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Employers championing their employee-caregivers

Key to a national caregiving strategy

In late February 2018, Torchlight's Vice President of Product, Carolyn A. Romano sat down with Grace Whiting, the President and CEO of the National Alliance for Caregiving, for Torchlight's Corporate Caregiving Conversations podcast. During their conversation, Grace describes the Alliance's efforts to advocate for innovation and systems change to support the needs of caregivers in this country. The two also discuss the recently passed federal law, RAISE—Recognize, Assist, Include, Support, and Engage Family Caregivers Act—which calls for the creation of a national strategy to address the caregiving crisis in America. Finally, Carolyn and Grace explore the challenges caregivers face navigating complex systems of care, work-life balance issues for caregivers who also work, and the important role that employers can play in helping to support the millions of caregivers in their employ. Here is the interview.

CAROLYN: I'm here today with Grace Whiting, the President and CEO of the National Alliance for Caregiving. Grace, welcome!

GRACE: Thank you so much for having me.

CAROLYN: I'm delighted to have a chance to speak with you today about caregiving and what's been going on at the national level, as well as what employers can do to support families who are caring for their loved ones. To get started, tell us a little bit about yourself. I know you're not new to the Alliance, but you are new to your current role.

GRACE: Absolutely. The National Alliance for Caregiving was founded in 1996, and our mission is really to advance family caregiving. We do that through research, mostly in public policy. We do advocacy work in the states, federally, and internationally. We also work on innovation to identify how caregivers can fit better into systems of care, in the workplace, in health care, and in community-based settings. I'm just so excited to be the head of the Alliance. I've been in the role about six weeks, so I'm still getting adjusted, but I have to say, everybody you meet has dealt with caregiving in one way or another. They either are a caregiver, or they are planning to be a caregiver, or they've experienced it in the sense of needing care. It's just been a tremendous, amazing opportunity to get my hands dirty with that and to think about how we can better support these families.

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CAROLYN: It sounds like really rewarding work, and I certainly know just from the role I'm in at Torchlight that looking at the caregiving crisis in America and educating folks about who caregivers are are essential. A lot of times people who actually are in the role don't always identify themselves as caregivers. So who are our nation's caregivers?

GRACE: We know, first off, that there are about 44 million people caring for someone across the lifespan. That could be anything from caring for someone with an intellectual or developmental disability to caring for someone because they're older and they need help just with Activities of Daily Living and everything in between, including illnesses like cancer, mental illness, chronic disease, rare diseases. That's the first thing to know about caregivers.

The second thing is that caregivers have a variety of needs when they are caring. For example, the process of caring can impact your ability to engage in the workforce. It can cause emotional strain while caring for someone at various phases of illness. It can impact your finances, too. There's been some data that your out-of-pocket costs when caring for an aging loved one can be up to $7,000 per year. People don't always think about that. They think about the emotional strain of caregiving. "It's hard to care for my dad because my dad's being difficult and he's upset about the condition that he's dealing with." But they don't always think about the finances, workplace, their social interactions, their own health and wellness, and also their ability to interact with the systems that are providing care to the person who needs it.

CAROLYN: There are so many facets to the whole caregiving experience especially if you're in the workforce, and you're trying to balance working and caregiving. Or, if you're part of the sandwich generation, caring for kids while taking care of an aging loved one. I wonder if you have any thoughts about Millennials. I've read recently that they comprise a large percentage of the nation's caregivers.

GRACE: We think about Millenials and Baby Boomers being at odds, but when you look at the data, about a quarter of America's caregivers are millennials. I think when you talk about Millennial caregiving, it's important to realize that caregiving isn't just about two people. It's usually a whole family that's engaged; millennials tend to be part of that constellation of care. So they're usually living with someone that they are caring for or they are close by. And they're caring in different ways. They're using technology like Skype or apps that allow them to help coordinate care. They're also thinking about solutions that are creative, like intergenerational living or Uber. Is there a way I can get Uber to help transport the person I care for to where they need to go?

CAROLYN: Can you speak to caregiver burnout and stress?

GRACE: So burnout is a really critical issue for caregivers. Caregivers tend to be so selfless that instead of saying, "You know what? I really need a break. I need to take some respite. I need to let someone else come in so I can go out and take care of myself whether that's getting a haircut, going to the grocery store, going out to get exercise, that type of thing." So sometimes, when caregivers don't invest in themselves, and they don't take care of themselves, then they burn out. And they are no longer able in that case to go take care of themselves or the person that needs care. This is especially true when caregiving for a loved one with a complex disease like dementia. You might be spending five, six, even ten years of your life caring for someone with dementia and you could burn out. In some cases, you hear about people who actually predeceased the person with dementia they are caring for.

CAROLYN: Wow. I hadn't really thought of it that way.

GRACE: Exactly. It's crazy, right? I'm spending all this time, this money, this energy caring for someone with dementia. It wears me out so I miss major things that are happening with my health. We see this especially with older caregivers. There's about 7 percent that are over 75 caring for someone else. I think it's also where people maybe aren't as connected to services as they need to be. Is there a way that some of the work that you are doing as a caregiver can be picked up by community services? Could you, for example, go to an Area Agency on Aging and find transportation or nutrition assistance or a caregiver support group where you can connect with others?

CAROLYN: I read a statistic where it costs 8 percent more in medical costs for folks who are in a caregiving role than folks who aren't which is fairly significant. It makes me think of my father who actually passed away in 2007 from pancreatic cancer. Towards the end of his illness, I remember sitting talking with him and he said to me, "You know, you need to remember that this is happening to your mother, too." Because she was in that caregiving role with him, and I thought, "It really is happening to her, too." It's happening to an entire family when someone gets sick and needs extensive care.

GRACE: Absolutely. A lot of caregiving is about that family unit. I think that there's also that sense of caregiving being in the aggregate. We talk about caregiving as a public health issue because if we have 44 million people who are going through the process of caregiving, and each of those people is just one person who is sort of the primary or secondary caregiver, you imagine that a disease or a disability has a broader ripple effect on the other people in that constellation. At that point, it does become a public health issue because it's several families added up. This is something we have to think about as a society: how are we dealing with this in the same way that we deal with the annual flu vaccine or other issues of public health? I think recognizing that people have that emotional burden, and they often have physical strain as well as health strain. It's something that we have to really be more thoughtful about than in previous decades.

CAROLYN: Grace, that makes me think about the RAISE Family Caregivers Act which was recently passed. Can you tell us a little about that and what it's intended to accomplish?

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GRACE: The RAISE Family Caregivers Act is really a landmark piece of legislation, not because the Act itself is that extensive, but because the Act is creating a national strategy for caregivers. It's a public commitment from Republicans, Democrats, Independents, and the President saying that we recognize that family caregivers need support across all ages, all diseases, and we're going to come up with a national strategy to tackle that. The Act itself was signed into law in January 2018, and we are looking at the Advisory Committee's being formed in the next year. Then, in the next 18 months, Health and Human Services and the Secretary of Health and Human Services will be announcing a national plan for caregivers that would address topics like workforce, respite care, training and support services, coordination of care, and even more touchy subjects like advanced illness or end-of-life care.

CAROLYN: Who will be on the RAISE Advisory Committee? Do you know how folks will be selected?

GRACE: Great questions. I think it's still open. There presumably will be some type of process where people will be nominated, or they'll be appointed to be on the Committee. The one thing I can tell you is the RAISE Family Caregivers Act outlines a list of 15 different roles, including nonprofit groups, actual family caregivers, older adults, people with disabilities, and then people from different sectors that might be impacted so financial services, employers, healthcare providers, and so forth. We know at the least that there will be a broad diversity of people on the RAISE Family Caregivers Act Advisory Council.

CAROLYN. That's great. It's exciting to think about what's possible when people get together to talk about these issues and actually develop a strategy.

GRACE: What's amazing about the RAISE Act is that other countries like Australia and the UK passed national strategies. They had that public commitment and that actually helped improve the situation of caregiving in those countries either by creating new services or supports or by better coordinating what was already in existence. For example, in Australia, it helps the folks who are providing disability services to work more closely with those who are providing eldercare. In the United States, we still see silos although people are continuing to work on bringing those communities closer together.

CAROLYN I know that I find in the work that I do where we support families of kids with disabilities and we support families who are caring for aging loved ones. There are so many parallel experiences that people have when they are trying to navigate complex systems and be strong, effective advocates for their loved ones. You worry because you don't know what you don't know while you are figuring out how to do the right levels of problem solving to help your family member. It's time that we put attention on improving systems nationally.

You mentioned, Grace, that employers are on the Advisory Committee. Can you reflect on why employers are at the table for these policy discussions?

GRACE: In recent years, a lot of employers have been thinking about what to do about family caregiving. Part of that is because people who are employers are dealing with caregiving themselves. We have an aging workforce, and we know that by the middle of the century, if projections stay true, about a quarter to 20 percent of our population is going to be over 60. So I think employers, first of all, are saying to themselves I'm trying to balance my aging parents, I'm trying to raise children on the other hand. It's challenging to do that and maintain my career, so how can we improve the situation and make our workplaces friendlier?

There's also a productivity impact where, when you have people in the workforce stepping out to provide care, it becomes an issue for the employer who wants to retain a great employee but also needs to find a way to address productivity. That's where people are trying to get more creative about programs like flextime, telework, onsite peer resource networks that can be used for caregivers, and other types of EAPs or employer-assisted programs where there can be, for example, a geriatric care manager who's there helping people navigate caregiving. These are things that I think of as a reality. I mean it's not possible for everyone to give up their job to provide care, and again in this sense we're facing a public health issue as a nation about what do we do about caregiving? I think employers are a major part of that solution.

CAROLYN. Definitely. Grace, you mentioned that not everyone can leave their job, but there are folks who are leaving the workforce altogether or shifting from full-time to part-time work. What's your sense of the numbers there?

GRACE: Typically, most people aren't necessarily exiting to provide care, but we know that, of those folks who are working, six out of ten do have to adjust their work life in order to accommodate caregiving. That could be anything from leaving their job and retiring early to missing work, coming in late, having to take time off. It's a major impact and it's again millions of people who are facing these challenges. There are evidence-based programs we know work, right? We know a geriatric case manager available through work can be helpful in improving the productivity of the workforce and also helping the caregiver navigate some of these challenges. But, it's tricky in many cases even when resources are available to employees. For examples, even with something as straightforward as a paid leave program, caregivers are reluctant to take it because there is a stigma attached with caregiving. They don't feel comfortable talking openly about what's happening with a loved one that has dementia or cancer or any other major medical condition. An employer really has to put effort into conveying that this is a safe environment for you to talk about your caregiving journey, and I'm willing to think through what types of resources might be available for you to be able to care and provide work.

CAROLYN: Grace, how much are you seeing employers really rolling up their sleeves and saying it's time we really crack this caregiving nut?

GRACE: Yes, there are companies that are thinking about it. There is actually a wonderful group, called the ReACT Coalition, and that coalition gathers major employers across the country and has them think through what type of corporate solutions might make sense for elder care. For example, Bank of America Merrill Lynch has been doing a lot of work around elder care, for their clients who are caregivers, but also creating new services and supports within Bank of America and Merrill Lynch to help support employees who are caregivers.

CAROLYN: That's fantastic. Is caregiving an issue, Grace, that disproportionately affects women?

GRACE: Yes, although I would say it's changing. Historically, caregiving has been mostly women on average with maybe about 20 to 30 percent of caregivers being men. The last time we did a big national study with AARP, we found that 60 percent of caregivers were women, so still more often than not, but that 40% of caregivers were men. Among Millennials, men and women were equally as likely to provide care.

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When we talk about it as an issue I think that perception is changing. In a lot of ways, conversations in the national sphere have talked about the importance of work-life balance, the importance of family and so the conversation around caregiving is changing in that same way. Caregiving is not "women's work." Caregiving is something that all of us have a stake in, even if the way we are caring by gender looks a little different.

CAROLYN: That's a really important point. What other companies are doing creative things to support caregivers?

GRACE: I think the most creative way to support caregiving is...well, I don't know if I'd call it creative! Rather, it's sort of the things we know that work like creating a culture of care so people feel comfortable talking about it. We know that respite works, onsite daycare programs work. Some companies are doing elder care on site so we actually have a facility or place onsite where you can bring someone that has special health care needs. We know that flextime and telework can be effective for certain types of roles. A big piece of this is recognizing that caregiving is a part of our life. Just like we need to take vacation as an employee. Just like as employees, we have to have development in our own career, I think recognizing that caregiving is a part of life and that you develop skills as a caregiver that can be useful in business and having that message conveyed down from the top, from the leadership, that would be truly creative and innovative.

There are a couple of companies that are doing that. One of the pharmaceutical companies that we are working with, EMD Serono, has gotten more involved in providing more caregiving resources and support to employees. They actually do a TED talk contest every year. One of their team members did a talk on caregiving, and it was selected and shared with 1000s of their employees across the world. Thinking about the soft part about it matters, too. How we talk about it, how we champion it, you know, recognizing that leadership needs to be involved and supportive of caregiving and that matters just as much as what actual benefit might be available.

CAROLYN: Yes, yes! That makes perfect sense and you're right: so many folks really don't feel like they have that safe place at work to be able to bring these issues forward. It really does start with the culture.

GRACE: Absolutely.

CAROLYN: Grace, what about folks who left work for caregiving responsibilities or other family responsibilities? How do we support them to be able to return to work?

GRACE: The first thing is encouraging people to identify what types of skills they picked up as a caregiver that might be valuable to an employer: things like resilience, the ability to work with multiple care systems. For instance, you might be coordinating care between a hospital, a long-term care facility and so forth. You might have done medical nursing tasks when you were a caregiver. Many caregivers also have developed the ability to navigate difficult situations and to find consensus between different family members. So that would be the first thing, sitting down and really thinking about, as a caregiver, what skills did I gain from this? At the Alliance, I've noticed sometimes we'll get applications and someone will put on their resume that he or she had a gap in employment because "I was a family caregiver." I wouldn't say do it without any thought or caution, but I do think it can open a conversation. It can help you identify employers who would be friendly to that, who understand what that caregiving journey looks like, and who recognize the value of it. You would be surprised to see how many people have been through that process themselves.

The other thing is making sure that as a caregiver, especially if the person has passed away, that you're taking enough time to really care for yourself after that happens. You see a lot of people who don't go immediately back to work; they phase it in so they have time to really process and grieve and that can be really hard to do when you are in the throes of caregiving.

CAROLYN: I agree. When we are caring for our loved ones, our identities can get intertwined. We see ourselves in that caregiving role and then when the need for caregiving ends or our loved one passes away. There is that space that is created. Then not only are you grieving, but you're also saying, 'What now? What next?' Taking the time to process it and figure out what your next steps are makes a lot of sense.

GRACE: What now? What next? That's a perfect way to describe it. It's been such a huge part of your life, and it's meaningful. Sometimes, especially when the disease is particularly challenging something like dementia or late-stage cancer, it's hard to make sense of that. I think identifying the positive side of caregiving can help a lot of people as well. For example, a lot of people say they have higher self-esteem because they were caring for someone, or they felt like it was able to bring them closer to that person they were caring for. Recognizing that it's not just a journey that has negative aspects but positive, life-sustaining aspects of caregiving that can enrich what you are doing and what you are experiencing.

CAROLYN: After my aunt, I was the back-up care for my grandmother who had severe osteoporosis. One of her real fears as she got older and older was that she would end up having to go into a nursing home. Other than some time in rehab, we were able to provide care for her at home.

It was hard though. Holy smokes, was it hard! And it really took a toll on my aunt more than anyone in our family, but to think that there could be more support for families so their loved ones could be home longer or until they pass…it just…it moves me tremendously.

GRACE: Me as well. It's such an intimate thing how we care for each other. It's very hard. It's easy for us to say "Oh, I love this person." It's an entirely different thing to say, "I will toilet this person even if they are yelling at me." It's really about being able to say, I want to live my values. If I say family is really important to me, what does that really look like?

As medicine advances, we hope that fewer and fewer people will have to deal with the burden of disease. But it is amazing that people are so selfless, that they are so giving, and that they are willing to share that with others. To share that experience and to say that as a community we really need to come together and support this.

CAROLYN: Absolutely. Grace, thank you so much for investing this time with me today. I appreciate all that you shared about caregiving in America.

About the National Alliance for Caregiving

www.caregiving.org

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

About President and CEO Grace Whiting, J.D.

C. Grace Whiting, J.D., is the President and Chief Executive Officer at the Alliance, where she leads the organization's business development, supports strategic planning, and develops relationships with key stakeholders in the family caregiving community. As President and CEO, she continues her tenure at the Alliance where she has previously served in various roles including as Chief Operating Officer and the Director of Strategic Partnerships. Ms. Whiting lead the launch of the Caregiving in the U.S. 2015 report with AARP and directed the first national study of rare disease caregiving with patient advocacy group, Global Genes.

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About Torchlight

www.torchlight.care

Torchlight is a first-of-its-kind, White House-featured innovation helping 70+ leading employers reduce the costs and complexities of modern caregiving for their employees. The Torchlight benefit currently covers over 1MM families across 50 states. Torchlight helps employees demystify the complexities associated with navigating education, healthcare, community, and government resources for children and aging adults with demanding needs. This level of contextualized support allows employee to master this second "job" so they can focus on their first at work.

About Carolyn A. Romano, J.D., Vice President of Torchlight

Carolyn has over three decades of experience advocating for and participating in systemic change efforts to improve the lives of children, the elderly, and populations at-risk. In her work at Torchlight, she relies on this expertise to raise awareness among employers about the need for effective corporate caregiving strategies and to support the hard-working employees at those companies who are working just as hard at home to take care of the most important people in their lives. She can be reached at cromano@torchlight.care.

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