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## When Dementia Fades Memory, Words Remain

### **Introduction**

As dementia progresses, literacy skills are commonly assumed to decline with memory and reasoning, leading to a misconception that reading and writing abilities are gradually lost rather than maintained. However, current research shows that even the most basic “forms of literacy are useful across multiple genres and situations,” supporting the idea that familiar aptitudes assist individuals with cognitive disabilities in their engagement with the world (Halvey 34). Similarly, caregivers must seek to understand that individuals’ perception of the world, including “their definitions of literacy, and their dilemmas” to better support both their interaction with reading and writing or “literacy-related decisions,” even though it sometimes differs from traditional social norms and expectations (Fishman 17). With these insights, researchers can apply observational strategies to bridge knowledge gaps and document how literacy practices enable individuals with dementia to function successfully, especially in everyday, non-institutional settings. Further research detailing literary activities can help challenge harmful narratives and adverse stigmas portraying cognitive decline solely as loss, rather than highlighting literacy’s potential for constructive adaptation, improvisation, and intervention within society. Grounded in these insights, this observational case study examines how basic reading and writing skills serve as important and adaptive resources for individuals

with cognitive decline, helping them organize daily routines, maintain independence, and preserve their coherent identity in non-institutional settings.

## **Methods**

This observational study incorporated natural strategies aimed at examining daily literacy practices as they occurred in the context of an elderly subject in his eighties living with vascular dementia, a progressive neurological condition often occurring after a cerebrovascular stroke. Qualitative data was gathered through informal observations on December 25, 2025, during a family visit to *The Villages* senior community located in central Florida. Due to the researcher's close relationship with family, this subject was chosen out of convenience and assigned the alias Dan. The study took place in Dan's home and focused on how he used traditional pen and paper literacy techniques to manage daily tasks, track health data, observe religious beliefs, enjoy leisure activities, and maintain effective communication with others. The researcher detailed interactions between Dan and family members, documenting how literacy practices supported his independence, critical thinking, morale, and identity. Data documenting cognitive challenges as they naturally occurred consisted of detailed notes, photographs, visual literacy aids, and observed interactive behaviors.

## **Results**

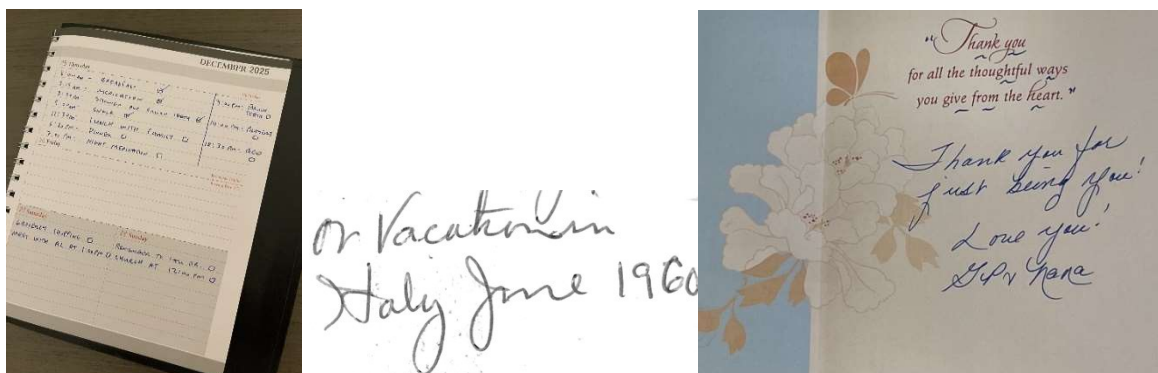
Dan used handwritten literary activities as crucial resources to manage daily tasks, maintain independence, and regulate emotions due to his limited technological proficiency. A handwritten planner was used considerably to organize basic needs and obligations, serving as his primary tactile memory aid (Exhibit 1). In the absence of the planner, Dan exhibited confusion and anxiety and, occasionally, responded inappropriately to situational demands. Handwritten literacy consistently supported memory, task completion, and emotional regulation

throughout the day. Dan's reliance on the planner corresponded with increased confidence and independence. Overall, his handwritten planner highlighted the critical role of literacy in maintaining organization and emotional stability within the home.

Effective daily safety and health management for Dan also relied heavily on his literary practices. Prior to this literacy solution, Dan would occasionally misread labels, confuse pills, and often missed or doubled doses when attempting to follow medical instructions. To address these safety concerns, he placed large-print labels on medication containers, demonstrating how written strategies are employed in critical situations to guarantee accurate identification and usage. As directed by his physician, he maintained a daily journal documenting blood pressure, heart rate, and subjective well-being, which he shares during medical appointments to help him remember trends. Moreover, financial limitations restrict Dan's access to doctor visits and prescribed medications, leading him to rely on health information in books, magazines, and newspapers. As a result, written literature served as an alternate source of medical guidance, directing his investigation into vitamins, herbal supplements, and other homeopathic treatments.

Despite cognitive decline, Dan's morale and well-being are closely tied to his literacy skills, which he used in leisure, religious, and personal activities. Rooted in traditional practices, his leisure activities relied entirely on printed mediums, including daily newspapers and crossword puzzles. He read and recited lengthy scripture verses, articulating their central meaning as he understood it. Dan's engagement with handwritten recipes passed down from his mother demonstrated literacy in cultural practices, accompanied by emotional storytelling about his youth. Literacy again served as a memory aid when he reviewed old photographs with handwritten annotations, helping him recall people, events, and past trips (Exhibit 2). Regardless of declining handwriting and motor skills, Dan continued to write greeting cards in elaborate

cursive, helping him to maintain meaningful relationships, express his identity, and convey affection, (Exhibit 3).



(Exhibit 1 – Handwritten Planner), (Exhibit 2 – Back of Photograph), (Exhibit 3 – Greeting Card)

## Discussion

Despite the effects of dementia, Dan’s varied literacy routines were fundamental to his daily functioning and provided a sense of constancy within his home. His engagement with literacy did not fade with cognitive decline; rather, it transformed into a stable, repetitive system that supported task organization, emotional regulation, and personal well-being. Handwritten planners, medical records, religious texts, and family artifacts acted as peripheral memory aids, enabling Dan to maintain control over his life and preserve his individuality within the domestic environment. Anxiety was noticeably reduced through these repetitive routines, and literacy strategies facilitated his functional participation in social, health, and leisure activities. Literacy also served to preserve Dan’s identity through familiar roles tied to family traditions, faith, and caregiving practices. Collectively, these findings challenge conventional assumptions about dementia, revealing literacy as a resilient resource that empowers individuals.

These results confirm Halvey’s assertion that basic forms of literacy remain meaningful across diverse circumstances, as simplified literacy practices strengthen intellectual integration and help individuals grasp fundamental patterns (Halvey 34). Dan’s reliance on monotonous

processes illustrates that literacy has enduring dimensions, sustaining individuals with cognitive decline. Similarly, these findings confirm Fishman's claim that writing serves as a creative outlet through which individuals navigate the gains and losses of communal assimilation (Fishman 16). By relying on literary activities to meet daily needs, Dan demonstrates that individuals with dementia retain a sense of control even as cognition degrades. Additionally, consistent use of familiar tactile literacy aids appeared to alleviate confusion and emotional distress on an observable level. Overall, simple literacy strategies preserve autonomy, routine, identity, and mental well-being, reinforcing Halvey and Fishman's view of literacy as an adaptive and meaningful resource rather than a skill inevitably eroded by dementia.

Works Cited

- Fishman, Andrea R. "Becoming Literate: A Lesson from the Amish." *UCF Writes A Handbook for Writing at the University of Central Florida*, edited by Matthew Bryan, Nathan Holic, Lissa Mansfield, Adele Richardson, Nichole Stack, Jacob Stewart, and Kevin Roozen, Fountainhead Press, 2017, pp. 8-17.
- Halvey, Madeline. "Simple Forms of Dance and Movement Literacy." *The Journal of the First-Year Writing Program at the University of Central Florida*, vol. 6, no.1, 2015, pp. 28-36.

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## Collateral background information on subject

- My Grandmother is my Grandfather's (Dan) main caregiver; she is in her 80's with her own medical issues.
- Dan is cognitively impaired (Vascular Dementia after Stroke) and has other medical comorbidities.
- Uses literacy that is child-like and basic to carry out tasks/ survive.
- Theory - Dementia victims revert to simple, adolescent-like literacy traits in old age.
- Suffered stroke, cognitive impaired due to vascular dementia
- Unable to go to Assisted Living facility due to finances; does not qualify for Long Term care services
- Safety concern – One time he woke up the middle of the night, turned the gas stove on and left it running for hours.
- Requires familiarity – Bought a new television and insisted keeping a 30-year-old stereo for sound even though the new television had a better sound output; unable to let things go, does not like change in his routine, insignificant things aggravate him to a point of aggression.
- Verbalized his fear of the progression of artificial intelligence.
- Childlike behaviors: stingy with blanket, did not want to share
- Emotional, sometimes combative when he does not get his way or feels challenged
- He has fallen many times after becoming confused/wondering
- Often asks the same questions repeatedly.

## Observation Notes – How Dan uses literacy to do work in the world

- Not technologically savvy and resists most innovations; uses pen and paper for most tasks even though he owns a smartphone.
- Relies heavily on handwritten daily planner to structure routine activities. Without it, he experiences confusion, anxiety, and repetitive questioning.
- He keeps a detailed medical log of blood pressure, heart rate, and how he is feeling. He shares these records with his healthcare providers and tries to follow written medical instructions, including medication schedules.
- Occasionally he misreads prescription labels, so large-print handwritten labels (e.g., "BLOOD PRESSURE PILL") used to support correct administration.
- Reads and recites passages from the Bible regularly, connecting him to his spirituality and identity.
- He prefers traditional print mediums for leisure activities; reads newspapers, complete crossword puzzles.

- Engages in family and cultural literacy by reading handwritten family recipes and sharing stories about family traditions, emphasizing the importance of shared meals. He refers to some recipes/ingredients as “secret” knowledge to pass down, fostering personal connection and belonging.
- Uses old photographs to recall memories, relying on handwritten cues on back to find people, places, trips, and dates.
- Takes the time to write greeting cards in cursive. Through handwriting is shaky and spelling sometimes is incorrect; this practice shows thoughtfulness, love, and effort.
- He researches alternative health information from books, magazines, and newspapers due to financial constraints, including vitamins and homeopathic remedies. Sometimes his decisions lead to non-compliance with doctor’s written order.
- Displays resistance to change, agitation when familiar objects change, repetitive speech, and childlike behaviors. It can become emotionally volatile, combative, or stubborn when routine fluctuates.

#### Discovery – Behavioral Pattern

- Does well when literary is basic, repetitive, and stable; they function as external memory aids.
- Literary memory aids vital in dementia management for supporting independence, identity, faith, and connection to family.

**Reflection**

Completing and documenting this study was both challenging and rewarding, requiring emotional detachment, unbiased critical thinking, and objective analysis within a structured academic framework. One of the greatest challenges was translating deeply personal, everyday moments from my grandfather's life into observable data that fit the organized Introduction, Methods, Results, and Discussion outline. I particularly enjoyed incorporating visual elements and developing the Results and Discussion sections, as they revealed how Dan's simple literacy practices closely aligned with the scholarly arguments highlighted by Halvey and Fishman. This literate activity report pushed me beyond rudimentary observation to clearly articulate the significance of straightforward literacy as a fundamental skill. I was especially proud to support my claim that literacy does not disappear with cognitive decline but instead remains a powerful tool for maintaining autonomy, health, spirituality, and overall well-being. Overall, this project reshaped my general understanding of literacy, revealing it to be a lifelong resource that encourages all individuals to navigate challenges with dignity and resilience.