Modern Caregiving Challenges Facing U.S. Employees

A report based on the data of over one million covered employees

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Welcome.

Torchlight's first annual report, *Modern Caregiving Challenges Facing U.S. Employees*, underscores the need for a more inclusive definition of "caregiver" and a more extensive and holistic approach to addressing the caregiving challenges employees face.

Torchlight offers real-time, caregiver decision-support services to over one million covered employees across all industries in the United States. In this report, we invite you to explore our most recent data gathered over nearly three years from a subset of users.*

Not only have we come face to face with the full range of modern caregiving challenges facing U.S. employees, we have also identified the ways in which busy, employee caregivers want and need help.

Real People. Real Issues. Real Life.
Real Modern Caregivers.

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*n = 18,222 users

Modern Caregiving (n.):

the state or disposition of tending to a loved one's extended and often complex array of care needs in today's fast-paced, frequently shifting world.

Modern Caregiving Defined

The United States is experiencing a caregiving crisis, one that will only grow in severity as people live longer and the incidence of conditions like Autism and Alzheimer's continues to rise.

The National Alliance for Caregiving's oft-quoted 2015 Report shared that an estimated **43.5 million** adults in the U.S. had provided unpaid care to an adult or child in the prior 12 months. Of these, **20%** worked full- or part-time; **70%** of working caregivers reported work-related difficulties due to their dual roles.

These statistics only tell part of the story and far underreport the number of people who are employee caregivers. Interactions with thousands of employee caregivers who are Torchlight users confirm that most people in caregiving roles do not identify themselves as caregivers.

"Caregiving" has traditionally been defined as care for an aging loved one or child with a diagnosis or disability. We have found that this definition is limiting and causes people to not identify as caregivers—when in fact they are. In addition, employee caregivers seldom include in their definition the additional daily life challenges that require care and attention. These circumstances, whether acute or chronic, often impact a family as much as any diagnosis or disability does.

"We need people to identify as caregivers. A lot of people think of themselves as a really good daughter, wife or husband, but they don't see themselves in a caregiver role ... and they don't see it as something they can talk to their bosses about."

Laura Poskin, Director of United for Seniors at United Way of Southwestern Pennsylvania

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I am a modern employee caregiver.*

Real concerns from real employee caregivers.

Mom won't even consider moving.

But she just can't manage the house anymore. I just want her to be safe, and it's a big fight every time we talk. My sisters are no help as none of us agrees about what to do, and we all live in different parts of the country. I don't know what to do.

The technology and screens in my house have totally taken over my family.

I feel completely ridiculous battling my kids about screen time, but it's dramatically impacting our family life. Where do I even start?!

I'm worried about my dad's driving.

He insists that he's fine, but I've noticed that the car has all sorts of new dings and scrapes on it. Dad just complains about other drivers being incompetent. We need to figure out if we need to get dad off the road. Help!

My daughter has Autism Spectrum Disorder.

Where can I find a summer camp or other programs for children with special needs? We live in South Carolina.

I live in Los Angeles. My parents are in Rhode Island.

Who can I contact to learn more about services where they live, since I'm the only family they have, and I can't get out there often enough to be sure they're really okay.

My son is in high school.

He experiences negative feelings, stress, and anxiety due to studying or from other people's attitudes towards him. He is starting to hurt himself physically. What can we do to help?

My mother-in-law has lived with us for almost 25 years.

In the past number of years, since a fall, fractured hip, and dementia, she has been receiving support through Medicaid. Whenever an aide leaves, it is a struggle … Both my wife and I work, so it is a challenge to balance her care and work until someone new is available. What options do we have?

My third grader is having trouble keeping up with his classwork.

His school recommended that he be held back in second grade. When I asked about testing for a disability the staff offered no assistance on how to make this happen. The next thing I knew, he was moved to third grade. How do I help my child get the educational help he needs, when the school system would rather push him through to the next grade?

*All personally identifiable information has been changed to protect the user.

The Demographics of Modern Caregiving

It's not *just* about the employee.
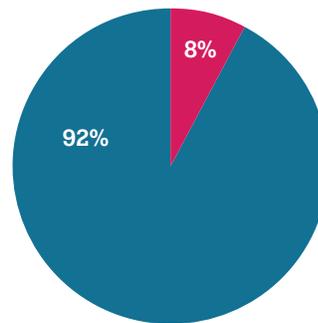## It's about their family, too.

Whether they are Millennials, GenXers, or Baby Boomers, employee caregivers are caring for loved ones of all ages and stages, with a wider range of crises and concerns than ever before.

Elder

The Typical Torchlight Elder Caregiver

Of the 92% of users, 39% "care" from a distance, often adding travel time/expense, childcare arrangements, and other considerations to existing responsibilities.
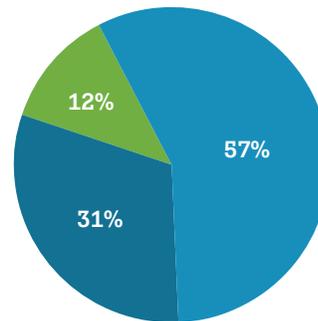
A surprising eight percent use Torchlight to plan for their own needs.

- 8%
- 92%

■ I'm a caregiver of an older adult
■ I'm here for myself
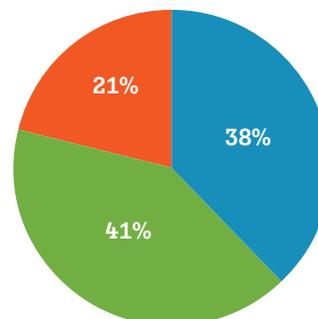
Loved Ones' Living Arrangements

Where an elder lives impacts the types of care needed and the solutions available around finances, legal decisions, safety, etc. Most users (88%) care for a loved one who is "aging in place."

- 12%
- 57%
- 31%

■ Elder lives independently, but with others
■ Elder lives independently, but alone
■ Elder lives in a facility

Presence of Cognitive Impairment

The presence of Alzheimer's disease or another dementia is a critical consideration when making caregiving decisions. Thirty-eight percent of users are helping a loved one with dementia; 21% worry they will face this in the near future.
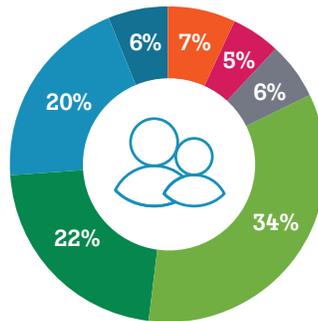
- 21%
- 38%
- 41%

■ Yes
■ No
■ I'm not sure

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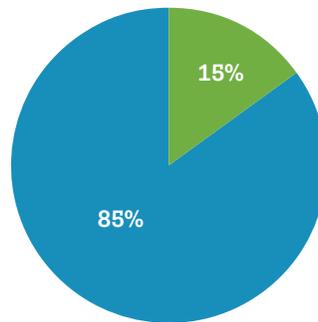
Child

Age or Grade of Children

Users are concerned with their children's success no matter their age. Knowing a child's age, however, is key to offering recommendations that account for relevant developmental stages.

- Birth–Age 3
- Preschool
- Kindergarten
- Grades 1–5
- Grades 6–8
- Grades 9–12
- Out of School, Independent Living, College

6% · 7% · 5% · 6% · 34% · 22% · 20%

Presence of Disability in Children

The majority of users (85%) report that their children do not have a disability or diagnosis. A small percentage will be evaluated and receive a diagnosis. The majority will not, but will still require support.
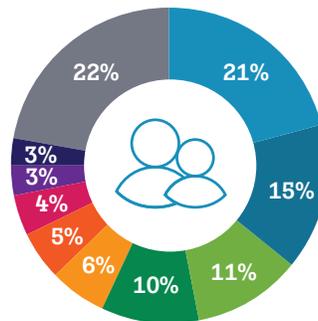
- Children without reported diagnoses
- Children with reported diagnoses

15% · 85%

Reported Disabilities or Diagnoses

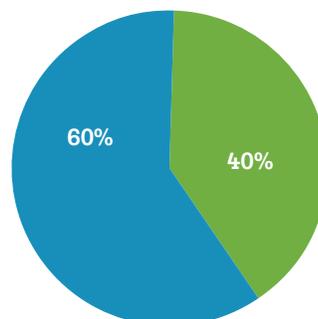Users report disabilities and diagnoses from the more widely known to the most rare.

* Includes conditions such as executive function deficit, physical disability, mental health diagnosis, food allergy, vision impairment, hearing impairment, eating disorder, genetic and other rare disorder, and chronic illness.

- ADHD
- Autism Spectrum Disorder
- Anxiety
- Learning Disability
- Sensory Processing Disorder
- Depression
- Intellectual Disability
- Communication Disorder
- Neurological Issue
- Other*

21% · 15% · 11% · 10% · 6% · 5% · 4% · 3% · 3% · 22%

Children Receiving Services Through a Formal School or Agency Plan
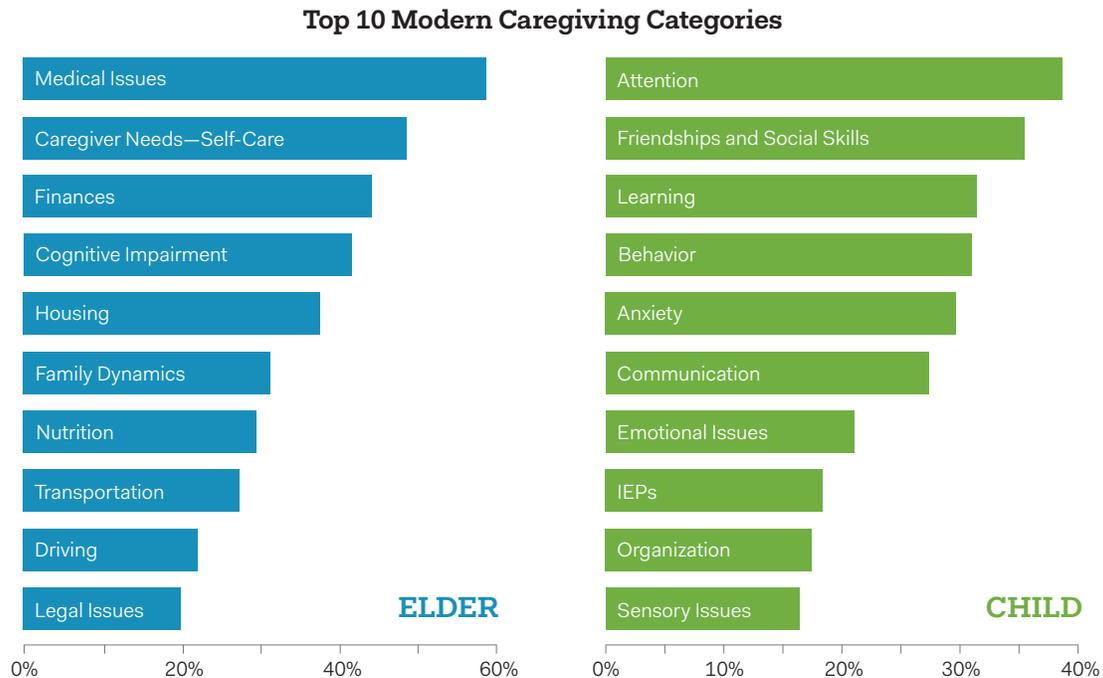
Once a formal plan is in place, users seek support to ensure its proper implementation.

- Formal Plan
- No Formal Plan

60% · 40%

A Look at Modern Caregiving Challenges

Twenty-first century life has expanded the concerns and stressors facing the modern family. The graphs below capture the broad areas of users' child and elder concerns.

Top 10 Modern Caregiving Categories

ELDER
- Medical Issues
- Caregiver Needs—Self-Care
- Finances
- Cognitive Impairment
- Housing
- Family Dynamics
- Nutrition
- Transportation
- Driving
- Legal Issues

(scale: 0%, 20%, 40%, 60%)

CHILD
- Attention
- Friendships and Social Skills
- Learning
- Behavior
- Anxiety
- Communication
- Emotional Issues
- IEPs
- Organization
- Sensory Issues

(scale: 0%, 10%, 20%, 30%, 40%)

Note: Data from January 1, 2016 through September 30, 2018

These graphs, however, do not paint the full picture. Further analytics, as shown on page 8, provide in detail the related day-to-day issues and complexities that impact modern caregivers' lives.

A user seeking information about a "typical" caregiving concern, such as Alzheimer's, certainly needs to understand the course of the disease. Data shows, however, that a host of immediate issues must often be dealt with first. These include handling Mom's unsafe driving, re-homing Dad's beloved pet before his move to a memory-care facility, or preventing an aunt from falling at home.

Raising children is also more complex; daily stressors move beyond basic categories of concern like attention, anxiety, and behavior. Top utilized tools and content pathways within the platform reveal users' daily struggles with managing morning and bedtime routines, obtaining special education evaluations in school, or navigating bullying and substance abuse.

These here-and-now problems further compound each caregiving situation, impact employees' lives, and must be resolved.

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Most Pressing Problems Solved for Users

	Elder		Child
1	**Housing:** Assessing home safety & available housing options, creating safe home environments, & moving a loved one		**Mental Health and Behavior:** Addressing anxiety, depression, & behavior challenges with concrete tools & strategies
2	**Cognitive Impairment:** Managing Alzheimer's & other dementias, tracking behaviors, ensuring safety, & planning ahead		**Executive Functioning:** Helping kids learn organizational skills, finish homework, manage time, & set goals
3	**Arranging Services:** Interviewing, hiring, & scheduling home-care providers & organizing key medical information		**Special Education:** Advocating for the right services & supports at school
4	**Caregiver Self-Care:** Handling one's own stress & well-being while balancing home, work & care duties		**Friendship and Social Skills:** Supporting kids to form healthy friendships & navigate peer pressure, bullying, or cyberbullying
5	**Legal Issues:** Getting affairs in order & hiring elder law attorneys for estate planning, guardianship, or probate		**Parenting:** Managing screen time, social media use or gaming addictions; supporting self-esteem; & providing support for kids who identify as LGBTQ+
6	**Complex Financial Planning:** Understanding reverse mortgages, signing up for Medicare, paying for long-term care, & qualifying for Medicaid		**Learning:** Identifying root causes of learning challenges & providing the right supports
7	**End of Life:** Supporting a loved one through the physical, emotional, & spiritual journey of death & dying		**Early Intervention:** Assessing progress toward developmental milestones of children birth to three & obtaining services to help
8	**Family Dynamics:** Balancing conflicting opinions, emotions, & contributions of other family members		**Financial Needs:** Estate planning for long-term needs of kids with disabilities
9	**Elder Abuse & Neglect:** Preventing & dealing with financial exploitation & scams		**Autism Spectrum Disorder:** Learning about new research & treatment, positive behavior supports, & gender differences
10	**Veterans Benefits:** Navigating benefits & services offered by the U.S. Department of Veterans Affairs		**Attention Deficit Hyperactivity Disorder:** Recognizing the symptoms & challenges, considering medication, & talking to a child about ADHD

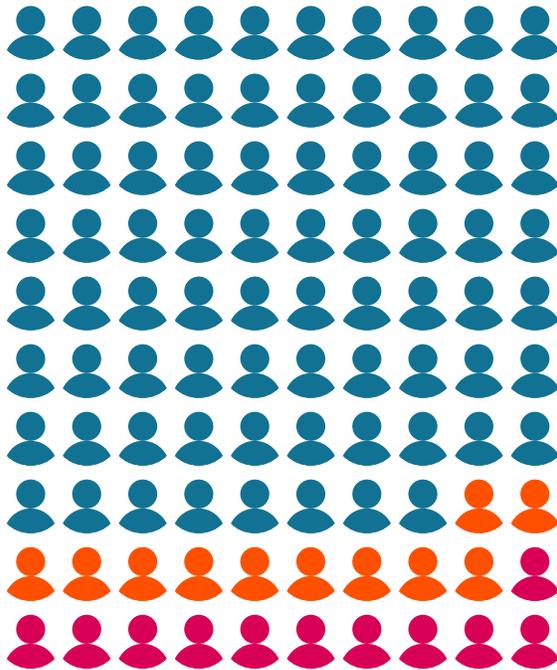Note: Data from January 1, 2016 through September 30, 2018

Remember: Caregivers also need care themselves; 25% of Torchlight's most popular content involves caregiver self-care, burnout, and the need for support.

How Do Modern Caregivers Want Support?

One size doesn't fit all.

Torchlight data reveals three distinct modern-caregiver personas:
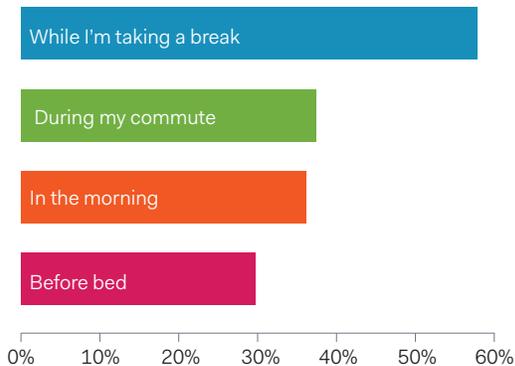
78% Users who want help getting started, then they want to navigate on their own

11% Users who prefer to search on their own for what they need from the beginning

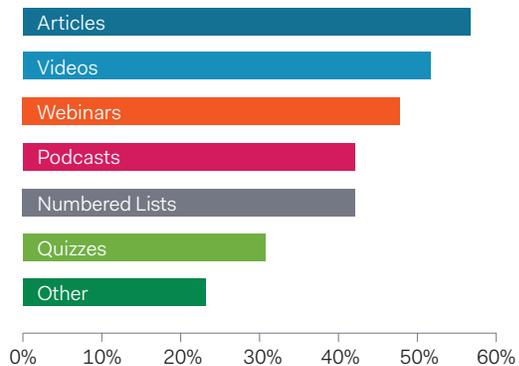**11%** Users who prefer someone with them throughout their problem-solving journey

Regardless of the persona, the majority of employee caregivers solve their caregiving challenges in and around their work obligations. As a result, they need access to real-time solutions on their schedule and in a range of formats that support their learning style and communication preferences, as shown below.

When do caregivers like to receive support and information?

- While I'm taking a break
- During my commute
- In the morning
- Before bed

0% 10% 20% 30% 40% 50% 60%

Most users choose to learn when taking short breaks throughout the day, wherever and whenever, it is convenient for them.

In which formats do caregivers want their information?

- Articles
- Videos
- Webinars
- Podcasts
- Numbered Lists
- Quizzes
- Other

0% 10% 20% 30% 40% 50% 60%

Users still prefer vetted, downloadable articles over other ways to learn and consume content.

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Conclusion

On a daily basis, modern caregivers address a host of issues, details, and other challenges related to their families' needs. They often feel overwhelmed and unsure about how to help.

Years of data underscore that employees don't just have "an autism concern," "an eldercare concern," "an anxiety concern." It may start there, but because each family's issues or particular circumstances are unique in some way, helping them requires a nuanced and personalized approach.

Therefore, when someone asks, "What do I do?", the correct—although frustrating—answer is, "It depends."

It takes expertise to address all the factors that go into an employee's need for help. And while there are no pat answers or categorical solutions, there are a number of societal systems (social, legal, governmental, financial, medical, mental, digital, and logistical) that can influence, impact, and help resolve every modern care challenge.

As the urgency to address the nation's caregiving crisis grows, you must do more than "check the family benefit box" to address employees' needs. To be truly effective, you must provide support that both recognizes the details and differences among your employees' caregiving challenges and accommodates their often chaotic, on-the-go lives.

Some modern caregiving issues impact many families, and others just a few. Yet all struggles have far-reaching consequences for employees and their families—at home and at work—which you can help them address.

Are you also a modern employee caregiver?

We bet that you are.

Torchlight is the only caregiver-support program for employers and health plans that provides real-time access to the strategies and solutions modern caregivers need most.

From screen time to Social Security, Autism to Alzheimer's, Torchlight has met caregivers where they are for over six years, providing the expert guidance, tools, and step-by-step action plans that solve even the most complex family challenges.

Torchlight serves over one million employees across all industries and company sizes. We are helping care for over 2.3 million family members no matter the age, stage, crisis, or concern.

Caring is _everyone's_ business.
Caring is _good_ business.

To learn how we help companies solve modern caregiving challenges, contact us at (844) 693-3477 or sales@torchlight.care

www.torchlight.care