

Caregivers and Care

Scott Gunn on Forward Movement

From the Pulpit

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Lessons from Four New Congregations

Caring for Caregivers

By Retta Blaney

In a storefront office, steps from Harlem’s legendary Apollo Theater in one direction and the Clinton Foundation in the other, the Rev. Gregory Johnson chats with Joel Rogers, who holds his year-old niece, Malia, while Malia’s mom seeks advice in an inner room. With



life buzzing along outside on 125th Street, the community’s busiest commercial thoroughfare, Johnson is ministry in motion inside. Few people know Johnson is a minister.

Johnson’s “congregation” is one of the largest in the city, or anywhere else for that matter. Nationwide they number 65.7 million. Years ago they had no name, though they toiled long and hard.

But for the last 13 years Johnson has made it his mission to shine a light on their identity. They are family caregivers, and Johnson wants employers, corporations, and most of all the caregivers themselves to recognize that identity and claim it. As he says repeatedly, they are “the backbone of the health care industry,” and it is his calling to see that their physical, spiritual, and emotional needs are met.

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Share The Care
SEVEN PRINCIPLES
FOR TEAM BUILDING

- 1 Sharing responsibility is key to not burning out.
- 2 Know your limits and stick to them.
- 3 It won't work unless everyone gains something personally.
- 4 There's no one right way to do it.
- 5 Anyone who wants to help should be encouraged.
- 6 Trust the group; support each other.
- 7 Keep your own life in good working order.

Share the Care: How to Organize a Group for Someone Who Is Seriously Ill is one of many resources available to help caregivers. © Sheila Warnock and Cappy Capossela, Simon & Schuster

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"It's been a circuitous road directed by God," said Johnson, 67, sitting behind his iPad in his tiny office in this neighborhood care facility, one of three established by EmblemHealth in multiple New York City neighborhoods. Johnson serves as the creator/director of the company's Care for the Family Caregiver Initiative.

It was an unlikely road for this son of Racine, Wisconsin, who grew up Lutheran and moved to New York to

study at Union Theological Seminary's School of Sacred Music and the Juilliard School. He knew nothing about the health-care industry, much less a major health and wellness corporation like New York-based EmblemHealth. But when a friend who was an executive of the company suggested that Johnson help it establish an outreach to family caregivers, regardless of their insurance coverage, he saw an unexpected pastoral opportunity.

"Talk about the gospel in action," he said. "It's a huge investment and I am so grateful."

With three supporting staff members, Johnson leads workshops and lectures throughout the city, the region, and the world. With his team he has compiled information booklets and an 80-minute DVD — all free regardless of coverage (goo.gl/xxlOke). EmblemHealth's initiative has many auxiliary partners, including the Episcopal Diocese of New York.

"Most people don't know all the wonderful things that are available," Johnson says.

But if he has a chance, he will tell them. His staff, Johnson says with a smile, believes he would show up at a garage-door opening if he could talk about family caregiving. The joke may not be far from the truth. Last year Johnson and his team put together 745 events, serving 213,000 people at civic presentations, health fairs, and in faith communities.

"I would have never defined ministry in this way, yet it's the core of it: serving others."

After beginning his day at 7 a.m. at EmblemHealth's headquarters in the financial district, Johnson heads out for meetings, presentations, community gatherings, seminars, city, state, and national committee meetings, the United Nations, the International Federation on Aging, and many other adjunct partners where he brings the voice of the family care-



Johnson

scottwynn.com photo

"The caregiver is often the silent patient."

—The Rev. Gregory Johnson

giver. Johnson does many one-on-one counseling sessions for employees, members, partner associates, and anyone else with family caregiving issues.

In all of his work he draws upon his Christian faith. He was received into the Episcopal Church in the mid-1980s and is a member of the Church of the Ascension in Greenwich Village, where he supports the music program. He also is a substitute organist at St. Clement's Church in the theatre district. Although he was ordained as an interfaith minister, he identifies as an Anglican, saying it was the prayer book that helped him care for his son who died of cancer in 2005, and for his partner of 41 years who died of cancer in 2011. Johnson also belongs to Marble Collegiate Church and leads its pre-service Sunday Prayer Circle. Johnson and the Rev. Marion A. Gambardella have published *Peace, Be Still: Prayers and Affirmations: Inspiration for Family Caregivers*. Thirty sections, each a page and a half, include a prayer, affirmations, and a Scripture reading, covering such topics as faith, gratitude, anger, acceptance, healing, and renewal. Only a few mention family caregivers specifically, so the book may

help anyone going through a trying time.

Recognizing the needs of family caregivers is more important than ever, Johnson says, because people are living longer. The traditional concept of a family caregiver — a grown child in charge of an elderly parent — is still relevant, except that now the caregiver might be retired as well, caring for a parent who is 90 or older. And the concept may include caring for a spouse, for veterans, and many other configurations, as medicine has increased life spans.

Family caregivers represent donated services valued at more than \$450 billion, Johnson says. They also can represent a loss of between \$17 to \$34 billion to corporations, as caregiving duties conflict with work, which is why Johnson says it makes sense for a company like Em-

blemHealth to invest in potential solutions, resources, and tools.

“The caregiver is often the silent patient,” Johnson says. “I didn’t know a thing about insurance. My background was in theology and theatre, but I was given a blank sheet of paper and told to bring awareness to their needs. It has blessed me. I find great ideas in listening to others. It’s the great gift of sharing our weaknesses. It gives me more appreciation of the doctrine of the communion of saints.”

He makes sure caregivers look after their own needs, and assures them that “it is not something you are going through, but something you are growing through.” That’s what he discovered during his periods as a family caregiver. “I kept finding God in the journey,” he says.

Johnson’s next big effort is “Name

It: Know Its Many Faces,” a free day-long seminar on family caregiving at the New York Academy of Medicine on April 30, sponsored by EmblemHealth and the New York City Partnership for Family Caregiving Corp. Topics will include legal and financial issues as well as self-care. Details and registration are available at corporatecaregivers.com.

While the seminar will consider contemporary challenges, Johnson likes to remember examples from Scripture to motivate him. He mentions Jesus’ final words as he was dying, when he looked to John and told him to behold Mary as his mother.

“That’s caregiving from the cross,” Johnson says. “Can I do less?”

Retta Blaney is the author of Working on the Inside: The Spiritual Life Through the Eyes of Actors.

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