



FAMILY CAREGIVERS: A COMMUNITY IN CRISIS



Atlantic
Health System



Research Led By

The Atlantic Center for Population Health Sciences

Ashley Anglin, Ph.D.

Sharon Johnson-Hakim, Ph.D.

Chris Kirk, Ph.D.

With Research Support From

Department of Psychology,
College of Saint Elizabeth

Michelle McCoy Barrett, Ph.D.

Chloe G. Bland, Ph.D.

Research Intern

Justina Hanna, Rutgers University

In Collaboration With

United Way of Northern New Jersey Caregivers Coalition

Carol DeGraw, M.S.W.,
L.C.S.W., D.R.C.C.

Angela Maceda, M.S.W. L.S.W.



THE CAREGIVER SACRIFICE

An Urgent Call to Action

We had heard the stories. Since establishing our first United Way *Caregivers Coalition* 13 years ago, we had heard countless stories of caregivers suffering from depression, missing their own doctors' appointments, and generally taxing their own health in their dedication to care for an ailing loved one.

We heard the son who talked about suffering from depression caring for two aging parents with dementia. And the sister who became borderline diabetic – eating on the run, juggling work, and caring for a sibling with a disability.

We heard from these caregivers that our support services were often a lifeline, combatting the loneliness and anxiety that comes with entering the isolating and complex world of unpaid caregiving.

What we didn't have:
Hard numbers to quantify the anecdotal evidence.

Leveraging a long-standing relationship with Atlantic Health System, our organizations agreed to each bring our expertise to the table to design a research study that would put numbers to the stories. Just how widespread is depression and compromised physical health among area caregivers and how does it compare to the general population?

Now we can say: Nearly 20% of caregivers show

moderate to severe depression versus less than 7% of the general population. And 20% reported being in poor health compared to less than 11% of their neighbors.

Unlike national caregiver studies, we did not limit the study to a certain caregiving group. Like our *Coalitions*, which annually serve 1,500 caregivers across the lifespan, we surveyed parents of children with disabilities, spouses of those with dementia, and children caring for elderly parents.

The evidence across the lifespan is undeniable: Caregiving takes a physical and mental toll on the unpaid family caregiver. These individuals are the backbone of our health care system and they are at serious risk.

Now, armed with both the data and the stories we can better address what is shaping up to be a public health crisis. That is why we launched an education campaign that spans from hospitals and doctors' offices to corporate headquarters and faith congregations. We are also advocating for public and corporate policies that recognize the contribution of family caregivers and supports them through tax credits, family and sick leave, respite, and other support services. Together, we can make a difference and improve the lives of our family caregivers. So, let's get to it!

A handwritten signature in black ink, appearing to read 'Carol DeGraw'.

Carol DeGraw,
M.S.W., L.C.S.W., D.R.C.C.
*United Way of Northern New Jersey
Caregivers Coalition*



INTRODUCTION

A Growing Public Health Crisis

Lee treasured the one hour each morning with her newspaper and coffee before starting a full day's work of caring for her husband of 54 years. A trained nurse and therapist who worked full time in the health care arena her entire adult life, even she felt unprepared when her husband Bud was diagnosed with Alzheimer's disease.

She had to retire from her job early, they downsized to a more manageable home, and everything about their lives changed. She felt guilty for longing to go food shopping without him, so as not to worry about losing him in an aisle. She worried about their finances and burdening their children. She missed her friends and the man she married, and some days were filled with nonstop tears. And, she had a medical issue of her own – a bone spur in her neck that caused pain daily.

And, yet, Lee was resilient and found happiness with Bud. She felt a sense of purpose. "Don't forget how good it is to be in the present moment," Lee advised new caregivers. "I can't imagine not having him with me."

As an unpaid family caregiver, Lee juggles this range of emotions daily and she is far from alone. This new study by the Atlantic Center for Population Health Sciences and United Way of Northern New Jersey *Caregivers Coalition* finds that for family caregivers of all types, their own physical and mental health suffers during caregiving.

Sheer numbers make caregiver health a pressing public health issue. In 2015, the National Alliance for Caregiving reported that almost 1 in 5 American adults – more than 43.5 million people – identified themselves as family caregivers for someone who is disabled, elderly, or chronically ill. In 2013 alone, AARP found that these people provided unpaid caregiving hours valued at an estimated \$470 billion. ⁽¹⁾

Caregiving is a unique challenge – a combination of physical and emotional labor, requiring attention, energy, flexibility, and both physical and emotional resiliency. Because caregivers spend so much time focused on and responsible for the health of another person, they often experience declines in their own physical and mental health.

As the U.S. population ages, the number of caregivers will only increase. In this demographic landscape, figuring out how to help caregivers stay healthy – despite the negative health impacts of taking on caregiving responsibilities – is key to the health of our population overall.

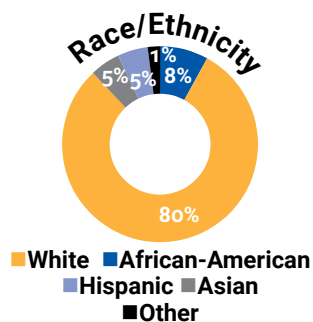
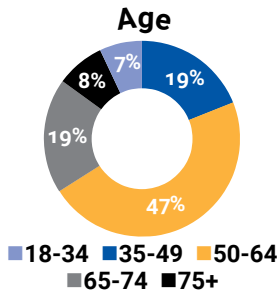
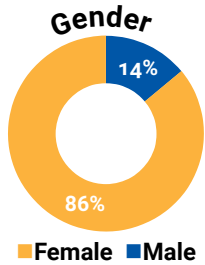
Source: (1) AARP Public Policy Institute

Don't forget how good it is to be in the present moment.

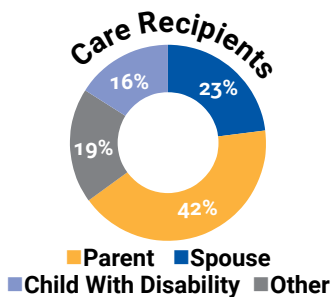
– Lee, caregiver to her husband Bud

Our Study's Respondents

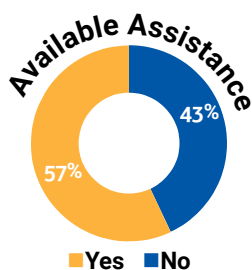
Demographics of Caregivers



Caregiving Relationships



Caregiving Assistance



INFORMATION IS POWER

What's Different About This Study

The lack of information about caregivers as a demographic group puts the population at significant risk. That is why United Way and Atlantic Health joined forces in 2014 to better understand caregivers. Together, they sought to better address their needs and vulnerabilities. Both groups knew that the physical and mental health of caregivers were at risk – but they also knew that something crucial was missing from most national studies of caregivers.

Existing research on caregiver health has already shown that people caring for family members with dementia have a higher risk of physical and mental health problems. The same is true for older caregivers and those logging higher numbers of caregiving hours. (2) Yet the existing research has generally focused on one of two types of family caregivers: family members caring for elderly relatives or those caring for adults with Alzheimer's disease or other specific conditions such as stroke.

This study instead looked at caregiving across the lifespan – by and for people of different ages and in different relationships to one another. Examples included people caring for vulnerable seniors or those with dementia, but also those caring for a child with autism or cerebral palsy, a spouse with kidney failure, an aunt or grandfather with cancer, or a sibling with mental illness. This study asked what additional factors might place caregivers at risk of poorer health. **These are the findings...**

Caregivers: At Risk Across the Lifespan

This caregiver health study sought out self-identified “caregivers” – people providing unpaid assistance to someone who has physical, developmental, or psychiatric disabilities, chronic illness, or issues of aging. This group of 970 people from northern New Jersey completed a survey about their lives, their caregiving responsibilities, and their health.

Source: (2) AARP Public Policy Institute and National Alliance for Caregiving

Broad Findings

Caregivers make up a distinct population – ultimately more alike than different and facing challenges that most non-caregivers never experience. The major findings of this study offer direction for improving caregiver health:

- Unfortunately, one of the most important things that caregivers share is **greater risk to their own health** as a result of their caregiving responsibilities. A range of supports, both at home and in health care systems, could help change that.
- Early intervention is the key to caregiver health.** Initially, a person experiences a dip in their self-reported “life satisfaction” after assuming the role of caregiver for a loved one. Interestingly, our study revealed that caregivers “settle-in” and find a satisfying sense of purpose after the first 12 months and don’t feel a decline in their life satisfaction again until they’ve been in the role for a decade or more. This suggests that the best time to intervene to support caregivers is when they first take on the role.
- Within the caregiver population, diagnoses, life circumstances, culture, heritage, and reaction to the caregiving role differ from family to family, often along a spectrum.** These responses can also affect health. Improving caregiver health also means being able to personalize assistance options depending on a caregiver’s individual situation.

Voices of Caregiving: A Spectrum of Experiences

In addition to the 970 completed surveys, the study included in-person interviews with a subset of 50 survey participants. These interviews showed that despite all that caregivers have in common, they also have a spectrum of very different responses to some parts of the caregiving experience. The themes that emerged from the interviews reflect the breadth and intensity of emotions and experiences that caregivers navigate every day. They show that there is no one “typical” caregiver or caregiving experience. The idea of a spectrum of caregiver experiences and emotions, rather than a single state, is one of the most important findings of the study. This continuum of reaction and response to caregiving is presented with each of the key findings. The following are some important parameters about these responses:

The two options at either end of each spectrum are not mutually exclusive. One of the signature characteristics of caregiving is its emotional complexity; caregivers often feel guilt and compassion, or devotion and anger, at the same time and in similar proportions.

How caregivers feel on each spectrum is never permanent.

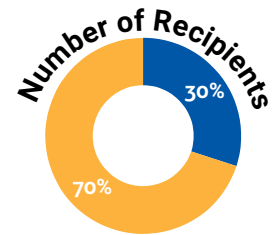
Several caregivers describe their lives as a “roller coaster,” emphasizing the ever-changing circumstances that accompany caring for a person whose needs vary over time.

How caregivers feel on each spectrum may influence their health and ability to cope. It may also influence how caregivers seek support (e.g., “If I don’t identify as a caregiver, I’m less likely to gravitate towards programs targeted at caregivers”).

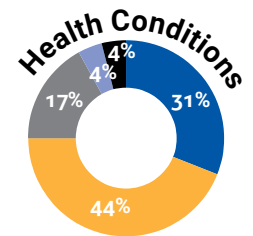


Our Study’s Respondents

Care Recipients



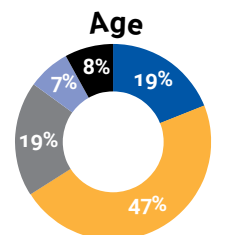
■ One ■ More Than one



■ Other ■ Physical Disability
■ Developmental Disability
■ Dementia ■ Mental Illness

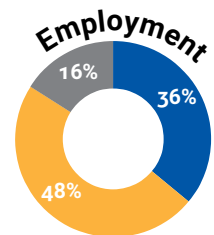


■ Different Household
■ Same Household

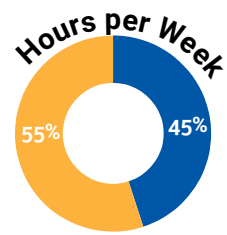


■ 18-34 ■ 35-49 ■ 50-64
■ 65-74 ■ 75+

Caregiving While Working



■ Full-time ■ None ■ Part-time



■ Less Than 15 ■ More Than 16

KEY FINDINGS #1

Caregivers Neglect Their Physical Health

The results of the study showed that **caregivers' physical health is at risk**. Responses to the survey showed widespread problems with access to health care, as well as a lack of support that affected caregiver health.

Key Insights

- **Caregivers' physical health suffers:** More than 20% of caregivers who completed the survey reported "poor" or "fair" health, compared to just under 11% of New Jersey residents during the same period. (3)
- **The toll of caregiving is clear:** Caregivers reported significantly worse physical health than before they took on a caregiving role. On a scale from 1 (poor) to 5 (excellent), caregivers on average reported a decrease of 0.5 (or 10%) worse health after becoming a caregiver: 22% reported "poor" or "fair" health as caregivers, compared to 6.2% before taking on a caregiving role.
- **Specific risk factors influence the physical health of caregivers:** Those who had been caregivers for longer periods (more than 10 years), who spent more time each week on caregiving-related activities (more than 40 hours a week), who were not employed, and/or who did not live with a partner or spouse were more likely than the general population to report poor health. This was true despite the age of the caregiver.
- **Access to care:** Getting to medical appointments was a persistent problem. As a group, caregivers seemed to be "in tune" with health care delivery systems, often as a result of their caregiving responsibilities. An overwhelming majority had health insurance (90.5%), prescription drug coverage (88%), and a primary care physician (88%). However, almost half (46.5%) reported having to cancel or postpone their own medical appointments due to caregiving responsibilities. While the survey included rural areas, cancelling or postponing medical appointments appeared to be related more to caregiving responsibilities than to travel time to doctors' offices.



Source: (3) New Jersey State Department of Health

Voices of Caregiving: A Spectrum of Experiences

"I am now concerned that it's taking a toll on my body...the stress can make you ill."

"[Caregiving] has been very challenging because I recently had to have knee surgery for myself. I really should have had it sooner, and I put it off because I need to take care of my mom."

"I have lost 20 pounds in the past month. I was yelled at by my doctor. He told me I have to eat. I told him I could not promise anything."





A New Caregiver's Journey: From Carefree to Prediabetic

It happened in an instant. The life Tanya knew of hanging out with friends after work and going to the movies came to an abrupt halt when her mother had a stroke and became paralyzed on her right side. That's when Tanya became a caregiver – both to her mother and an adult sister who has Down syndrome.

Her 71-year-old mother had been the primary caregiver for her sister. As her mother moved into a nursing home, Tanya took in her sister. The first four months of this new life, Tanya went to work daily, picked up her sister, and the two would visit their mother until 8 p.m.

In addition to visiting her mother, Tanya took over caregiving for her sister, who also has a health condition that needs daily monitoring. Her sister works part time, allowing Tanya to continue working, but Tanya prepares her meals and arranges all her appointments.

"So, now, I have no personal life," Tanya said. "I don't date, I don't go out with my girlfriends ... Even through all this, I don't feel like this is a burden at all."

A Warning Flag

The wake-up call came when Tanya got sick and couldn't visit her mother for three days. Tanya went to the doctor and had a comprehensive physical and bloodwork analysis. It was determined that she was insulin-resistant. She had not been eating right, eating on the go, grabbing chips, and making other unhealthy choices. She was prescribed medication as she had become borderline diabetic.

"I feel bad because you can't do everything, you'll kill yourself," Tanya said through tears. "The thing about being a caregiver is that you don't know how long you're going to be a caregiver."

I'm very religious and I think that's what's carrying me. I believe in God strongly and he gives me a lot of strength when I'm weak.

– Tanya, caregiver to her sister and mother

KEY FINDINGS #2

Caregivers' Mental Health at Stake

The second major finding of the study revealed that **caregivers' mental health** is impacted by their caregiving experience; many caregivers experience depression and loneliness as they advance through their caregiving journey.



Key Insights

Depression was the most prevalent mental health issue for caregivers:

- One in five caregivers (19.5%) showed moderate to severe depression, compared to just under 7% of the general U.S. population. (4, 5)
- Caregivers reported more than double the rate of severe depression reported in the general population (8% vs. 3%). (6)
- While 76% of Americans in the general population have no clinical indicators of depression, only 37% of caregivers in our study had no indicators. (7)
- Caregivers with symptoms of depression tended to have worse physical health status.
- Working caregivers showed fewer depressive symptoms than their retired or unemployed counterparts.

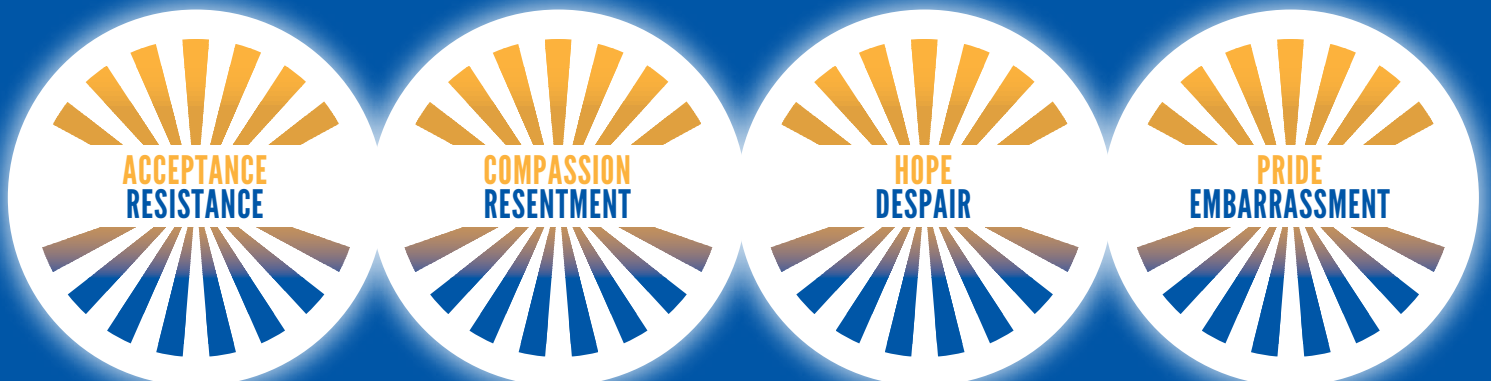
Loneliness and lack of control also figured prominently:

- Nearly one-third of respondents (31%) reported that they were “almost never” or “never” able to control important things in their lives during the last month.
- One-third reported feelings of loneliness during the preceding three weeks. Another source of distress, reported by more than 33% of caregivers, was that their care recipient(s) had changed significantly from their former self/selves, which could tie into and amplify feelings of loneliness.
- In addition, caregivers who had more than one care recipient (23% of respondents) or spent more hours each week on caregiving were more likely to report poor mental health.

Sources: (4) National Institute of Mental Health; (5) Centers for Disease Control and Prevention; (6) National Center for Health Statistics; (7) Tomitaka, Kawasaki, Ide, Akutagawa, Yamada, Ono, & Furukawa, 2018.

Voices of Caregiving: A Spectrum of Experiences

“You struggle with what you deserve. You say, ‘I did not sign up for this.’ At the same time, you realize that you cannot blame him. And after dealing with my parents... With your husband you have love, compassion, and a lot is being asked of you, but the sacrifice is different.”



Stress, Guilt, and Depression – the Tolls of Caregiving

Sherry's caregiving journey began as a child and has continued into adulthood. Growing up, her mother struggled with both mental and physical illnesses, turning Sherry into a caregiver before she was even a teenager.

As a married woman working full time as an accountant, Sherry remains dedicated to her mother. While her mother lives in a nursing home, Sherry speaks with her daily, manages her finances, makes doctor's appointments, picks up her clothes, and does her laundry. Plus, she visits her mother once a week.

But it was a battle to move her mother into the nursing home; her mother didn't want to leave her own home. Sherry began to see a therapist, feeling conflicted and unsure of whether she was making the right decisions. She struggled with guilt and concern about whether her mother would be in good hands. In addition to attending therapy, she was prescribed anti-depressants to help manage her emotional distress.



Struggling to Balance Emotions

"At one point I had terrible illness, where I would vomit or I couldn't eat because I was so upset. Or I couldn't sleep. It was terrible," Sherry said. "Now, I've learned not to sweat the small stuff."

The doubts never fully disappear however. Sherry wrestled with the idea of moving her mother into her home and quitting her job. She tried moving her in briefly, but found it was too difficult and not feasible long term.

Sherry struggles to balance finding time for her own life with her husband and spending time with her mother. While there are other family members who do visit her mother occasionally, Sherry is the primary caregiver.

"Even when I say I'm not stressed by it, of course I still think about it," Sherry said. "Clearly, I did not have to do this. I would probably be much healthier. I go up and down."

Sherry finds strength in her husband, close friends, pets, exercise, and charity work.

"I have to remember to always keep exercising, always eating right," Sherry said. "I love animals and nature. Exercise, running, scuba diving. I do charity work. It all allows me to break through from the caregiving role."

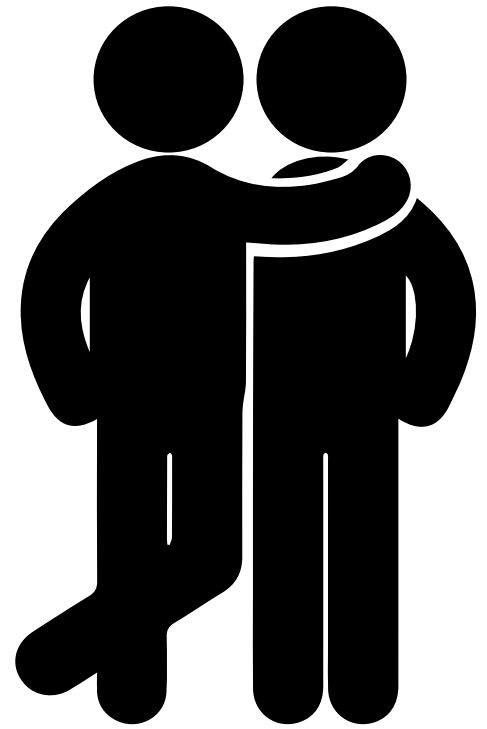
It has made me who I am. I probably would not be who I am, meaning that I have traveled the world for business, taken up scuba diving. I probably would not have had the desire and drive to live, live, live.

– Sherry, caregiver to her mother

KEY FINDINGS #3

Caregivers' Resilience Tied to Supports

The third major finding of the study revealed that support has an important influence on caregivers' mental and physical health. Having support was linked to greater general health, fewer symptoms of depression, and less perceived stress. **Yet nearly two-thirds of caregivers (65%) reported having less than adequate support most of the time.**



Key Insights

- **Social support less common than household support:** The majority of respondents were more likely to have household support (such as someone to help with chores) than social support (someone to listen to them or to give affection).
- **Help with caregiving tasks less beneficial:** Interestingly, while household and social support boosted caregiver health, having direct help with caregiving tasks such as home health aides, adult day centers, or help from relatives or friends did not improve overall physical health, life satisfaction, or mental health.
- **Less support, more isolation:** Isolation was a byproduct of lack of support: More than one-third of caregivers (36%) reported that they had felt they couldn't leave their care recipient(s) alone at some point in the preceding two weeks.

Yet caregivers were unexpectedly resilient:

- Over 60 percent of caregivers reported feeling useful and needed.
- One in five caregivers (19%) reported being dissatisfied with their life at the time of the survey.
- Caregivers had higher-than-average levels of resiliency, given their scores on a test that specifically measures the "bounce back" and "adaptability" components of resiliency. On average, caregivers in this study scored one point higher (on a scale of 1 to 5) than the general U.S. population, with higher scores demonstrating better perceived resiliency. ⁽⁸⁾

Source: ⁽⁸⁾ Vaishnavi, Connor, & Davidson, 2007

Voices of Caregiving: A Spectrum of Experiences

"Another thing is that I have nobody to talk to about this. I don't touch another human being for a couple of days. We sleep apart. I can't sleep with her, she'll kick and then I won't be able to sleep. It has a devastating impact when you're not seeing people each day."



Finding Blessings in the Maze of Support Services

Lorraine always has a Plan B. Spontaneity is a luxury her family can't afford. After more than 30 years of caregiving for her daughter Aaliya, who sustained brain damage from a complex seizure disorder, Lorraine is trained to plan for emergencies.

Lorraine gained this education through trial and error and by listening to parents of children with disabilities. Early on, Lorraine got connected to what she called the disability community, where she received advice that she never forgot and tapped into regularly. For example, she was cautioned to pay equal attention to all her children, not just Aaliya because of her disabilities. Lorraine and her husband worked hard to make individual time for their two other children as well.

Lorraine was bolstered by the community through support groups and agencies that encouraged her not to back down when she knew what was best for her daughter. That led to Aaliya being placed in her neighborhood schools with peers her age, instead of being separated with children with disabilities.

"She was included and she was able to learn more from her peers than from us," Lorraine said. "This was all thanks to the groups that I was a part of."



I recently discovered mindfulness and we get to do it Fridays in my job and I used to be like: I don't have time for this. And now, I think it's great to have a half hour where I just got to be centered in the moment.

— Lorraine, caregiver for her disabled daughter

Room for Improvement

Where the support groups were a lifeline, her family was frustrated by the governmental systems in place that could be inflexible or unreliable, she said. There are few resources in terms of financial assistance as well as a lack of quality aides, she said.

"There are so many changes that happen with state systems, for example, with a new governor," Lorraine said. "So, sometimes, things that were provided are now gone or reconfigured. We're always looking for some kind of sustainability and permanence in care. I have to do a lot of the research myself because the information just isn't out there."

Lorraine said there is a lot of room for improvement in many areas, but most importantly, caregivers need opportunities to focus on protecting their health and wellness. Just hearing that you're not alone on the journey is critical, she said.

"There are some people who are so isolated when they're caregiving and that could have very easily been me if I didn't reach out to become a part of all these groups," Lorraine said.

SHINING A LIGHT ON CAREGIVERS

Take Action to Improve Caregivers' Health

Because caregivers are a somewhat “invisible” population (e.g., not all caregivers even see themselves as “caregivers”), finding them, and raising awareness of the health burdens related to unpaid caregiving, are the first steps toward improving their health. After that, the following represents specific recommendations that can help keep caregivers healthier:

Businesses



- **Acknowledge caregiver resiliency.** Because caregivers scored higher than average on the survey's measures of resiliency, any proposed intervention to improve caregiver health should acknowledge and try to leverage that strength. This is particularly true for caregivers who are also employees; companies should be encouraged to view their caregiving workers not as liabilities, but as highly resilient assets to the workplace. Appropriate supports such as flexibility in work scheduling can go a long way for these employees.

Nonprofits

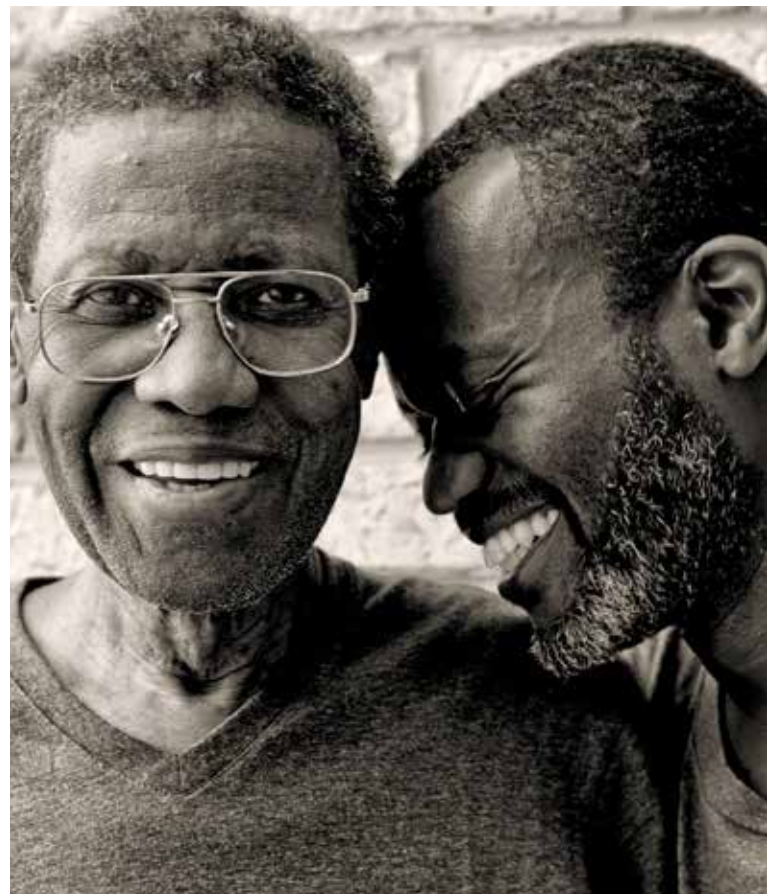


- **Increase access to functional and social support.** An array of more robust and affordable services could mitigate the negative effects of caregiving on both physical and mental health. This can include assistance with housework or meal preparation; help with specific caregiving duties such as toileting and bathing; access to safe, high-quality care programs outside the home; respite options to allow caregivers to tend to their own needs; or simply someone with whom to share experiences, frustrations, fears, and joys.

Health Care



- **Make health care delivery caregiver-friendly.** The time demands of caregiving often prevent caregivers from getting the medical care they need. Modifying service delivery (especially of mental health services) would help meet caregivers' unique needs; for example, locate caregiver health resources in the same offices or clinics where care recipients have their medical appointments.
- **Acknowledge the mental and physical strain of caregiving.** Primary care physicians can recognize caregiving as a health risk and screen for it regularly, asking patients whether they are providing care to another person. In caregiving situations, physicians can look for early signs of depression or other types of distress.



Community



- **Increase social support.** Because caregiving is often isolating, adding social support can be crucial to caregiver mental and physical health. Social support can include caregiver support groups or events designed to bring specific types of caregivers together (e.g., caregivers for spouses with dementia).

Government



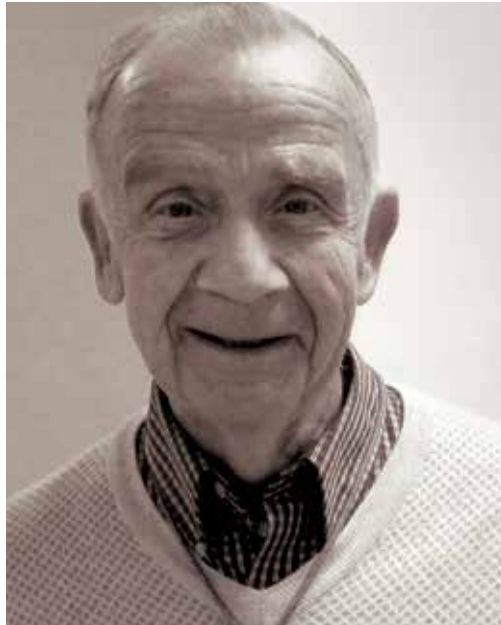
- **Institute caregiver-friendly policies.** New policies need to be considered to support the growing number of caregivers nationwide. Legislation such as the Caregiver Corps Demonstration Act could recruit and train volunteers to work with seniors and people with disabilities who need extra help in order to live independently. In exchange, volunteers could gain credits for health insurance and other benefits, such as tuition assistance. The Social Security Caregiver Credit Act (S1255) would adjust total career earnings and future benefits for caregivers who spend a minimum of 80 hours a month providing care to a loved one.
- **Broaden research.** While the results of this study show that caregivers are a distinct population, sharing common challenges and health risks, they also have a wide range of responses to their roles. More consistent research of caregivers could track this population's health outcomes, reveal critical new insights, and guide the development of appropriate interventions.



We are acutely aware of the issues facing caregivers, both inside and outside our company's walls. As an expert resource, the United Way helped us raise awareness and provide workplace supports for our employees who are caregivers.

— John Spinnato, Vice President, Corporate Social Responsibility, Sanofi North America

FACES OF CAREGIVERS





A JOURNEY OF LOVE

GUILT ACCEPTANCE
EMBARRASSMENT

DEPRESSION LOVE

CAREGIVERS

OVERWHELMED HOPE

DEVOTED EMOTIONAL

COMPASSION STRESS

PRIDE RESENTMENT