

# Right Brain: A Medical Student's Reflections on Creating Space for Dementia Discussions

Kayla Sue Murphy, BS, and David M. Atkinson, MD

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## Correspondence

Ms. Murphy  
kayla.murphy.3939@  
gmail.com

## Abstract

The following narrative describes the experiences and reflections of a fourth-year medical student who longitudinally cared for a patient with dementia in an outpatient geriatric psychiatry clinic and inpatient medicine unit. The student, through these experiences, emphasizes the importance of creating space for honest and realistic discussions, balanced with empathic support, when discussing dementia diagnoses with patients and families. In addition, she recognizes the importance of engaging families in these discussions to promote proactive care planning and reminding patients and families that they are not at fault for their disease.

Mr. P sat in his hospital room, eating porridge, confused by the presence of a staff person sitting quietly across from him. I entered his room, introducing myself as a medical student working with his neurologist and asked if I could sit down to talk. "Sure!" he said pleasantly, welcoming me into the room. When I asked what brought him to the hospital, he said "I wasn't sleeping well." I said, "It sounds like things are getting harder at home." He agreed.

Mr. P was hospitalized after becoming increasingly agitated at home, making it difficult for his wife to care for him. He had dementia, likely Lewy body disease, based on the fluctuations in his cognition and worsening motor symptoms. I had previously discussed his dementia diagnosis with him and his family a few weeks prior during my longitudinal geriatric psychiatry outpatient clinic rotation. Although he had moderate-stage dementia, he was able to engage with me, his wife, and his geriatric psychiatrist through telehealth to discuss the diagnosis and the likely prognosis. His psychiatrist, my preceptor, suggested I lead the discussion about his dementia diagnosis, emphasizing the importance of honest and realistic discussion of the prognosis, along with empathic support.

At that clinic visit, Mr. P shared that he was increasingly frustrated with his thinking, although he described it as "mild memory problems." He also had occasional hallucinations and delusional thoughts, thinking that his wife was someone else or there were other people in the home. I validated his frustrations and asked if I could share my thoughts about his symptoms. He agreed and then, although I felt uncomfortable, I stated the diagnosis. "Mr. P, the symptoms you have shared with us and the testing you have done fit with a diagnosis of dementia. Does this come as a surprise to hear? What do you know about dementia?" I was unsure how he would respond. I thought his wife would be upset hearing the diagnosis stated so clearly. I feared my preceptor, his psychiatrist, would think I was insensitive. Finally, I thought the straightforwardness may add to Mr. P's distress. To my surprise, no one was upset. His wife was grateful to hear the diagnosis clearly stated and felt validated to hear it confirmed for both herself and her husband. Mr. P also expressed gratitude and did not appear distressed by the news since he too suspected something was wrong.

What followed was a thoughtful discussion about the prognosis, necessary preparations, and realistic support. We discussed that although the rate of decline varies between individuals, cognitive and functional abilities inevitably change over time. Upon invitation from Mr. P and his wife, the discussion ultimately allowed us to answer questions about the disease to the best of our knowledge and thus provide

From the Department of Psychiatry & Behavioral Sciences (K.S.M., D.M.A.), University of Minnesota, Minneapolis; and Older Adult Mental and Behavioral Health Team (K.S.M., D.M.A.), Minneapolis VA Health Care System.

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empathic guidance. Mr. P and his wife were interested in learning and asked thoughtful questions, while still remaining hopeful. They both sought to better understand the challenges that would come with worsening disease, but still recognized Mr. P could continue to have meaningful experiences. Throughout the discussion, it was clear that we were all on the same team. Mr. P's family was present and supportive, which is not always the case, and would likely have made this discussion more challenging. They were appreciative of the support and, for the time being, felt they were managing well at home. His wife, a loving and devoted caregiver, also understood the importance of avoiding correcting his logic or perception of reality because it would likely exacerbate his distress and agitation, so we validated this approach.

Because of the nature of Lewy body Disease (LBD), Mr. P had more periods of lucidity and attention than most, which likely made it easier for him to reflect on his condition.<sup>1</sup> Mr. P died a few months after his hospitalization. After learning more about LBD and the uniqueness of each individual's experience, which is especially well-highlighted in the article *Twilight and Me: A Soliloquy*, I wish I had the opportunity to ask him more questions about his experience and prompt an even deeper level of reflection.<sup>2</sup> After his death, Mr. P's wife asked if she should have done anything differently, like sent him to a nursing home. While helping her process the last few months of his life, I realized the importance of these moments of guided reflection for families as well. Going forward, I plan to make these intentional moments a part of my practice.

Initially, I was uncomfortable directly delivering the diagnosis of a terminal, incurable disease that drastically changes patients' and families' lives. However, I quickly recognized the importance of this honest and empathic discussion. By contrast, I have seen situations in which accurate information was provided without compassionate guidance, leaving patients lost and confused. Conversely, when critical facts are withheld because of a misguided attempt to protect the patient (and sometimes the provider) from uncomfortable emotions, patients are deprived of the knowledge that can help them plan and adapt for the future. These conversations allow patients and families to feel supported, have an open discussion about the disease, make greater sense of the distressing symptoms by organizing them around a diagnosis, and start to plan practical next steps to honor the patient's wishes and goals of care. Giving difficult news about incurable disease, especially dementia, is sometimes avoided, but it allows clinicians to partner with patients and their families to plan for the future and openly discuss challenges.<sup>3</sup>

I learned a great deal from this encounter. First, treat older adults with dementia with the same dignity as any other patient. Although I have always loved working with patients with dementia, I realized my own biases and assumptions, likely driven by media representations and stereotypes propagated by other medical professionals, while caring for Mr. P. Because of these biases, I was surprised Mr. P was able to engage in an in-depth conversation and clearly state his wishes. Therefore, I plan to always create space for patients and families to discuss the

**Table** Important Themes and Lessons for Dementia Discussions

THEME	Lesson
Regard	Older adults with dementia with the same dignity as any other
Create	Space for honest and realistic discussion balanced with empathic support
Guide	Families in proactive care planning
Remind	Patients that they are not at fault for their disease and they are valued and loved

diagnosis with providers in a supportive way, avoiding assumptions about their ability to meaningfully engage. In addition, clinicians who care for patients with dementia often serve families just as much as the patients themselves. Having these conversations with families helps them plan for the future, raise concerns to their health care team, and ultimately improve their loved one's quality of life (Table).

Returning to my subsequent discussion with Mr. P in his hospital room, I asked him how he was doing. He again referred to his memory concerns. I said, "dementia is a really difficult disease." He agreed and became tearful. He shared that his granddaughter, who he loved dearly, had sent him a letter. In a portion of the letter she asked, "Grandpa will I be like you when I get older?" (referring to his symptoms). He felt guilty and responsible for her fears. I could tell he wanted to be strong and brave. He was used to protecting his family. However, in this moment, he felt weak and responsible for causing his young granddaughter to worry. He became more tearful while describing a trip to the grocery store when he mistook his wife for someone else and became angry at her. He could not believe he would do such a thing and felt he was hurting his family. Despite his dementia, he had a deep understanding about the way his behaviors were affecting his loved ones. I reached for his hand and told him "It's not your fault. This is part of the disease, not a part of who you are." It was a simple response, but he seemed comforted by it.

Walking out of his room, I was not sure if he would remember the reassurance I provided or if he would have similar moments of grief in the future. However, I resolved that going forward, no matter the degree of cognitive impairment, I would not disregard moments like this with older adults with dementia. Instead, I would use these moments to be empathically attuned to, process, and reframe the patient's and family members' experiences of shame, as well as blame, that often accompany a diagnosis of dementia.<sup>4,5</sup> I would use my clinical experience to be realistic, while avoiding the propensity to underestimate their emotional or cognitive reserve. I would try to create space to have open discussions with patients with dementia and their families. I would recognize that patient-specific and family factors play an important role in these discussions. Finally, I would try to remind patients that they are not at fault for their disease and that they are still valued and loved.

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## Appendix Authors

Name	Location	Contribution
<b>Kayla Sue Murphy, BS</b>	Department of Psychiatry & Behavioral Sciences, University of Minnesota, Minneapolis, MN; Older Adult Mental and Behavioral Health Team, Minneapolis VA Health Care System, Minneapolis, MN	Drafting/revision of the manuscript for content, including medical writing for content

## Appendix (continued)

Name	Location	Contribution
<b>David M. Atkinson, MD</b>	Department of Psychiatry & Behavioral Sciences, University of Minnesota, Minneapolis, MN; Older Adult Mental and Behavioral Health Team, Minneapolis VA Health Care System, Minneapolis, MN	Drafting/revision of the manuscript for content, including medical writing for content

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