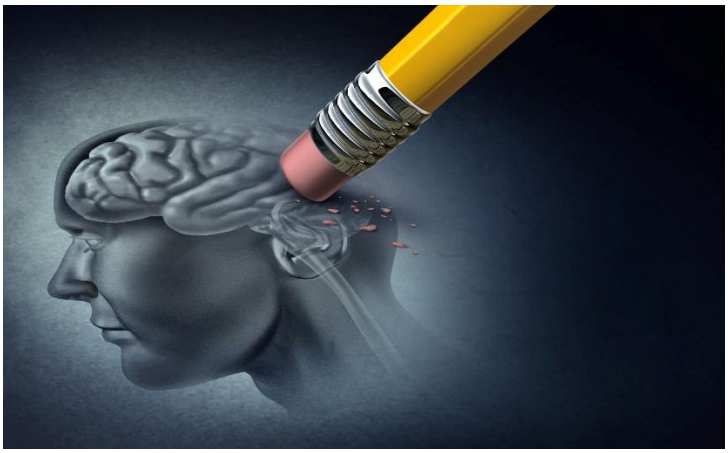
The Hidden Burden of Young-Onset Alzheimer's Caregiving Revealed by a Wife's Account

The author Karina Acton Reid described the lived experience of caring for her husband with YOAD presenting as PCA while raising two elementary-school-aged children, highlighting the emotional, practical, and social challenges faced by affected families.



Study

What happens when AD develops during the busiest years of family and professional life? Although most people associate AD with old age, the author notes that approximately five percent of people with AD have PCA, a rare syndrome that primarily affects visual and spatial processing rather than memory.

Individuals may struggle to navigate familiar environments or to recognize objects, despite eye examinations revealing no ocular abnormalities. These losses affect not only individuals with PCA but also their family members, who take on caregiving duties and adapt to changing family roles at the same time.

The author's family life changed dramatically after her husband was diagnosed with YOAD, specifically PCA. Before receiving the correct diagnosis, he experienced gradual visual difficulties even though repeated eye examinations showed no abnormalities. Because he had worked in healthcare during the COVID-19 pandemic, he initially wondered whether stress might explain his symptoms. He was later diagnosed with epilepsy, which seemed reassuring and, for some time, offered hope for a full recovery. However, this diagnosis did not fully explain his symptoms, and after ten months, he was diagnosed with YOAD. The delayed diagnosis brought emotional devastation and forced the family to reconsider the future they had imagined together.

Before the illness, her husband had built a successful career in leadership and change management while also encouraging teamwork through dragon boating. Losing his career became one of the earliest and most significant consequences of the disease. However, he kept looking for meaning by getting involved in work at a community center, where he supported children and used humor to navigate difficult moments. It was this experience that inspired the author to separate the disease from the man she loved and focus on preserving his identity and dignity.

Unlike more common forms of AD, PCA mainly affects visual and spatial abilities. Although Andrew could appear unchanged to an outsider, PCA profoundly altered how he perceived and navigated his surroundings. He often bumped into walls, had trouble figuring out whether he held anything in his hands, and gradually lost the ability to read and write, relying entirely on voice-to-text technology. Everyday actions such as navigating stairs, getting dressed, or locating objects became increasingly confusing as his brain could no longer reliably interpret what he was seeing, and objects seemed to disappear from view. To improve safety, the family introduced visual cues and red stickers throughout their home, although these measures could not eliminate the daily cognitive burden created by the disease.

The family also experienced unusual and disorienting situations that showed how PCA changed Andrew's perception. Once, he thought he was holding a lime that did not exist. During another incident, he mistook a pillow for his 11-year-old son's head while trying to pat him on the head. Although these incidents could be disorienting, sometimes the family found relief in humor. To help relatives understand the changes in his perception more easily, the family shared a short Rare Dementia Support video about PCA, which enabled the youngest son to better understand what his father was going through.

Findings

The diagnosis also transformed the author's own identity. During the first neurological consultation, hearing herself described as a caregiver was difficult to accept, even though she had already assumed that role. She experienced grief, frustration, and anger while recognizing that many of the family's future plans had disappeared. Over time, she began learning to separate her husband from his disease, let go of some of her anger, and adapt to their changing relationship. However, being a caregiver was still challenging physically and mentally, requiring her to remain constantly alert to their surroundings and his safety.

The disease also affected the couple's children, whose relationship with their father gradually changed as his independence declined. He could no longer help with homework, read bedtime stories, or confidently navigate public spaces with them. Watching these changes unfold created additional emotional challenges for the entire family. At the same time, the family faced financial pressure as the author worked full-time while caring for the household following Andrew's career loss. He had been the primary breadwinner, and they were now a single-income family. Most dementia programs were designed for much older people, while families affected by YOAD may have limited access to financial assistance and specialized support. The author therefore expressed hope for a Caregiver Relief Fund offering low-barrier grants for respite care or caregivers' personal well-being, while recognizing the invisible burden carried by caregivers.

During a recent canoe trip, it quickly became clear that the activity was no longer safe, as her husband could not judge how to enter the canoe, struggled to paddle, and sometimes did not know whether his paddle was in the water. Though it was heart-wrenching to lose these experiences, the author described the river as a symbol of life with AD: unpredictable, shifting, and resistant to control. Nevertheless, the family continued moving forward together, finding resilience, humor, and love amid continuing uncertainty.

Conclusion

The Perspective illustrates that YOAD presenting as PCA extends far beyond neurological symptoms, profoundly affecting relationships, family responsibilities, employment, and

emotional well-being. The author's experience reflects the ongoing adjustments required to support a loved one with deteriorating visual, spatial, fine-motor, and other cognitive abilities.

Caregivers may experience ongoing or anticipatory grief, while humor and resilience can also be part of their daily lives. Greater awareness and improved support systems could help families navigate these complex and life-changing experiences more effectively.

More research is needed to deepen the understanding of PCA and to develop care models that better support patients and their families.

Source:

https://www.news-medical.net/news/20260716/A-wifee28099s-account-reveals-the-hidden-burden-of-young-onset-Alzheimere28099s-caregiving.aspx