



# NAVIGATING A GAUNTLET OF CHALLENGES

Regardless of a man's age, caregiving for a partner or family member can take a toll on a person.

By DON VAUGHAN

**C**assie Cramer, 52, of St. Paul, Minnesota, received a diagnosis of early-stage breast cancer in 2002. She underwent a mastectomy and lived disease-free until summer 2018, when she began to experience fatigue and chest and back pain. A positron emission tomography scan revealed that Cassie's breast cancer had spread to her lungs; she was told it was manageable but incurable.

In that moment, Cassie's husband, Dan, saw his world turn upside down. He went from being a consultant and business owner to a full-time caregiver overnight, providing for Cassie's medical needs as well as her emotional support and encouragement.

"There's a word I use to describe living with metastatic cancer: unrelenting," says Dan, 54. "There's never a day, never a moment when Cassie doesn't know she has cancer. And because of that, there's never a day when I'm not her caregiver. When you love someone who has cancer, you're with them all the time. The emotional toll has been significant for me." »

Dan Cramer is one of a growing number of men who are taking up the gauntlet of caregiving for a spouse or other family member with cancer. Many are wholly unprepared for the job's grueling emotional, physical and psychological challenges, yet they readily accept the responsibility, often because there is no other choice.

According to a March 2017 report from the AARP Public Policy Institute titled "Breaking Stereotypes: Spotlight on Male Family Caregivers," 40% of family caregivers are now men compared with 34% eight years earlier. This equates to approximately 16 million male caregivers in the United States. More than half (63%) reported that they were the primary caregiver in their family after their partner became ill.

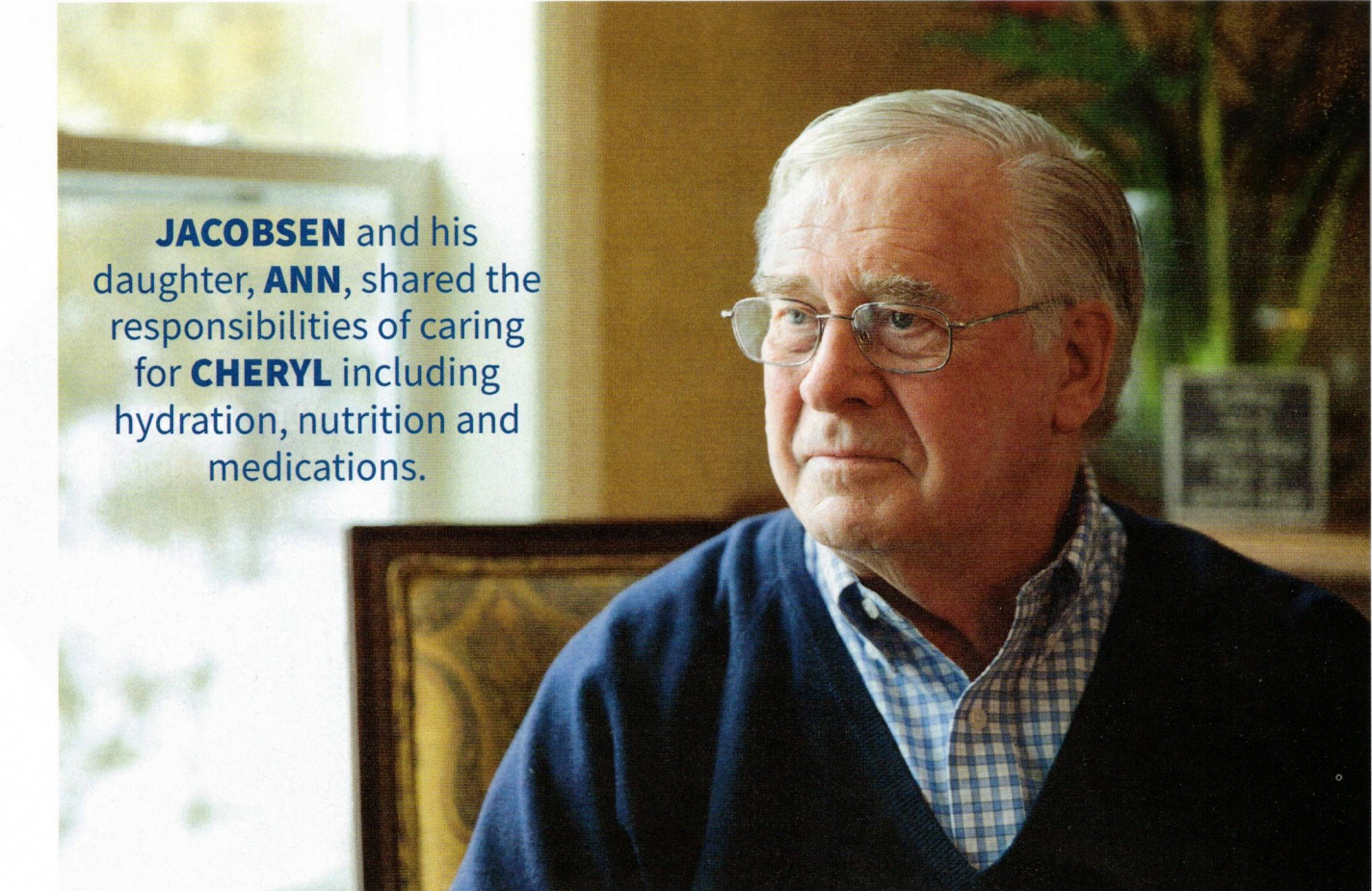
As men increasingly find themselves in the caregiving role, societal attitudes have also changed, experts note. "Traditionally, women have been socialized into the caregiving role," observes Susan R. Mazanec, an assistant professor at Case Western Reserve University Frances Payne Bolton School of Nursing in Cleveland, Ohio, and a nurse scientist at University Hospitals Seidman Cancer Center in Cleveland. "However, in contemporary society, as women assume other roles in terms of work and family, male caregivers have stepped up and helped out with providing care and other needs. It's very important for oncology nurses to recognize that the primary caregiver in a situation could potentially be a man and that they, like women who are caregivers, will need to be educated, trained and supported in their role."

Men bring unique skills and experiences to the caregiving role, reports Allison J. Applebaum, a psychologist specializing in cancer and caregiving at Memorial Sloan Kettering Cancer Center in New York. "A recent systematic review of studies enrolling male caregivers found that men appear to focus on the more traditionally masculine behaviors that accompany their caregiver role, including their ability to take control, use of their technical skills and (completion of) practical tasks such as managing finances or providing transportation," she notes. "Male caregivers were also found to value independence and autonomy as a caregiver and often reframe their role from 'carer' to 'protector' or 'provider' of the patient."

A 2008 meta-analysis on gender in caregiving, published in *Psychological Bulletin*, found that male caregivers tend to report experiencing a higher quality of life and life satisfaction than female caregivers, as well as lower rates of depression and anxiety, Applebaum adds. "While these relationships are certainly not definitive, the gender differences here may reflect male caregivers' 'problem-focused' approach to caregiving that views each issue that arises during caregiving as a problem to be solved," she explains. "It may also be a reflection of the fact that overall, male caregivers tend to be less comfortable admitting that they are experiencing difficulties."

A variety of factors can influence the degree of stress and responsibilities a man may face in his new role as caregiver, including his relationship to the patient, employment status and age. Compared with all older caregivers, younger ones





**JACOBSEN** and his daughter, **ANN**, shared the responsibilities of caring for **CHERYL** including hydration, nutrition and medications.

struggle with different challenges because caring for a person with cancer at a young age is atypical, notes Applebaum. They may lack the experience and coping skills to manage the emotional and communication challenges that accompany caregiving, and as a result often have a difficult time adjusting to the caregiving role. Young adult caregivers may have to forego pursuing higher education, career advancement or romantic relationships due to the time demands of caregiving, which can have a long-term impact on their developmental trajectory.

Daniel McLeod, 36, of Perry, Florida, was in his mid-20s when he was asked by his mother and aunt to assist in the care of his grandfather, Pete Lavoie, who was recovering from bladder and prostate cancer. McLeod was between jobs, divorced and had shared custody of his young son, Peyton, which added to his responsibilities. Worse, Papa Pete, as McLeod called his grandfather, was also in the throes of Lewy body dementia, a particularly pernicious form of dementia that often results in paranoia, agitation and aggression.

Initially, McLeod's caregiving consisted of assisting his grandfather with the usual activities of daily living, as well as maintaining his stoma and ostomy bag. But when Lavoie's dementia worsened, McLeod moved into the home to attend to his care full-time and keep him safe. "Papa Pete would sometimes wander into his woodworking shop when I was preoccupied with Peyton," he explains. "He couldn't safely work the machinery anymore, and I would have to gently redirect him back into the house."

As his grandfather's cognition declined, McLeod's responsibilities increased. His social life dwindled and the constant stress had a negative impact on his interpersonal relationships, including with his fiancée. Other family members helped when they could, but McLeod remained responsible for most of his grandfather's care.

"I went through crisis training when I was in law enforcement," McLeod notes, "but when it comes to a family member, someone you care deeply about, that all goes out the window. The care was nonstop, and there were times when I would put Papa Pete and Peyton to bed, and just sit on the couch thinking, when am I going to have a life?"

Jake Jacobsen, 76, of Eagan, Minnesota, had an altogether different experience. In 2019, as he was enjoying life as a retired executive, his wife, Cheryl, was diagnosed with stage 1 pancreatic cancer. She received chemotherapy, radiation and a pancreaticoduodenectomy (a surgery to remove the head of the pancreas, the gallbladder, the first part of the small intestine and the bile duct) and was deemed cancer-free until August 2021, when she learned that the cancer had spread to her liver. She died in December 2021, too ill to continue treatment.

"I cared for Cheryl 24/7," Jacobsen says.

Jacobsen was luckier than many male caregivers in that he shared the responsibility with his daughter, Ann. "She remotely participated in all doctor calls and made a record of all discussions," Jacobsen reports. "This was extremely helpful in making necessary care changes. Ann also prepared »

“Before, I never asked for help because to me it was a sign of weakness.”

—KYLE WOODY

charts that directed us in what to do for pain, anxiety, constipation, diarrhea, etc., and created daily logs specifying the timing of meds and recording of hydration, nutrition and bowel movements. The careful organization improved our ability to care for Cheryl.”

A notable difference found among male caregivers is a reluctance to ask for social support from loved ones and the community (38% versus 47% of women, per the “Caregiving in the U.S. 2020” survey). “As such, they tend to be more isolated and lack emotional support ... compared (with) female caregivers,” Applebaum observes. “This may be due to societal expectations that stigmatize male vulnerability and make asking for help seem like a weakness.”

Kyle Woody, 42, was caregiving for his wife during her treatment for metastatic colon cancer when some family friends asked what they could do to help him. Woody was perplexed; it was his wife who needed help, not him. They then told him the story of a friend named Jack who had been through the same difficult experience.

“Jack told them, serve the caregiver — they’re always forgotten,” Woody recalls. “So that’s what they were going to do, bring his wisdom into my life. That moment inspired me after a lot of reflection, and in 2014, we founded Jack’s Caregiver Coalition, a nonprofit organization dedicated to improving the way guys think, feel and act through every phase of their caregiving journey. Before, I never asked for help because to me it was a sign of weakness.”

Another big challenge is a lack of preparedness for the caregiving role, especially if someone is thrown into it unexpectedly. Mazanec worked with oncology nurses to conduct a 2018 study of 50 male caregivers of women with gynecological cancer post-surgery, which found that the



caregivers had a number of informational needs, as well as a necessity for training specific to equipment and procedures.

Additional struggles arise if the caregiver is the sole financial support for the family. In 2015, according to “Breaking Stereotypes,” two-thirds of male caregivers reported having to make changes in the workplace as a result of their caregiving experience, including shortening working hours or taking a leave of absence. “Caregivers of all genders report conflicts between their work and caregiving responsibilities; however, men’s societal expectation to be financial providers for their families could make these conflicts more difficult to reconcile,” notes Applebaum.

Left unaddressed, the challenges that commonly face male caregivers can become overwhelming and negatively affect their health and quality of life. Jake Jacobsen, for example, gained 30 pounds during the two years he was his wife’s caregiver because he no longer had time to exercise and rarely left the house because of the COVID-19 pandemic. This is why outside support can be so helpful.

“There are phenomenal support services available to all caregivers, though male caregivers may have unique needs,” says Applebaum. “For example, male caregivers I see in our Caregivers Clinic often report feeling ill-equipped to carry out medical as well as personal or intimate caregiving tasks such as dressing, bathing and toileting. As a result, they may especially benefit from support services that provide »



To hear more about how **KYLE WOODY** started Jack's Caregiver Coalition, **SCAN THE QR CODE AND LISTEN IN!**

education on how to complete these tasks, as well as disease-specific information and education.”

Peer support, in particular, can be a critical component in helping male caregivers cope with and manage the stress of the job, Applebaum adds. “Support groups can help men feel validated and less isolated and alone in their caregiving journeys,” she explains. “Peer-to-peer mentoring, (in which) men who were once caregivers can provide support to current caregivers, is one model of care many male caregivers have found helpful. Support services such as these can help to normalize the emotional challenges associated with caregiving and encourage male caregivers to continue to take care of themselves while taking care of a loved one with cancer.”

Jake Jacobsen and Dan Cramer both found support through Jack's Caregiver Coalition, where they worked with trained facilitators. “It gave me the sense that it can be done, you just have to learn how to do it,” Jacobsen says. “It was helpful to me, and I regret that I didn't get in touch with them earlier.”

Male caregivers may find it helpful to ask themselves a series of questions as they go through their caregiving journey, says Mazanec. Because they are often thrown into

the role with little preparation, the first question should be, “What do I need to learn, and who can I turn to for that information?” Once they become immersed in the role, they should ask how they can find time for themselves, whether it's a visit with friends or a daily walk, and who they can turn to on those days when they simply aren't able to give 100%.

Applebaum agrees, noting, “As a caregiver, you cannot meet all of your loved one's needs on your own. It's important to give yourself permission to ask others for support — for yourself emotionally and for support around helping with caregiving responsibilities.”

The caregiving role can be fraught with anxiety and have as dramatic an impact on the caregiver's life as on that of the patient. But it also is an opportunity for caregivers to learn new things about themselves, Applebaum observes, including their deep capacity for strength and resilience, and the ability to create a deeper, more intimate relationship with the patient for whom they are providing care. “For all caregivers, the challenges endemic to caregiving have the potential to eventually serve as learning and growing experiences that can help them to live more full, authentic lives both during caregiving and after,” she says. ■

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