

When the elder caregiver is a man

By Stacey Burling
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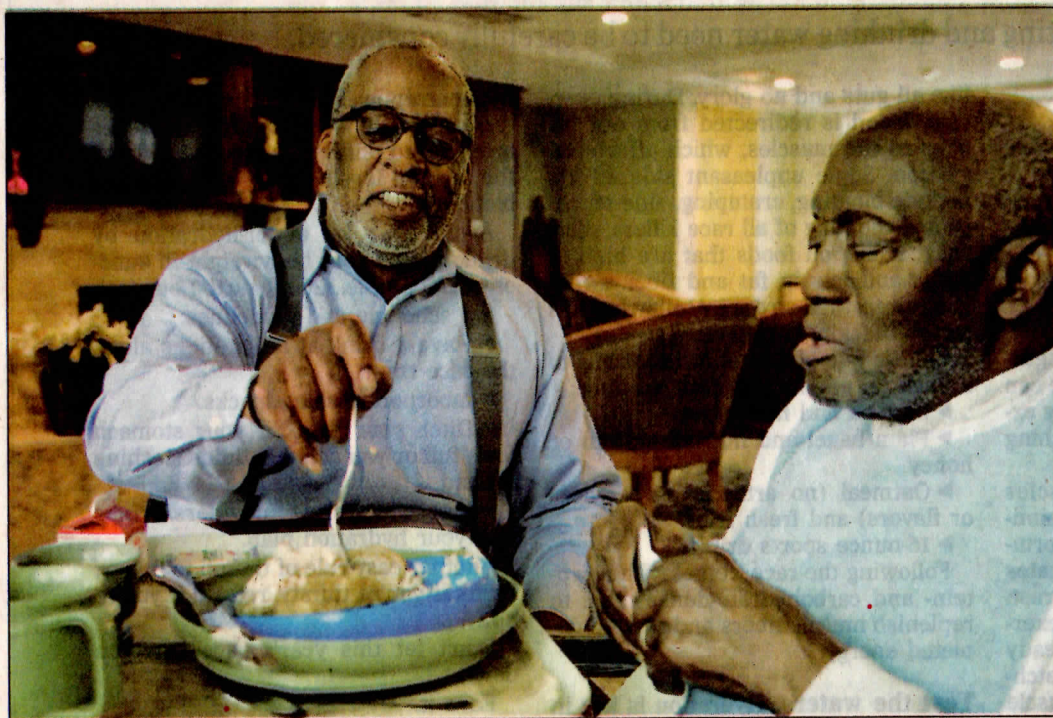
During the years when Michael Lewis' mother declined with Lewy body dementia, his father took care of her. When she got too sick to stay home, James Lewis visited her in the nursing home every day.

She's dead now and James Lewis, 92, is in a nursing home. He lost his sight to an infection about a year ago and had to leave his North Philadelphia home.

Now it is Michael's turn to be the caregiver. His responsibilities started out small, checking to make sure his father was safe and taking him to the grocery store and medical appointments.

These days, he visits his father in his new home — Saunders House near Lankenau Medical Center — three or four times a week and calls daily. He gives him dinner, does his laundry, buys his clothes, pays his bills, shaves him and cuts his white hair, brings him his beloved lottery tickets, goes with him to the doctor, gets to know his aides at Saunders, and checks on his old house two or three times a week. Mostly, he talks with the Marine and former Postal Service worker.

"The biggest thing is loneliness," said Michael Lewis, a



Michael Lewis helps his father, James. A new effort is lauding men who take on the role of caregiver.

social worker whose day job is directing residential programs for a community mental health center.

"Without him," his father said, "I don't know what I'd do."

The son says he's following the example set by his father and other men in his church. "I don't see it as a burden," he said. "This is the way I was raised."

In a recent report, AARP esti-

mated that there are 16 million male caregivers such as Lewis.

"I think the male caregivers have sort of been overlooked," said Amy Goyer, a family and caregiving expert with the organization, which advocates for older adults.

The report estimated that 40 percent of family caregivers are men, up from 34 percent eight years ago. The men are

slightly younger on average than female caregivers — 47.8 vs. 49 — and provide slightly less care per week — 23 vs. 24.4 hours. They do similar things, from paying bills and driving to medical appointments, to hands-on care such as bathing and using medical equipment. Many wish they had more training.

See **CAREGIVING** on G7

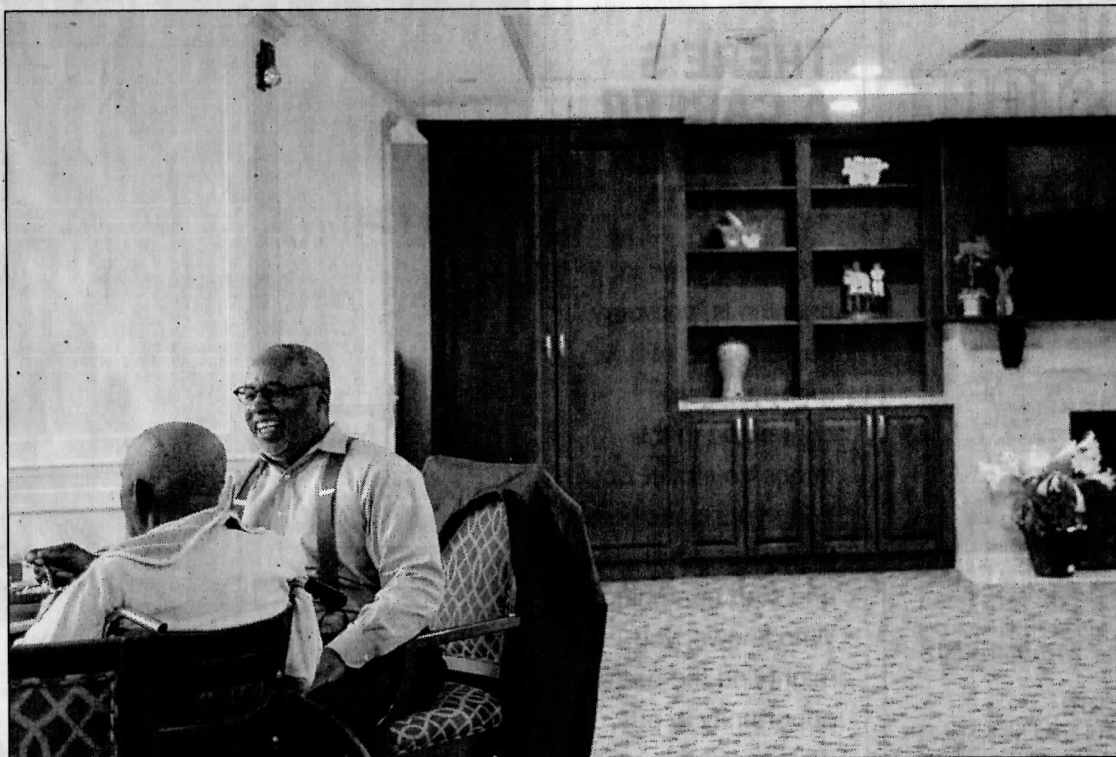
Caregiving

Continued from G1

Male caregivers were more likely than women to be employed, but 37 percent did not tell their bosses about their caregiving responsibilities even though many said they had to come in late, leave early, or take days off to take care of a loved one.

AARP has teamed with the Ad Council to produce videos lauding male caregiving. Goyer said that organizations such as hers typically have targeted marketing to women and that support groups also are more female-oriented. On the other hand, she thinks men are less likely to seek support, and she's heard from many women who believe that they are expected to be caregivers while their brothers are not.

Barry J. Jacobs, a psychologist with the Crozer-Keystone Health System who specializes in work-



Michael Lewis feeds his father. "Without him," James Lewis says, "I don't know what I'd do." TOM GRALISH / Staff

ing with caregivers and has been one himself, said previous research has shown that men tend to do less hands-on care, accept more help, and seek more outside services. Jacobs, whose mother eventually moved to a nursing home and died last month, said mothers may have a harder time accepting hands-on care from sons than fathers do from daughters.

Expectations are different. "It's like an amazing thing if the man actually becomes a caregiver," Jacobs said. He finds that attitude "dismissive" and said families need to think differently. "We have to think of men as being as responsible as women for family members."

He was not surprised to learn that men surveyed by AARP often did not tell their bosses they had caregiving responsibilities. "It's only been in the last few years that employers have come around to being supportive of family caregivers at all," said Jacobs, coauthor of *AARP Meditations for Caregivers*.

In the AARP survey, 56 percent of male family caregivers were performing medical and nursing tasks. Sixty-three percent said they were primary caregivers. Only about a quarter reported helping with eating, bathing, and showering. More than half "found it moderately to very difficult to help recipients with their personal, intimate care needs."

Louis Colbert, vice president of operations for the Philadelphia Corporation for Aging, has helped run a monthly support group for caregivers at Pinn Memorial Baptist Church for 12 years. Two years into it, he learned that his own mother had dementia. He and his three brothers and three sisters, plus some nieces and staff, created an elaborate schedule to care for her.

"My mother was never left alone," Colbert said. She died five years ago, but he still runs the group. Eight of its 30 members are men. Colbert helped pull together male caregivers from three churches to talk with an AARP film crew for the new campaign.

He said many men had not expected to care for their wives. The men had assumed they would die first. They step up when they have to, Colbert said. "All they wanted was the validation that you stuck to your wedding vows." Many see caring for a parent as both an honor and an obligation.

Michael Lewis, who was in Colbert's AARP gathering but doesn't have time to join a monthly support group, said expectations are especially complex for African American men. "People think that we're not there," he said, "or they're kind of shocked when they see me."

Lewis, 66, knows he's lucky that his wife, who is caring for her own mother, is supportive of



Michael Lewis sorting laundry.

his many late nights with his father. "It's crazy. You feel guilty that you should do more, but then, on the other side, it does change your whole lifestyle," he said. "It just sucks you dry sometimes. ... I don't mind the work so much because that's your daddy."

Leonard Keith, 75, cares for his 95-year-old mother, who lives with him in Wynnefield. He knows at least 10 other men at his church who care for their parents. He feels blessed that his mother is still with him. "It's not a hardship for me to take care of

my mother, whom I love very, very dearly," he said.

Jerry Johnson, a Penn Medicine geriatrician, was also part of the AARP gathering that Colbert organized. He was impressed with how open the men were when surrounded by other men.

Colbert was, too. He said that kind of "rawness and honesty" is unusual when men are playing their husband and son roles. Johnson is working on creating some male caregiver support groups that will help men understand caregiver stress, medical aspects of their family member's illness, community resources, and planning for a good quality of life in their last days.

Johnson helped care for his mother-in-law in his home and is now managing his father's care in Memphis. He lauded AARP's report, but said it doesn't tell the whole story. "I have a sense of the challenges and the emotional burden of those challenges that doesn't come across on paper," he said. As a doctor, he's a special case, but he thinks men often know less about health than women and are reluctant to ask.

"Men more often are winging it," he said.

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