each other in a nearly subconscious, compensating process, and then separately in a predictable but emotionally crushing insularity.

Yet the uncertainty is most profound for those directly affected by this attack in which the boundaries between reality and other planes of existence are blurred beyond recognition. A separate compass of this altered state looks very similar to

psychosis, as the dementia progresses, but, at first, it appears as simply discomfiting as the looking in or looking out of a surrealist painting—like the experience Nemerov related in his poem “The Human Condition,” in which he described a Magritte painting referred to earlier in this chapter.

For a lengthy period of time, I didn’t know what I was dealing with and, even less, how to approach the problem. People with Alzheimer’s look lost and sporadically afraid or angry—the two emotions increasingly conspicuous and oddly interchangeable. Whether subjective or not, most of us move within parameters that distinguish between past and present if not the future. But someone with advanced Alzheimer’s disease can no longer make those distinctions.

More than once, I looked up to find my mother staring at the kitchen counter—rubbing a spot repeatedly. “What are you doing, Mom?” I was compelled to ask, even though it should have been clear that the action was symptomatic. She proceeded with a paradoxical, indifferent urgency.

“What?” she would ask, pulled back from this other place, annoyed or frightened of the implications of my seemingly innocuous question. “I’ve got too much to do,” she would say almost angrily and then sigh at the same moment that I wondered what it was she had to do. If I didn’t distract her again, she would return to rubbing the counter, and a line from Shakespeare’s *Macbeth* popped into my head: “Out, damned spot!”⁴ but, thank goodness, I never said it aloud.

Any discussion of Alzheimer’s is going to be focused on loss and the state of angst caused by that loss, as well as the uncertainty. Yet the subject also demands that we consider the bounty of our memories before those losses. In the words of Nabokov in his autobiography *Speak, Memory*: “How small the cosmos . . . how paltry and puny in comparison to human

consciousness, to a single individual recollection, and its expression in words!"⁵ I would only add to his truthful, lyrical words that this constellation of bright spots from antecedents compels us, causes us to turn and look back in reflection, regardless of the visions we face.