



The Ambiguous Loss of Dementia

How Absence and Presence Coexist

The test of a first-rate intelligence is the ability to hold two opposed ideas in the mind at the same time, and still retain the ability to function.

—F. SCOTT FITZGERALD, *THE CRACK-UP*, 1945, p. 69



Rarely in human relationships are people completely absent or present. For this reason, loss and ambiguity are core elements in the human experience. With dementia, however, they merge into what I call *ambiguous loss*.¹

Ambiguous loss is a loss that is unclear; it has no resolution, no closure. This unique and devastating kind of loss can be physical or psychological, but in either case, a family member's status as absent or present remains hazy.

Dementia creates ambiguous loss. The duality of your loved one's being absent and present at the same time is confusing, and finding meaning (or making sense of





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your situation) becomes immensely challenging. Without meaning, it's hard to cope. It's hard to manage even your day-to-day responsibilities. Ambiguous loss ruptures your relationship as you knew it. What you had before your loved one's dementia set in, and the way you were together, are now gone.

With dementia, something is definitely lost; you feel it, but no one comes to you—as they do after a loved one dies—to validate or support your loss. People even say things like “You're lucky; you still have your mate” or “You still have your parent.” But you know you don't, really.

Health care professionals might distance themselves from you because you're not the patient, just the caregiver. Making you feel even more confused and alone, none of the usual customs and rituals used to manage grief fit your kind of loss. You are on your own in a limbo that all too often goes unnoticed (or denied) by the larger community. Perhaps it is simply convenient for society to let unpaid family caregivers deal with dementia patients on their own. Or perhaps it's too troubling for others to see what they cannot fix. For many reasons, it takes extraordinary strength to be a caregiver.

Gone, Not Gone

In my therapy practice, I worked with Jenny, who told me her husband was “slowly slipping away into another world.” She knew the diagnosis, dementia due



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to Alzheimer's, and realized that the journey would be long—years, maybe decades. But she was desperate to find some relief from her anger and confusion. She wanted her husband back; he'd been a successful businessman, a loving husband and father—but he was no longer the man she knew. Gone—but still there.

The event that made Jenny reach out for help came when her husband of forty years became short tempered. He no longer treated her kindly. She said she felt as though there was a stranger in the house. This was not the relationship she wanted. She felt betrayed and abandoned.

Such uncanny transformation brings shifts not only in relationships but also in the way we see ourselves. Consider these difficult questions:

Am I still married if my spouse doesn't know me anymore?
Is he still a parent to our children if he doesn't know them anymore?

Am I still the daughter if I am now mothering my mother,
my father?

People vary in how they answer such questions, but they all struggle with them. Jenny felt as if she were alone now and thus obliged to rethink who she was. With deep sadness, she said, "I feel like I'm leaving the shore for an unknown place."

Jenny was experiencing the loss of her husband's mind and memory—and also their relationship as it had



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been prior to his Alzheimer's diagnosis. He was with her physically, but virtually absent psychologically. This incongruence was confusing and painful.

I told her that what she was experiencing was ambiguous loss—the most difficult kind of loss because there is *no possibility of closure*.

Having a name for the problem, she could begin her coping process. We talked about possible choices. She might choose to act as if nothing were wrong or, going to the other extreme, as if he were already gone and out of her life. She said she had tried the former and couldn't do the latter. I suggested she consider the middle ground.

“What is that?” she asked.

“You can learn how to live with the ambiguity that comes with dementia.”

Although living with ambiguity is not an easy task in a culture that values certainty, Jenny chose to wrestle with not knowing what was coming next or how it would end. But now she understood that the culprit was neither her husband nor herself, but the illness. Dementia brings with it something mysterious that skews a relationship beyond human expectation. Knowing that it was not her fault, she was better able to begin coping—*not* to find a solution to the problem but rather to live with the lack of solution and the unanswered questions.



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Loving Half a Person

In my therapy practice, I see many people like Jenny—women and men who come to me because they are at their wits' end trying to figure out what is happening to them and their relationship with someone they love. It is not just about the exhausting and lonely caregiving role, but also about how to make sense of the situation they now find themselves in—without losing who they are in the process.

Regardless of its cause, dementia's ambiguous loss can debilitate even the healthiest of us. This is the struggle: making sense out of a nonsensical situation. You come to realize that life now is dramatically altered. Your loss is great, but there is no sympathy card; no one sits Shiva or holds a wake. Instead, there is a lonely and oft-misunderstood mourning—a chronic sadness²—with an indefinite beginning and indefinite end.

A New York psychologist who was also a caregiver, Carolyn Feigelson, asks a painful question: “How is it possible to lose half a person? Half is dead, half remains alive. . . . Unlike a fairy tale whose premise is poetic reality in which nothing can surprise the reader, the uncanny story violates the observer's trust in reality.”³ To be sure, caregivers who live with ambiguous loss live with a reality that is broken and no longer trustworthy. Their loss is irrational, illogical, and absurd, and yet real.



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Whether dementia stems from illness or injury, the challenge is to embrace the ambiguity and confusion. This doesn't mean passively submitting—or settling. Rather, it means discovering your choices and making decisions about how to find some continuity in the midst of chaos and change. It means trying to find some clarity in the midst of ambiguity. And live with ambiguity we must, if not earlier in life, then certainly as we grow older.

Even in normal times, we are most often apart from those we love. I go to work in one place, my husband in another, and our children in yet another. Some are in other states, thousands of miles away. Friends are scattered around the globe. In this mobile society, most of us are separated from those we love most of the time. But contemporary families seem to take what dissonance there is between physical and psychological presence in stride. Is this because we know that we can come together again whenever we wish? Unlike with dementia, such loss is retrievable. We can fix the loss with an airplane ticket or phone call. (There are, of course, obstacles that prevent reunions, such as cost, war, or political strife.)

Once we see how rare it is for couples and families to be fully present for one another, physically and psychologically, we realize that most of us already possess some skills for living with the ambiguity of separation and distance—and surviving it. This previous experience, albeit different, helps teach us how to survive loving someone with dementia.



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Finding the Middle Ground

With dementia, absence and presence coexist. Struggling too hard for clarity can lead to false answers that are attempts to erase the ambiguity. What I see most often is either premature closure (she is already dead to me, so I don't visit her anymore) or a denial that anything has been lost (he is just naturally forgetful, so he can still drive). Unless we consciously work hard to think about embracing ambiguity, any of us could quite easily fall into absolute thinking. This does not work with ambiguous loss and the real complexity you face.

When someone you love has dementia, the task is to increase your tolerance for the stress of ambiguity. To begin doing this, work at learning how to hold two opposing views at the same time—my parent is here, and not here; my mate is no longer the person I married, but still someone I love and will care for. Don't give up on loved ones when they are no longer able to be who they were.

Paraphrasing F. Scott Fitzgerald, learning to hold two opposing ideas in your mind at the same time allows you to move to the middle ground instead of sticking with the extremes. In the case of dementia, rather than the unfortunate extremes of either denial or acting as if the person were already dead and gone, there is a better choice: see absence and presence as coexisting. This is the best way to survive ambiguous loss.



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With more paradoxical thinking, we live with the tension of conflicting ideas about absence and presence. Someone we love is both here and gone. When there's no cure to an illness or condition, the only window for hope is to become more comfortable with ambiguity and a less than perfect relationship.

Thinking in a more open way requires us to focus on the meaning of our relationship with an ill person rather than on what is normal. Gradually, as we accept the ambiguity, we can make sense of even an ambiguous loss, and thus more easily cope with it.

Adjusting Goals

Ultimately, the goal is not to end your relationship but to achieve a psychological shift or transformation in your thinking that fits a relationship which is now drastically changed by dementia. The goal is to accept the ambiguity.

When to Say Good-Bye

I continued to see Jenny when she had time. As I typically do with the caregivers I work with, I encouraged her to say good-bye to her husband at some point, even before death. She would know when that time came. Jenny kept a journal, and shares parts of it to help us understand how difficult the process really is:



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January, after diagnosis

This is such a lonely disease. I am surrounded by people, but so lonely. The loneliness comes from being with someone who is no longer able to reach back to me. Loneliness is a different emotion than solitude. I have always enjoyed moments of solitude in life . . . but the loneliness is deafening. There is such an “empty space” in my life now. Sometimes I look at John while he is sleeping, trying to remember what our life was like.

July, two years later

My son called today. I am so thankful for his weekly calls from another state. It has been a great gift to me because he is not afraid to give me insight to help me keep perspective. Today I told him I am fighting for a quality of life for John . . . and he gave me a reality check in his answer. He said, “The fact is, Mom, Dad’s quality of life is not going to get better, he will progressively deteriorate . . . and your hoping he will get better is keeping you from fighting for a quality of life for yourself.” He continued, “You need to realize that the man you have been married to for 40 years is now gone, and it may even feel that you are married to a stranger, one that you don’t even like.”

After that conversation, I took a drive to clear my head. I popped in a CD by Josh Groban that my granddaughter had left in my car. It was new



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to me. The song, “You’re Still You,” came on and the words stunned me—especially the ones about “through the darkness I still see your light.” I realized that I still hold the memories of our years together, so I could see that light of him in the midst of the darkness, but no longer could he see my light since his memories were not only diminishing, but also leaving altogether. I pulled off to the side of the turnpike and listened to that song again and again, letting the tears flow down my face in convulsing sobs. I realized the time had come to say “good-bye” to the man who was, and say “hello” to the man who now is. That became a turning point. I let the tears of grief flow freely and let myself really feel the loss of my best friend, confidant, and biggest cheerleader in life.

April, three years later (after her husband was placed in a nursing home)

Today I went to see John as usual and take him for our daily walk. Today we walk inside the facility because it is still too cold for an outside jaunt. Fran (not her real name), another patient, came to me and wanted to walk with us. She calls John her boyfriend, and they have developed somewhat of an attachment. “Sure, walk with us, Fran,” I answer. There we were, walking down the halls of the facility, she on one side and I on the other side of John, holding hands. The two of them carry on a disjointed conversation, and I can tell that somehow through it they connect to one another. It may sound strange, but I was glad



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for their friendship with each other. I am glad that they both receive some pleasure through their interaction. She tells me, "This is my boyfriend." And I answer, "Well, he certainly is a good one." She pats his hand and he smiles.

As I get ready to leave, I hug John and he says to me, "It's so nice to meet you." I knew this day would come, but somehow I am not ready for it. The tears course down my face. The last tie of recognition he had is gone. I walk with him every day, but I am alone now in knowing about our precious life together over these many years. I grieve.

June

Today when I arrived, John was lying down and I could tell he was thinking about something. He suddenly showed a moment of lucidity when I asked him, "What are you thinking?" Most of the time I can't understand what he is saying, but he said, "I'm scared." When I asked him what scared him, I couldn't understand his answer, so I asked, "About the future?" He said, "Yes." I was overwhelmed with compassion for him, knowing that somewhere inside of him he is still feeling and has no way of expressing the thoughts. I hugged him, assuring him that I was scared, too, but that we would walk each day together. I assured him about how much I loved him, how much his family and friends love him, and we all wish he weren't having to go through this. And as



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quickly as it came, that moment of awareness was gone.

John is deteriorating quite rapidly now. I can't imagine a world without him in my life. The essence of who he is has been gone for a long time now. And he is changing almost daily. His long journey is almost over. And I grieve each change. And I say another good-bye.

Jenny's poignant story tells us that saying good-bye to someone who has dementia is not a one-time event. You do it over and over again each time you see a new loss. But doing so helps bring about a more peaceful parting for both.



Balancing Individuality and Togetherness

When one person in a couple is healthier than the other (not an unusual circumstance in families today), the marital or parental relationship becomes skewed, with the healthier person making most of the decisions and the ill person primarily on the receiving end. But herein lies the caregiver's conundrum. You need both individuality and togetherness.⁴

Indeed, there are many caregivers who say they receive as much benefit from taking care of their partner or parent as they give, but they also report being isolated, overworked, lacking in sleep, and unable to attend to their





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own needs. Although we hope there is mutual benefit for both patient and caregiver, the startling statistic from researchers is this: caregivers die at a rate 63 percent higher than people the same age who are not caring for someone with dementia.⁵

What this means is that caregiving is dangerous to your health. This is all the more reason for professionals and the larger community to work more patiently with the persons who give the care and now bear the burden of their loved ones' survival. They deserve empathy and respect. For the sake of their health, they need community and professional support to maintain a separate identity along with the role of caregiver.



Thinking Both-And (not Either-Or)



When someone is both here and gone, the way to lower your stress is with *both-and thinking*—that is, understanding that two contradictory ideas can both be true. This is the reality of dementia.

Paradoxical thinking can help you see ambiguity as a natural, even spiritual, condition. Living with dementia, even from a secular perspective, requires a trust in the unknown that things will work out, and that whatever happens can be managed. If you're still hanging in there, it means you have already expanded your tolerance for ambiguity. I congratulate you. That resiliency is needed to carry you through on this journey of dementia.





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Changing Perceptions

Living well usually means having access to information that enables you to make choices and decisions about how to think, feel, and act. Most of us prefer to stay in charge and avoid what has no answer. However, when there is a lack of clear information, as is the case with an ambiguous loss, we think and feel on the basis of our perceptions. We go with what we *think* we see. To live well in the absence of clear information, know that your perceptions are pliable; you can change them to lower your stress. Try a new way of thinking to avoid the stress of unrealistic absolutes. With dualistic both-and thinking, you may find you can shift your perceptions more easily.



To lower your stress, use both-and thinking to change perceptions:

- * She is both gone and still here.
- * I take care of both him and myself.
- * I am both a caregiver and a person with my own needs.
- * I both wish it was over and wish that my loved one keeps on living.
- * I am both sad about my lost hopes and dreams and happy about some new hopes and dreams.





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I thought of shifting perceptions while standing in the Louvre a few years ago looking at the Mona Lisa. Is she smiling or not? The answer depends on my perception—and *that*, fortunately, can change. We can see in ambiguity what we want. And therein lies the hope for Jenny and all of you who live with dementia.

When you are living with an illness or condition that has (as yet) no cure, hope lies in your perception and ability to change. This is creative adaptation. Seeing yourself and your situation in a new light can open doors. You begin to meet new people while also sticking by your loved one. You expand who you are beyond the role of caregiver by making new connections either in person or virtually on the Internet. Or you see ambiguity suddenly in more normal, even fun activities—playing cards, gaming, fishing—and you become less stressed by it. Your perception of ambiguity as terror is changing.

It is not easy to let go of the need for certainty, but in the mysteries of ambiguous relationships, there is also an opportunity to grow stronger. Hope lies in understanding that you are doing the best you can.

To be sure, most of us don't like to "settle." We won't go down without a fight. Good. Let's find a cure for illnesses and conditions that cause dementia. Let's find help for caregivers so that their health is not compromised. But in the end, regardless of how hard we work or fight, we can't win this game. Death is part of the circle of life, with or without dementia.





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What we can do is live each day well, with more tranquility and peacefulness, recognizing that things will not always go our way. Bad things can indeed happen to good, smart, hardworking people.

We must, of course, fight for what is reasonable, but we must also choose sometimes to let go. To do this means balancing control with acceptance. It means embracing the ambiguity when a loss has no closure. We live lives of curiosity instead of lives focused on expectations.

What is around the next corner? We don't really know, do we? Like exploring the mountains or riding the rapids down the Colorado River, it's another adventure.



When Jenny's husband came back home for his last months, he required around-the-clock care, and her tasks became extremely difficult. I was concerned that she was losing herself in the work. But eventually this changed. As she realized she couldn't control everything, she began to see the situation differently:

There is still the element of control that is not only unhealthy for me, but for the poor people around me. So I have fired myself from being my world's organizer. I think I monitor the environment in order to keep everyone happy and away from conflict . . . not good. So I am working



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on making peace with the idea of conflict being healthy sometimes. I realize that I make decisions based on “Will someone be upset if I do this?” and allow the “What if they get upset?” to cheat me from some healthy decisions for myself which will give my life meaning and purpose.

And then Jenny suddenly shifts, balancing her story of loss with one of new hope:

I am going to the University tomorrow to make arrangements for the “interests test” and to start the process of application. I don’t know what the future holds, but getting ready for fall classes will be good, even if something happens to delay this goal.

Jenny never made it to classes that fall. Her husband died, and after the funeral, there were months of details that needed her attention. Then she found out she was ill, got the necessary treatment, and also packed up and moved to a smaller house in an area she loved. Now, a few years later, Jenny is thriving. She is settled in her new home, energetic as usual, and surrounded by good friends and activities, with children and grandchildren not too far away. She has not forgotten what she calls “walking through the heartbreak of dementia,” but she is also moving forward with her life in a new way.





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The ability of people to grow stronger despite loss continues to amaze and teach me. Human beings are naturally resilient—if others don't stand in their way with judgment and stigma. Each person, each couple, and each family finds ways of transforming despair to hope, but overall, at the core of this process is increasing their tolerance for ambiguity. Even if they don't know what the future holds, they're willing to try something new. To do this, it helps to have more information. One has to know what the problem really is. People continue to tell me that it helps to have a name for what they are experiencing. Knowing what the problem is and that it's not their fault, they can more easily cope with a new and difficult situation.

Ambiguous loss is a unique kind of loss that not only challenges coping but also seriously complicates the grieving process. I will explain further in the next chapter.

《《 *Ideas for Reflection and Discussion* 》》

- ✦ Most of you already possess some skills for living with the ambiguity of separation and distance—and knowing how to survive it.
- ✦ Before you can manage the stress that comes with caring for someone with dementia, you must know what the problem is. Label it.



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- ✧ The culprit causing distress is not the person who has dementia, nor is it you. It's the ambiguity that surrounds your loss.
- ✧ When someone you love is here, then gone, then here again, then gone again, his or her presence has two meanings. Not knowing which of the two is real, you may feel distressed and anxious. Try accepting both perceptions as true.
- ✧ Promote both-and (not either-or) thinking.
 - ✧ Because there's no perfect solution and no absolute answer to whether your loved one is here or gone, you need to be able to think both-and—dualistically. It is helpful, therefore, to practice. For example, see your loved one as *both* here *and* gone; see yourself as doing *both* caregiving *and* connecting to other people. Create some more both-and lines to fit your situation.
 - ✧ Although some stress will remain, balancing two different ideas in your mind at the same time is less stressful than continuing to search for an absolute solution.

