A Publication of Del Oro Caregiver Resource Center

Pathways Serving families and caregivers of brain Impaired adults and the frail elderly

In Sickness and in Health: Experiences of Men as Caregivers By Simone Nazzal

"I MADE TWO BRILLIANT DECISIONS in my life: one, to ask my wife to marry me; two to enjoy the ride." For Dr. Richard Haynes, the "ride" refers to his journey as a spousal caregiver. Haynes began caring for his wife Sherry 13 years ago after she was diagnosed with Alzheimer's disease. A seasoned medical professional, Richard shared his frustration that, "There's no course that you go to learn about [caregiving]." Like most caregivers, men caring for a spouse or partner commonly learn "on the job;" however, their experiences of caregiving involve unique challenges and rewards that demand a closer look.

According to AARP's study Caregiving in the U.S. (2020), caregivers of an adult with a disability or chronic condition now represent 19.2 percent of the total population; moreover, they "find themselves providing care for 4-5 years, on average, and an increasing proportion have been providing care for 5 years or longer . . ." (AARP, 2020). Unfortunately, the pandemic has taken a toll on family caregivers, making daily tasks more complex while also limiting outlets for self-care. Overall, health outcomes have declined since 2015 with greater numbers of caregivers reporting moderate to high amounts of stress (AARP, 2020).

Even though women have historically shouldered the burden of family caregiving (for both children and older adults), growing numbers of men are taking on this responsibility. Research about male caregivers remains limited, but some studies highlight shifting gender dynamics in caregiving. It is estimated that 40% of informal or unpaid family caregivers are men. However, "Men caregivers are not a monolithic group . . ." (Lopez-Anurabe & Kohli, 2019, pp.1,3). In fact, the AARP observes that "husbands play a significant role caring for a spouse or partner, provide more hours of care, and are more likely to be primary caregivers with little to no support from other unpaid family members compared with other male caregivers" (Accius, 2017, p. 2). In other words, unlike their caregiving counterparts (e.g. adult sons), husbands or male partners often work harder and with less help than people may assume.

Assumptions, nevertheless, impact reality; indeed, personal and social definitions of gender shape how men care for their partners. A study in *The Gerontologist* indicates that "husbands" approaches to caregiving and their strategies for dealing with the work and feelings involved were rooted in their sense of selves as men" (*Calas*- anti & King, 2007, p. 516). How they understand masculinity defines how they understand themselves, especially within the context of their work supporting a partner. Yet, "as men move through their various networks, they interact with people in ways that affirm or alter the importance of various kinds of masculinity to them" (Calasanti & King, 2007, p. 526-27). So, the experience of caregiving can also change how men define masculinity—and thus how they define themselves. Gender and caregiving experience, then, have a dynamic relationship-informing and transforming each other throughout the caregiving journey.

Changes & Challenges:

Caregiving inevitably comes with challenges. For men like Richard Haynes, caring for a spouse or partner with dementia can last a decade or more. Such a commitment to abide "in sickness and in health" involves losses and transitions that ultimately change what it means to be a man.

Some men may not initially identify as caregivers. John Garland admitted, "I didn't even realize I was becoming [one]." When his wife Kay, who has Mild Cognitive Impairment (MCI), lost the ability to carry out several activities of daily living (or ADLs), John assumed

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what were once Kay's responsibilities, particularly cleaning and cooking—the latter of which, he joked, has been "one of [his] biggest challenges."

Even if they identify as caregivers, men find that their roles and relationships still change. After his wife Debbie's MCI progressed to Alzheimer's characterized by aggressive behaviors, Les Campbell had to adjust how he interacted with her on a daily basis. "I had to take my wedding ring off, because she [doesn't] want to be married," he revealed. "My wife is gone, and now I'm taking care of Debbie."

Men may "masculinize" their caregiving by focusing on practical skills and problem-solving, seeing their job as that of "a protector or provider" (Mott et al., 2019, p. 18). Both John and Les demonstrate a desire to protect and provide for their wives; however, practical problem solving has not been enough. In fact, Les reflected that over the last seven years of caregiving, "What worked yesterday may not work today." Therefore, sensitivity and adaptability are also necessary approaches to this work. Perhaps one of the greatest struggles for male caregivers, then, is not just learning new skills but learning to see themselves and their relationships differently.

Loneliness and isolation remain significant challenges for all caregivers, despite the shifting landscape of the pandemic and easing of shelterin-place restrictions. Interestingly, in general men "are at a greater risk for social isolation" than other family caregivers (Mott et al., 2019, p. 22). Not only may they have less time to socialize, but they also tend to lose some of the companionship they once enjoyed with their partner.

To illustrate, Les Campbell, who is determined to keep his wife Debbie at home, noted that she experiences hallucinations and often wanders. She has become protective of her body, and refuses Les' help with dressing and undressing, even though this activity of daily living (ADL) is difficult for her. Debbie's persistent fear and aggressive behaviors make intimacy—even just that of sharing the same space together—difficult.

John Garland initially struggled to communicate with his wife Kay, whose speech has become increasingly limited. In the past, some of Kay's irrational behaviors (e.g., leaving her glasses in the laundry hamper) frustrated John; but he has learned that "she is not doing it on purpose. It just is what it is."

Nevertheless, with fewer opportunities to touch and talk to their wives, the caregiving experience is that much more isolating. These husbands must now provide support for someone they would have turned to for support previously.

Many caregivers learn about the importance of self-care only when they are on the verge of burnout. They may also develop unhealthy coping mechanisms that negatively affect their overall well-being. Male caregivers may try to cope in ways that seem consistent with their ideas of or even stereotypes about masculinity-e.g., the "strong, independent, laconic" provider-but lead to poor health outcomes. For example, Walt Packard did not really think too much about himself during the first few years of caring for his wife Nancy; he believed he was just doing his duty. Ignoring his own needs, he gained weight, stopped exercising, and, admittedly, drank too much. After a difficult conversation with his adult son, Walt finally "sat up and took notice" of the way his own health was deteriorating.

Frank Arujo's body, however, gave him a rude awakening. A former professor of linguistics and anthropology in the Los Rios Community College District, Frank began caring for his wife Mary when she was diagnosed with Alzheimer's disease in 2015. After three years of providing in-home care, he developed a bleeding ulcer, which landed him in the ER. Even from his hospital bed, he continued to worry about his wife. At this point, his family "staged an intervention," and Frank realized that he could not continue to care for Mary as he had—24/7 and without any outside help. When asked how he initially understood self-care, Frank said, "I didn't. I understood it in a rational way. I was doing lousy, but I was a in a state of denial.

Richard Haynes knew something had to give when his wife Sherry's wandering started to affect his sleep. He observed that, "The worst thing about Alzheimer's is that it takes down two people, not one." In fact, according to Family Caregiver Alliance (FCA), older spousal caregivers of individuals with dementia have a 63% higher mortality than peers who are not in a caregiving role (FCA, 2006). Often, this greater risk of premature death boils down to the fact that caregivers do not engage in basic forms of selfcare—e.g., sleeping, eating, exercising, attending doctor's appointments for physical and mental health, etc. As with so many caregivers, bodily distress would teach Walt, Frank, and Richard that self-care was a necessity—not a luxury.

When the needs of a care receiver outstrip the capacities of the caregiver, placement in a care setting may seem like the only viable option. For Walt, the decision to pursue placement for his wife Nancy was critical to her well-being and his self-care. Although he experienced some tension with his wife's sisters, he felt confident that placement was the best option, because Nancy's wandering meant she required constant supervision. After permanently relocating from Illinois to California, Walt placed Nancy in a smaller residential facility where she stayed until she passed away in 2019. He observed that in her new living situation Nancy seemed calmer and more comfortable, which, in turn, gave him greater peace of mind. During visits, she would "light-up" when she saw him, and they could devote their time together to more enjoyable activities, such as reveling in their shared love of the Chicago Bears.

In contrast, Richard struggled to find the right care setting for his wife Sherry. Because in-home care options were so limited in his South Lake Tahoe community, even getting occasional respite was difficult. So, it became impossible to keep Sherry at home and essential to find somewhere that provided ongoing care as her needs increased. Ultimately, he found a facility that fit, but COVID-19 still casts a shadow over Sherry's successful placement.

Overall, placement may become a necessity, but it is often a last resort for caregivers who would prefer to keep loved ones at home. It can offer more space for self-care but also comes with logistical challenges, even without the added wrinkle of a global pandemic. When caregivers place a loved one, they do not stop being caregivers. Instead—as Walt and Richard can attest—they enter into a new phase of their caregiving.

Rewards & Making Meaning:

Despite its challenges, caregiving includes important rewards, too. The caregiving journey, or the "ride" as Richard Haynes calls it, provides meaning and purpose. Because the challenges and rewards are really mixed together, they both contribute to the essential significance of this experience. Gaining new perspectives can help caregivers find opportunities in difficult circumstances.

Shifting roles and responsibilities provide the chance to learn new skills and foster new talents. John Garland may have learned how to cook and clean as a result of becoming a caregiver, but he and his friend Les Campbell also discovered a gift for building community. John and Les participate in a men's caregiver support group offered through Del Oro Caregiver Resource Center. John cited this support group as a "lifeline" and an important means for making connections with others to combat his isolation. In fact, he and Les connect at least once a month outside of group to check in and support each other. Les has learned to cope with the stresses of caregiving more effectively by processing aloud his feelings with John and the other men in the group. Both men have also gained fresh understanding about their individual caregiving situations from peers.

Walt Packard participates in another support group for men who have placed their partners in a care setting, offered through a Sacramento-based company called Senior Care Solutions. In this group, Richard Haynes has discovered many commonalities between his experiences and those of the other participants. Within this space, he now counsels other men about self-care. One of Richard's peers, Frank Arujo finds the group most helpful for identifying some of the harder emotions he has experienced but denied while supporting his wife. During one session, another man asked Frank, "How are you doing?" This simple question gave Frank pause: he realized that he had been so focused on Mary's care that he had not slowed down to check in with himself. Now, with the outlet of this support group, he has become more skilled at assessing his own emotional state.

A study in the *Clinical Journal of Oncology Nursing* found that, "Peer support has been shown to be a vital component of supporting male caregivers" (*Mott et al., 2019, p. 22*). The men interviewed for this article who participate in support groups would likely agree. Walt Packard even went so far as to say, "I would advise any man to find a support group."

While formal education fails to

prepare most people how to be caregivers, the demands of caregiving still require learning new things. These include not only medical tasks but different outlooks (e.g., about aging, selfcare, etc.) Therefore, caregiving invites a new season of learning.

Les Campbell turned to a number of different books (see Recommended Titles) to help him understand Alzheimer's, specifically how he could adapt to changes in his wife Debbie's behavior. Some of these texts have helped him communicate more effectively with his wife.

Howard Woods gathered as much information about cancer as possible, exploring different lifestyle interventions outside standard treatments (like chemotherapy) that could improve his wife Connie's health outcomes. He also began a new diet and regular exercise regimen not only as ways to relieve stress but also to prepare his body for the physical demands of caregiving (e.g., lifting, transferring, etc.). However, at the late stages of Connie's disease, he struggled with some of the complex medical tasks associated with her care. After her cancer metastasized, Connie required regular doses of morphine to manage pain, but Howard feared overdosing her. He occasionally misinterpreted normal physiological changes—such as her trouble with swallowing—and perceived that he was doing something wrong. To negotiate these challenges, he continued to read and rely on medical and hospice professionals to answer questions about those caregiving responsibilities for which he had no training.

Importantly, male caregivers have reported a desire for better training, especially around complex medical tasks. In particular, they have asked for more hands-on training as well as disease-specific and end-of-life education (*Mott et al., 2019, p. 22*). Although independent reading certainly helped Les and Howard—who were both open to learning—they may also have benefitted from structured caregiver education, as well.

Finally, caregivers discover new things about themselves as they weather this journey. They may affirm their value system or gain a stronger sense of self. Investigators for the journal *Family Relations* discovered that "male [spousal] caregivers were more likely than female caregivers to find positive meaning from care provision" (*Lin, Fee, Wu, 2012, p. 354*). Howard Woods reported that caring for his wife Connie up until her death in 2022 gave him valuable personal insight: "I'm not as selfish as I thought I was." He cited his Christian faith as the driving force behind becoming Connie's primary caregiver in the first place. Howard's beliefs, which sustained him during the caregiving journey, now allow him to make sense of and integrate his grief as he navigates life without his beloved wife.

Les Campbell has also drawn on his faith to sustain him as a caregiver and to derive meaning from the experience. He shared that his Christian faith has offered a new lens on life, allowing him to look at Debbie "through a different set of eyes," adding, "I'm learning to love her the way the God I love loves her." For Les, love is covenantal rather than just a flight of feeling.

Richard Haynes gleaned some secular wisdom from a neurologist who advised him just to enjoy being with his wife Sherry rather than focusing on "finding a cure." While this was difficult for the good doctor, he ultimately surrendered to the fact that Sherry's Alzheimer's would progress and "learned how to do all kinds of things." When reflecting on his experiences, he shared, "Enjoy the ride; you can't change it."

Conclusion:

The diverse experiences of men who provide care for a sick or disabled partner should factor into how we understand the challenges and rewards of caregiving. They remind the rest of us to question popular assumptionsspecifically those that see women as somehow better suited or more "naturally" inclined to caring for a loved one. They also help us see how we need to support male caregivers differently and with a more nuanced consideration of how gender factors into the care exchange. This is a heterogenous group of individuals, and they may transform and be transformed by "what it means to be a man" as they assume the role of caregiver. By accounting for how men make meaning out of their experiences, we can develop better strategies for sustaining them throughout the long and life-altering "ride.

A heartfelt THANK YOU to the men interviewed for this piece for their incredible insights and vulnerability. To learn more about the Men's Support Groups at Del Oro Caregiver Resource Center and Senior Care Solutions, visit www.deloro.org and www.seniorcs.com.

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Recommended Titles:

- Jan's Story: Love Lost to the Long Goodbye of Alzheimer's (2010) by Barry Peterson
- *The 36-Hour Day,* 7th Edition (2021) by Nancy L Mace and Peter V. Rabins
- Creating Moments of Joy Along the Alzheimer's Journey (2016) by Jolene Brackey
- When Reasoning No Longer Works: A Practical Guide for Caregivers Dealing with Dementia and Alzheimer's Care, 2nd Edition (2022) by Angel Smits
- How to Starve Cancer (2021) by Jane McLelland

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A Journey in Mindfulness

by Judy Feyka

This road called Dementia is difficult at best,

- For It can cause caregivers to lose sleep and much needed rest.
- As you face the unknown and life's untold surprises,
- You wonder and ask yourself, "How will I get through this crisis?"
- You're worn out and tearful, tired beyond belief.
- You ask, "Where can I turn? How do I get some relief?"
- You draft a list of all the things you feel you need to do,
- But what you left off the list was taking care of you.
- That, my friend, must be on your list, written as Number One,
- For without your self-care first, the rest will remain undone.
- You must treasure you first and carve out time for you alone:
- That means having to stop the world and even unplug your phone.
- Mindfulness is a whole new word and curiosity is the key,
- For each moment spent with loved ones gives insight for us to see
- Into their world and understand why they react the way they do,
- For they are struggling with the world as it is; and then as if on cue,
- They say or do something that embarrasses us or doesn't make any sense,
- But it's okay to feel it, to own it, says Del Oro and Project Care Presence.

- Our life doesn't change, but it's how we react that's the new tool in our hand.
- We have learned how to cope with these instances, and now we understand!
- The important thing to remember is that it's not what they say or do
- But the making of the Connection first between the Me and the You:
- Stepping into her world, her reality, and seeing what is there
- Can help me understand her fear and show her that I care.
- Meditation and quiet are tools we use to ease the churning mind;
- Peace, compassion, calmness of heart, and more will result, you will find.
- We learn from Ymkje¹ how to cope when on that runaway train:
- "S.T.O.P., Take a breath", "be in love with yourself", and, yes, we even try some R.A.I.N.
- This is a life-long journey, friend, for practice it will take.
- Peace of mind can result, but since your sanity is at stake,
- I encourage, "Practice Mindfulness", do this as often as you can.
- Your life will be better for it, with Ymkje close to lend a hand.

¹Ymkje Dioquino, MS, LMFT facilitates the eight-week series called Mindfulness-Based Dementia Care that Del Oro offers. She is a Family Care Therapist at the Ray Dolby Brain Health Center in San Francisco, where she provides psycho-therapeutic services and support to persons with Dementia and their families and friends.

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