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## THE CAREGIVER CRISIS IN NEW JERSEY

# ‘Consuming and isolating’



Frank Joseph of Belvidere is a caregiver for his wife, Margie, who was diagnosed with early onset dementia at the age of 53. Joseph left his job — one that he loved — and retired earlier than planned to provide full-time care for his wife. COURTESY OF FRANK JOSEPH

## How caregiver issues could impact public health

**Cheryl Makin**  
Central Jersey Courier News  
USA TODAY NETWORK - NEW JERSEY

*Editor’s note: This is the first part in a three-day series focusing on the caregiver crisis in New Jersey.*

With an undergraduate degree in gerontology, a master’s in aging services and a career advocating for the elderly, Linda Schulman thought she would have been well prepared for being a caregiver — again.

Having nursed her husband for five years through his battle with Myelodysplastic syndrome and then raised three children as a young widow, Schulman said she still faces stresses as caregiver to her 83-year-old mom who lives an hour away. She shares this duty with her sister, but that doesn’t make the constant feeling that “the other shoe is about to drop” go away.

“It’s hard,” said Schulman, director of Community Relations at Daughters of Israel in West

Orange, a nursing home and short term rehabilitation center. “It’s like having a second full-time job. It’s very time-consuming. My mother is fairly independent — she can walk, she drives locally to get groceries and to the senior center a couple of days a week. But, my sister and I make sure she has one of us on the weekends. And my sister takes her to her doctors’ appointments. Basically, we pick up all the loose ends because if we didn’t do that, I’m not sure she would be able to live as independent as she is living.”

Schulman is one of 1.7 million in the state who live the life of an unreimbursed caregiver.

“It is my day and night,” said Schulman, who lives in East Hanover. “I lived it. I breathed it.

See CAREGIVER, Page 4A

### More inside

Some caregivers don’t self-identify. Page 6A

### You may be a caregiver if you ...

- Help with daily duties, such as shopping, cooking, cleaning, physical therapy
- Perform medical interventions—injections, feeding tubes, wound treatment, breathing treatments
- Arrange medical appointments, drive to the doctor, sit in during appointments, monitor medications
- Handle crises and arrange for assistance—especially for someone who cannot be left alone
- Handle finances and other legal matters
- Act as a companion

SOURCE: FAMILY CAREGIVER ALLIANCE

## Over 100 police departments in NJ have no random drug testing

**Andrew Ford** Asbury Park Press  
USA TODAY NETWORK - NEW JERSEY

At least eight New Jersey police officers last year failed random drug tests, a reform put in place after the Asbury Park Press found more than 100 departments across the state had no random testing policy.

The tests uncovered law enforcement officers using drugs like marijuana, cocaine and the powerful prescription opioid painkiller oxycodone.

At least one officer detected using drugs would not have been discovered if the reforms had not been put in place following the “Protecting the Shield” series published by the Press and the USA TODAY Network New Jersey in January 2018.

The mandatory drug testing policy for all law enforcement officers was enacted in March by New Jersey Attorney General Gurbir Grewal following a public recommendation by the Network series.

In “The Shield” stories, the Network exposed the lives ruined and tens of millions of taxpayer dollars spent as a result of secretive practices and fragmented police oversight in New Jersey. The series also prompted a statewide early warning system that triggers a re-

view of troubled cops by county prosecutors’ offices.

The eight municipal cops who failed tests came from six towns. Two officers tested positive in Weehawken and North Bergen, the records showed. Officers also tested positive in Franklin Borough, Ridgewood, Piscataway and Woodland Park.

The drug tests also exposed at least three county corrections officers using illegal substances, according to reports filed with the counties under the new testing policy. The officers who tested positive are a fraction of the more than 2,800 tests performed and roughly 34,000 officers in the state.

The Network obtained records for 20 of 21 counties — the Essex county prosecutor’s office provided none. About 3,300 cops work in Essex County, according to pension data.

Officers who test positive for illegal substances or legal drugs without a prescription are supposed to be fired and logged in a state database of cops who failed drug tests, according to a longstanding attorney general policy. But the records on tests last year, obtained by the Network, don’t always show what happened to an

See TESTS, Page 11A

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After three back surgeries, Mary experienced chronic pain as well as neuropathy in both feet. The 73-year-old had trouble finding a bathing solution to accommodate her mobility challenges. She lives alone in her Texas home, and was not ready to move.



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# Caregiver

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And then it became my life.”

## ‘It becomes totally consuming and isolating

Every day, compassionate Americans devote time, energy, and resources to ensure that family members who are disabled, elderly, chronically ill, or injured can remain in the stability and comfort of familiar surroundings. These Americans are caregivers — a growing group who often sacrifice much in their own lives for their loved ones.

“For those who do it, they obviously do it because they want to help out. It’s a labor of love,” said Serena Collado, director of Community Health at Robert Wood Johnson University Hospital Somerset. “It makes them feel good to be able to help another person. You definitely need to applaud the caregiver because there is nothing more honorable than putting someone else’s need in front of your own.”

Frank Joseph of Belvidere is a caregiver for his wife Margie, who was diagnosed with Early Onset Dementia at the age of 53. Joseph left his job — one that he loved — and retired earlier than planned to provide full-time care for his wife.

“There is no way to understand the depth of caregiving unless you are in it. And then it becomes totally consuming and isolating,” said Joseph in a United Way impact statement.

Forty one years ago, when Joseph took his marriage vows, he had no idea the words “in sickness and in health” would truly test him. He takes care of her every need — from bathing, dressing and keeping her “as beautiful to others as she remains to me,” Joseph said.

“She needs my help for everything,” he said. “Being a caregiver is 24-7, which is overwhelming. I get a ton of support from my amazing family, but even if you are not providing physical care every moment, you are monitoring medications, managing paperwork, scheduling appointments, and always thinking about what that person needs.”

Joseph has been Margie’s caretaker for a decade. He said there is “a certain loneliness in caregiving for the woman you’ve loved for so long.”

“Having been doing this for 10 years now, I think I finally understand the journey,” Joseph said. “It has not always been easy, in fact, it never was, but I finally saw it for exactly what it always was, an amazing opportunity to grow, express love and become the human being I ultimately wanted to become.”

## A growing public health crisis

Chances are you will become a caregiver for someone in your circle — even if you can’t possibly see that fact in your future.

According to a 2015 study by the The National Alliance for Caregiving and AARP, it is estimated that one in five people — 43.5 million adults in the U.S. — have provided unpaid care to an adult or a child in the past 12 months. Just five years ago, in New Jersey, there were more than 1.1 million family caregivers in New Jersey who provided an estimated \$13 billion in unpaid care per year who are helping to keep their loved ones at home where they want to be, said Crystal McDonald, assistant director - Advocacy at AARP New Jersey.

That is more than double what the state spends on Medicaid nursing home care.

“That’s really important because not only do they help people to live at home where they want to be, but it also helps out state budget,” McDonald said. “If people could not stay at home and we didn’t have family caregivers, it would impact things like our Medicaid budget and the state would be having to find proper care in things like nursing facilities or other home community-based services that family caregivers had been providing.”

Currently, there are an estimated 1.75 million people in the state providing varying degrees of uncompensated care to persons who are elderly or disabled and limited in their daily activities, said Jacqueline Moskowitz, senior vice president of Resource Development at Family Resource Network.

“That number has grown so much,” Moskowitz said. “People are living longer. The autism rate in New Jersey is out of control. It’s either the highest or second highest in the country. Also, I certainly think that modern medicine is keeping people healthy and alive much longer. I think that there was a lot of caregiving going on that was not self-identified when people lived closer to their families — it was just being a daughter or just being a neighbor. Now that people are living further apart or working multiple jobs, they really feel the pressure of that more. I do think that more are self-identifying now.”

Already considered a growing public health crisis, those numbers are expected to increase in the coming years as the U.S. population ages. According to the U.S. Census, by 2050, the number of people 65 plus is expected to double.



Being a caregiver to her mother Ann took a physical and emotional toll on Sherry Maklary. She said finding a balance is extremely difficult but key in being a caregiver for another. COURTESY OF SHERRY MAKLARY



Crystal McDonald, associate state director – Advocacy AARP New Jersey, said that there is going to be a huge increase in the number of people who are aging and a corresponding need for caregivers. COURTESY OF AARP NEW JERSEY

“So we are going to see a huge increase in the number of people who are aging,” McDonald said. “The number of people who will be needing caregiving services will increase and research is also showing that the number of available caregivers will be on the decline. So people in their primary caregiving years are between the ages of 45 and 64 and the people who are most likely going to need caregiving services, long term care and support services are people over 80.”

The ratio — in 2010 — of caregivers to those that needed caregiving was 7:1. By 2030, this ratio is expected to decline sharply to 4:1. By 2050, when the Baby Boomers will be at the highest risk in needing caregiving support it is going to go down to 3:1, said McDonald.

“The dramatic decline requires us to take strong action now so we can support family caregivers and make it as easy as possible for them to be able to do their good work that they want to do,” McDonald said.

“If you think about and look at demographics, its not surprising that we are seeing an increase in need for caregiving,” Collado said. “You look at the Baby Boomers and see that continue to rise. We knew that. With the birth of the Baby Boomer generation, we have an influx of population just from there. And as that population ages, there is a need to care for those individuals.”

## The physical and financial toll of being a caregiver

Yet, there can be a high cost — emotionally, financially and physically — to putting another’s needs first.

According to a newly released United Way study of 970 caregivers titled Caregivers: A Community in Crisis led by the Atlantic Center for Population Health Sciences, with research support from the College of Saint Elizabeth’s Department of Psychology and in collaboration with the United Way of Northern New Jersey Caregivers Coalition, caregivers are a community in crisis, often suffering from and neglecting their own mental and physical health ailments, as they put themselves last in their desire to care for another. Caregivers may feel stress, grief and other difficult emotions while providing care.

The study was precipitated because of the many stories staff heard from caregivers themselves, said Carol DeGraw, director of Health Impact Area, United Way of Northern New Jersey. DeGraw herself is a former caregiver for her mother.

“Seeing so many of the caregivers engaged with our Caregivers Coalition having health issues themselves or talking about having to cancel doctor appointments or delay surgery because they couldn’t get someone to stay with their loved one,” DeGraw said. “The study came out of seeing the impact of caregiving on so many of the caregivers. We started saying we need to know more about this and we really wanted to have more solid data around that. Our mission is to really ensure that caregivers take care of their own physical, emotional and financial health for that matter.”

## Who is considered a caregiver?

By definition, a caregiver is an unpaid individual, such as a spouse, partner, family member, friend or neighbor, who is involved in assisting another, either a child or an adult, with activities of daily



A former caregiver for her mother, Carol DeGraw is director of Health Impact Area, United Way of Northern New Jersey. DeGraw said caregivers are a community in crisis, often suffering from and neglecting their own mental and physical health ailments, as they put themselves last in their desire to care for another. COURTESY OF UNITED WAY OF NORTHERN NEW JERSEY

living and/or medical tasks. You are not technically considered a caregiver if you are a parent of a healthy, typically developing child.

Caregivers are often the immediate family members of the individual being cared for, but may also be friends or community members.

This could be someone of any age who is caring for a family member, friend, neighbor or coworker who is aging, with disability, has mental health issues, chronic illness and substance abuse issues. If you are making doctor’s appointments, managing finances and /or medications, helping with daily living from cooking, bathing, dressing and getting out of bed, then you are a caregiver.

While there also are formal caregivers who are paid care providers (and often underpaid), the looming public health crisis stresses it is the unpaid caregivers that are most at risk.

Caregivers are a diverse group, spanning generations, race and cultural background. In the 2018 United Way study, the respondents completed an anonymous survey about their lives, caregiving responsibilities and health. Resulting demographics found that most (86 percent) are female between the ages of 50 to 64 (47 percent) and white (80 percent). Caregiving relationships were mainly for a parent (42 percent) with a caregiving for a spouse (23 percent), for other (19 percent) and for a child with disability (16 percent) close behind. Most also had some other form of caregiver assistance (57 percent).

These findings held consistent with the previous NAC/AARP study of 2015. “Most people will become family caregivers, will need one or are one, but the average caregiver is a woman in her 40s who is doing 20 hours of family caregiving in addition to a part- or full-time job,” McDonald said. “They face a lot of hurdles that come with caregiving. Their caregiving can span from things like helping mom with the groceries or paying bills to help, with bathing and preparing meals all the way to things like medical and nursing tasks. Family caregivers are more and more doing things like wound care, injections and medication management and all these things without any training. It’s getting more difficult. They are often juggling their caregiving along with full-time jobs and other family responsibilities like raising their own children.”

Within the United Way study, the majority of the respondents (70 percent) are caring for only one other person aged 50 to 64 (47 percent) living in the same home (51 percent). The health conditions they are caring for range with most (44 percent) coming under an other category and the remainder a physical disability (31 percent), dementia (17 percent), developmental disability (4 percent) and mental illness (4 percent).

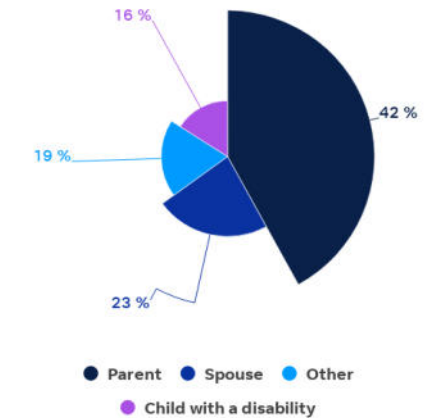
Most of the caregivers also work a full-time job (48 percent) with others either not working (36 percent) or holding down a part-time job (16 percent). The amount of caregiving hours were found to range from less than 15 (55 percent) or more than 16 hours (45 percent).

## The impact of caregivers

Caregivers need to be considered the backbone of the long term care and sup-

## A breakdown of caregiving relationships

A 2018 United Way study indicates that a majority of caregiving relationships were for a parent.



Source: United Way



Lucille H. Deutsch, certified geriatric care manager and owner of LHD Eldercare Solutions, previously cared for her mother for 15 years. That led to to want to be part of a solution and led her to it as a profession. COURTESY OF LUCILLE DEUTSCH

port system of health care as it could never absorb all that caregivers do, DeGraw said. Unpaid caregivers shoulder 80 percent of long-term health care, contributing an estimated \$470 billion nationally, said the AARP Public Policy Institute in 2013.

“We want to get the word out that this is the impact that caregiving can have on people. Caregivers are the backbone of our country’s long term care system,” DeGraw said. “What they do is valued at over \$470 billion which I believe is more than the national Medicare/Medicaid budget. And if we didn’t support the caregivers and keep them in their role, certainly as a country we couldn’t afford to do that and vulnerable people would not be able to get the care that they need.”

More than one million family caregivers in New Jersey provide an estimated \$13 billion in unpaid care per year.

“That’s more than double what the state spends on Medicaid nursing home care,” McDonald said. “It’s a critical piece of our long term care services and it is critical to keep supporting them so they can keep doing that work.”

For Lucille Deutsch, a personal experience in caregiving led her to it as a profession. The owner of LHD Elder Care Solutions, a geriatric care agency, Deutsch previously cared for her mother for 15 years. That led to to want to be part of a solution.

“I saw how difficult it is for people who are very often thrown into a caregiving role without any preparation or any experience because there has been some kind of crisis in the family,” Deutsch said. “If you have never done this before you don’t know where to go, who to talk to, what questions to ask, what’s important, what’s not, how to evaluate good services, how to access services in the community — you don’t know where to start.”

As her mother’s primary caregiver, Deutsch had to “learn as she went.”

“That was the only way,” she said. “When I went through that with my own mother — she actually broke her neck at the time — all of a sudden I was thrust into this emergency situation. It was so hard for me to navigate the system. I took a couple of years but I decided to change careers and get involved in the system and hopefully make it better for caregivers to negotiate the options out there, all the services, all the resources and maybe help — at least point them in the right direction.”

## ‘It’s been tough for as long as I can remember’

The United Way study results, which tallied 970 caregivers across the lifespan, revealed undeniable evidence that caregiving takes a physical and mental toll on the unpaid caregiver.

“Caregiving is tough and its been tough for as long as I can remember,” Collado said. “In Somerset County, a caregiving need has been identified in the 2016-2018 Community Health Improvement Plan and it also came up as a need and an issue for our present plan as well. Caregivers are dealing with physical, psychological, emotional — everything on any given day.”

Nearly 20 percent of caregivers show moderate to severe depression versus the less than 7 percent of the general population, the United Way study found. Further, 20 percent reported be-

See CAREGIVER, Page 5A



Caregiver

Continued from Page 4A

ing in poor health compared to less than 11 percent of their neighbors.

“What a lot of caregivers don’t realize is because they are so focused on caring for the person that they love they very often neglect themselves and 60 percent of caregivers end up more ill than the person they are caring for,” Deutsch said. “They don’t keep their doctors’ appointments, they are not eating right, they are not getting enough sleep, they don’t exercise because they are so focused on caring for this person that they love.”

Deutsch believes many need to be “woken up to” the fact that they are caregivers.

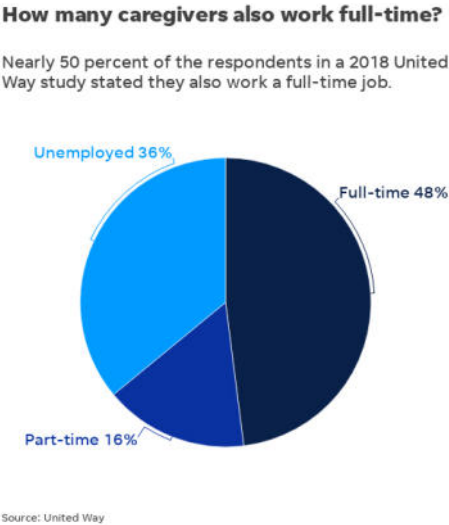
“I’ve met so many sons and daughters over the years who say ‘No, I’m not a caregiver, I just go food shopping for my mom and do her laundry or I’ll run to the bank.’ Those are caregiving activities,” she said. “You are a caregiver if you are doing those things. People don’t realize, they don’t even self-identify as caregivers because they don’t believe that what they are doing qualifies under the heading caregiver. But it does.”

Schulman knows her mother is lonely and she and her sister do their best to meet her needs and meet their own needs as well.

“She wants us around and there is only so much we can be around,” Schulman said. “I have a granddaughter that I want to see on the weekends. You are working during the week and on Saturday doing your food shopping and then at night, hopefully see your grandchild and then on Sunday, run up to your mother to hopefully take care of what she needs and then on Monday, you go back to work again. It’s a lot. It’s absolutely exhausting. It’s easy to become overwhelmed.”

For Schulman, the future is unknown. Her responsibility as a caregiver most likely will stretch her even further.

“I can’t tell you what the future will hold and how much more we will have to take over if she becomes more ill or more confused,” Schulman said. “We are very fortunate right now that she can do as much as she can. But for how much longer? Because I’m on United Way and part of that whole support system, I see how quickly things can deteriorate. It’s something I’m always on the lookout for because I hear the stories all the time.”



Caregivers are assets, resilient but in need of assistance

According to DeGraw, the results of the United Way study showed that “the resiliency piece is really strong with caregivers.”

“They are showing a higher resiliency rate than the general population — they have the ability to bounce back and adapt to different situations,” DeGraw said. “That too goes to show their value. That’s what you want in a good employee, as well as in a caregiver. These are people that can rock and roll with the punches.”

For Collado, the person that can solve the challenge that has created the caregiving crisis “should win the Nobel peace prize.”

“The more education we can do about services and support and things are available to caregivers, the better because some people see lots of challenges and they don’t know what to do,” she said. “We all need help sometimes and we shouldn’t be ashamed or embarrassed to ask for it. We are in this together. We should be helping one another.”

There are many organizations, groups and agencies that offer assistance in the form of much-needed support to caregivers. Founded in 2007, United Way’s Caregiver Coalition, which solicited the study, does much for caregivers to help alleviate stress, offer education and awareness and perhaps give caregivers a break.

“In 2007, we had 45 people at the first meeting and 40 were providers and five were caregivers,” DeGraw said. “We immediately started with a Caregivers Advisory Panel because we wanted the work to be guided by caregivers. It’s grown from then to now over 3,600 people engaged with five coalitions and over 1,600 are caregivers, who still guide the work of our coalition. Everything that we do is based on what caregivers tell us that they want or they need.”

How caregivers spend their time

- 13 days each month**  
Time spent on shopping, preparing food, housekeeping, laundry, transportation and giving medication
- 6 days per month**  
Time spent feeding, dressing, grooming, walking, bathing and assistance toileting
- 13 hours per month**  
Time spent researching care services or information on disease, coordinating physician visits or managing financial matters

Source: Family Caregiver Alliance, Gallup

ple engaged with five coalitions and over 1,600 are caregivers, who still guide the work of our coalition. Everything that we do is based on what caregivers tell us that they want or they need.”

Another source for help, the Family Resource Network is nearing its 50th anniversary. It is a statewide nonprofit organization made up of four affiliates — Autism Family Services, Caregivers of New Jersey, Epilepsy Services of New Jersey and the Family Support Center. Each of the affiliates deal with caregiving differently, Moskowitz said.

While Schulman’s career has somehow become her life, she is serious about taking her own professional advice. Giving caregiver’s a break is key.

“I do a lot of presentations because of the field I am in. I am living what I speak about. I spoke about it so much it became my life,” she said. “When I do presentations to civic centers and senior centers, I speak about trying to find a couple of minutes of happiness. I tell people to read books and comics and whatever — sometimes just watching a half hour of a sitcom is enough to alleviate that heaviness you feel all the time. For me I am a creative person, I paint and I draw. That’s my outlet. I try to carve out some time every day to do something just for myself. I don’t know if people realize how demanding that (caregiving) is.”

A member of the Sterling Committee of the Caregiver’s Coalition, Deutsch firmly believes that it is crucial for caregivers to get “some direction.” If they go to a care manager like a builder would go to a general contractor they can access the most advantageous services,

Deutsch said.

“This has become a real passion for me,” Deutsch said. “I have lived it and now I’ve made it my life’s work and I am delighted to help in any way I can.”

Take action

For more information, contact United Way of Northern New Jersey at [www.unitedwaynnj.org](http://www.unitedwaynnj.org), AARP at [www.aarp.org](http://www.aarp.org), Daughters of Israel at [www.daughtersofisrael.org](http://www.daughtersofisrael.org), Robert Wood Johnson University Hospital Community Health at <https://www.rwjbh.org/rwj-university-hospital-somerset/treatment-care/community-health-education/>, LHD Elder Care Solutions at [www.lhdeldercaresolutions.com](http://www.lhdeldercaresolutions.com), Family Resource Network at [www.familyresourcenetwork.org](http://www.familyresourcenetwork.org) and the National Alliance for Caregiving at [www.caregiving.org](http://www.caregiving.org).

Copies of the United Way Caregivers Coalition “Pathways for Caregivers” guide are also available for pick-up at the offices of the Courier News / Home News Tribune / My Central Jersey. Stop by 92 E. Main St., suite 202 (second floor) in Somerville between 9 a.m. and 5 p.m. Monday to Friday to pick up your copy or multiple copies for friends or organizations that will find them helpful. For details, contact Carolyn Sampson at 908-243-6624 or email [csampson@gannettnj.com](mailto:csampson@gannettnj.com).

Staff Writer Cheryl Makin: 732-565-7256; [cmakin@gannettnj.com](mailto:cmakin@gannettnj.com)

**COMING MONDAY:** *Dealing with the emotional, physical and financial impacts of being a caregiver*

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# ‘It’s just something you do’

For some people, caregiving is a family or cultural tradition

**Cheryl Makin**  
Central Jersey Courier News  
USA TODAY NETWORK - NEW JERSEY

For some, being a caregiver is not a title or label they would bestow upon themselves. Some cultures and/or individuals do not self-describe or identify themselves as caregivers. Rather, it is a familial expectation, complete with hierarchy, traditions and generations of caregiving.

Many who come from an Asian, Indian or African-American culture see caregiving as a loving duty. For others, it is simply family tradition — expected with no questions asked and none needed.

Whether culture or hereditary-driven, this caregiving experience is an expectation — as a member of the family, the position as such potentially entails being or becoming a caregiver for a relative in need at some point.

According to Serena Collado, director of Community Health at Robert Wood Johnson University Hospital Somerset, caregiving is expected in some cultures, with the younger take care of the elder, so they tend not to report themselves as a caregiver. At Robert Wood Johnson University Hospital Somerset, there is a new Chinese Asian Indian program to help with these cultural aspects and issues, Collado said.

“There are some cultures that absolutely view it as family takes care of family,” Collado said. “That’s just the expectation. But not everyone feels that way, and again, there are still challenges. Actually, in some of those cultures, it’s an insult if you actually would use subservices and not do it yourself. This also means that an extra burden is added — there’s psychological, financial, physical and now, cultural. And it is tough. There is no universal answer to this challenge.”

**A natural role**

According to a recent United Way study of 970 caregivers titled “Caregivers: A Community in Crisis” led by the Atlantic Center for Population Health Sciences, with research support from the College of Saint Elizabeth’s De-

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Serena Collado, director of Community Health at Robert Wood Johnson University Hospital Somerset

partment of Psychology and in collaboration with the United Way of Northern New Jersey’s Caregivers Coalition, caregivers are a community in crisis, often suffering from and neglecting their own mental and physical health ailments, as they put themselves last in their desire to care for another. Caregivers may feel stress, grief and other difficult emotions while providing care.

The study was precipitated because of the many stories staff heard from caregivers themselves, said Carol DeGraw, director of Health Impact Area, United Way of Northern New Jersey.

These caregivers who do self-identify as culture or hereditary-driven are often better equipped to fulfill this role for various reasons, said Ashley Anglin, production director of the ALICE Project at United Way of Northern New Jersey and a former Atlantic Health researcher.

**Not a caregiver, just something you do**

According to Anglin, many caregivers who fall into this category truly do not see themselves as caregivers. For the United Way study, when asked “Do you identify as a caregiver?,” some at first, did not. Rather, Anglin said these caregivers “never had seen themselves in that role because it was just something you do.”

“The feeling that this was a role that they just came into naturally,” Anglin said.

Responses were anonymous but An-

glin shared a few responses. One United Way survey participant said they now identify as a caregiver, but only since attending therapy sessions.

“I didn’t even realize this whole thing,” the participant said. “It was when I was trying to get validation, that my therapist let me know that I was a caregiver.”

“I expected this to some extent,” said another participant in the United Way survey. “I remember my parents taking care of their parents. It’s just part of our culture.”

A third United Way survey participant “just saw” herself “as a good daughter.”

“Not something special because it’s just what you do in my family,” she said. “But now I think it’s important to say I’m a caregiver so I can get some help with all of this.”

Anglin added that because the caregiver role was something familiar and previously witnessed in the family or culture, the negative impacts may still be there, but were lessened.

“When it came to that back and forth between accepting it and not accepting it which we saw in a lot of people, folks in that situation were at least accepting of the role,” Anglin said. “We heard a lot of ‘This is what happens, I kinda of know what to do’ or ‘I saw my grandmother take care my uncle who had special needs’ or ‘I saw my mother care for her elderly parents when they got older’ and ‘My aunt takes care of her neighbor.’”



Ashley Anglin, production director of the ALICE Project at United Way of Northern New Jersey and a former Atlantic Health researcher, worked on a recent United Way study of 970 caregivers led by the Atlantic Center for Population Health Sciences, in collaboration with the United Way Caregivers Coalition, that found that caregivers are a community in crisis, often suffering from and neglecting their own mental and physical health ailments, as they put themselves last in their desire to care for another.

COURTESY OF ASHLEY ANGLIN

**Unreported, so unknown**

Collado said caregivers are one of the most unreported statistics that exist.

“If you ask a parent, ‘Are you a caregiver?,’ they will say ‘No.’ But they are because they are taking care of kids,” she said. “Similarly, if you ask a neighbor who runs their elderly neighbor to the bank every week, ‘Are you considered a caregiver?’ They probably would say ‘No.’ They just look at it as doing a good deed, but that by definition it is considered caregiving.”

Lucile Deutsch, owner of LHD Elder Care Solutions and caregiver herself, believes many need to be “woken up to” the fact that they are caregivers.

“I’ve met so many sons and daughters over the years who say ‘No, I’m not a caregiver, I just go food shopping for my mom and do her laundry or I’ll run to the bank.’ Those are caregiving activities,”

See TRADITION, Page 7A



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Tradition

Continued from Page 6A

she said. “You are a caregiver if you are doing those things. People don’t realize, they don’t even self-identify as caregivers because they don’t believe that what they are doing qualifies under the heading caregiver. But it does.”

So often, many of the caregivers Crystal McDonald, assistant director - Advocacy at AARP, speaks with “don’t want to sound like they are complaining.”

“The person they are caring for did a lot to care for them,” McDonald said. “They love them unconditionally. When they are telling their story, every other sentence is ‘I don’t want to complain.’ Sometimes sharing their story is a relief and they find it a little nerve- wracking to recognize themselves that way.”

Jacqueline Moskowitz, senior vice president of Resource Development at Family Resource Network, said when discussing the topic of caregiver identification, she is often reminded of a woman who was caring for both a parent and a child with disabilities.

“It was a lightbulb moment for her when she realized she was a caregiver,” Moskowitz said. “It is a lightbulb moment even for those who are in the field.”

Moskowitz is like many other “in the field” professionals who are now identifying with the population they are helping.

“My mom has always been so young and independent, and suddenly, she has some health issues. Now, I am calling her every day. And suddenly, I’m not ready for this and I have the tools,” Moskowitz said. “It’s really scary. When those roles reverse caring for a parent, it’s tough. And I have three of my own children. I’m also starting to see some of my friends caring for a spouse. They are now caring for their husband because there was some tragedy. It’s life-altering.”

Accepting the role of caregiver

Anglin said those who may not have first identified as caregivers but had familial or cultural expectations have “a little more preparation.”

“You can never be fully prepared, but there was more of ‘I know what this is going to look like. I know what to expect good or bad,’” she said. “Whereas people who kind of fell into the role and/or hadn’t seen that in the family have no

Caregivers with depression

Nearly 20 percent of caregivers show moderate to severe depression, while only about 7 percent of the general U.S. population show it.



Caregivers with depression Other caregivers



People with depression Others in the U.S.

Source: United Way’s Family Caregivers: A Community in Crisis



Currently, there is an estimated 1.75 million people in the state of New jersey providing varying degrees of uncompensated care to persons who are elderly or disabled and limited in their daily activities. Typically, these are relatives, such as sons or daughters caring for an aging parent. COURTESY OF PEXELS

preparation and can be caught off-guard by these issues. If they didn’t have that background, they are more likely having trouble accepting that role.”

Anglin is quick to add “that’s not to say they are not going to do a good job, or that they can’t do that role.” More people in that category had more questions

and were taken aback by the caregiving role they felt thrust into suddenly. The learning curve is bigger, she said.

“Because of that, we also saw a lot of the caregivers having a balance between hope and purpose, and anger, frustration and resentment in their role,” Anglin said. “I think some of the folks thrown into it without seeing that modeled by their family or culture are more likely to be more frustrated or resentful of the person they are caring for whereas people who feel this is their role, feel more of a purpose. ... It doesn’t mean they don’t have the same responsibilities in terms or their jobs, their wages or their health because that is across the board regardless of culture and regardless of length of caregiving. It takes a toll, but they feel it is a more natural role for them. Those that said that, said it comes naturally, and when they say that they mean their culture and their family. It’s part of their personality, but its also what they have seen modeled and part of their expectations.”

Expanding awareness

Many organizations, agencies and institutions such as the United Way, AARP, Family Network and RWJBarnabas system are trying to reach out to expand awareness of the health impacts of caregiving as well as get those who identify with a particular culture or familial tradition. McDonald said the more the role of caregivers is publicized, the more caregivers will recognize themselves as such.

“There are a lot of caregiving groups and the more folks talk to each other about the experiences they are having as caregivers they really come to realize they are doing more than they realize,” she said. “Part of doing this outreach is to let folks know they are not alone. And to help them see that it is not just your duty, not just helping your family, but overall helping the state (New Jersey) kinda keep it together (financially.) There is a bigger picture and you (the caregiver) are not the only one doing it.”

There are so many caregivers in the state and we need to recognize the hard work that caregiving is, McDonald said. “And let them feel validated,” she said.

“I think there are potential solutions, potential opportunities and potential services for people to use, but again, cultural beliefs you may or may not change through education,” Collado added. “We can’t change belief.”

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