

BOSTON COLLEGE

CENTER FOR WORK & FAMILY

EXECUTIVE BRIEFING SERIES

In this Issue:

- *Definition of Exceptional Caregiving and reasons why it is a significant workplace issue*
- *Statistics and research data on the business case for supporting exceptional caregivers*
- *Highlights of special cases: Caring for People with Alzheimer's and Cancer and Careers*
- *Strategies and solutions for employers from leading organizations*

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Exploring the Complexities of Exceptional Caregiving

Many researchers agree that the challenge of finding affordable, quality child care drove the work-life agenda in the 1980s – and into the 1990s. As the country ages and family demographics continue to shift, caregiving is similarly driving policy development and employer responses today.

“Caregiving touches us all. Either we have been caregivers, we are caregivers, we will be caregivers, or we will need caregivers. Because of rising life expectancies and the ability of medical science to prolong the lives of people who require long-term care, the need for caregivers is not going to go away.”

— ROSALYNN CARTER, FORMER FIRST LADY

PRESIDENT OF THE BOARD, ROSALYNN CARTER INSTITUTE FOR CAREGIVING

Caregiving has become more complex for many reasons:

- Americans are living longer, and due to advanced medical care and sophisticated technologies, they often live longer with disabilities and chronic illnesses.
- The traditional family structure and lifestyle with a breadwinner father and stay-at-home mother has changed dramatically as dual-income couples, single parents, and grandparents raising grandchildren head more households.
- People are choosing to have children – and fewer of them – later in life.
- Families that once lived for generations within limited geographical boundaries are moving many miles apart.
- Children with severe disabilities and chronic illnesses are living longer and staying home with their families as opposed to being placed in institutional care.
- Mid-career workers are addressing their own aging and self-care needs, while raising children and caring for parents – and even grandparents.

This Briefing focuses on Exceptional Caregiving, a term we have coined to describe caregiving situations that have emerged from these societal shifts to extend beyond the traditional scope. Whether we refer to them as the sandwich generation, elder caregivers, parents of children with special needs, or well spouses, these exceptional caregivers are feeling the squeeze — between family and career, guilt and ability, time and distance, and finances and responsibilities.

Who Are the Caregivers?

- **40 million family members, partners, or friends**

About 40 million family members, partners, or friends in the United States provide an estimated 37 billion hours of care to adults with self-care needs (AARP Public Policy Institute, 2018).

- **Elder caregivers**

Nearly two in three (63%) of employed family caregivers--17% of employed Americans--are caring for an individual age 65 or older (AARP Public Policy Institute, 2018; Family Caregiving Alliance, 2012). 75% of all caregivers are female, and may spend as much as 50% more time providing care than males (Institute on Aging, 2016).

- **Sandwich generation**

Nearly half (47%) of adults in their 40s and 50s have a parent age 65 or older and are either raising a young child or financially supporting a grown child (age 18 or older). About one in seven middle-aged adults (15%) is providing financial support to both an aging parent and a child (Pew Research Center, 2013).

- **Adult children caring for parents or other relatives with dementia**

15.7 million caregivers (almost 40% of all caregivers) are providing care to someone with dementia (Family Caregiver Alliance, 2016).

- **Parents of children with special needs**

14% of family caregivers (16.8 million caregivers) care for a child with special needs (National Alliance for Caregiving and AARP, 2009). The National Survey of Children with Special Health Care Needs identified nearly 1 in 5 children ages 12-17 as having special health care needs (U.S. Department of Health and Human Services, 2017).

- **Spouses or partners of people with chronic illnesses or disabilities**

7% of adult caregivers provide care for an aging spouse/partner (Pew Research Center, 2015).

- **Caring for Veterans**

About 5.5 million Americans are caregivers for former or current military personnel (Ramchand et al., 2014). 96% of these caregivers are female, and 70% provide care to their spouse or partner (National Alliance for Caregiving and United Health Foundation, 2010). 30% of veterans' caregivers provide care for a duration of 10 years or more (National Alliance for Caregiving and United Health Foundation, 2010).

Caring for People With Alzheimer's Disease

Caregiving for persons with Alzheimer's is physically and emotionally demanding. Over half of individuals with dementia (53%) receive assistance from family members or other informal caregivers for normal daily activities compared with 11% of older adults without dementia (Alzheimer's Association, 2018).

- Nearly 80% assist with personal daily tasks including feeding, bathing, dressing, or grooming (Alzheimer's Association, 2018).
- 42% of caregivers of people with dementia provided an average of nine hours of care per day (Alzheimer's Association, 2018).
- More than six in ten (63%) Alzheimer's caregivers expect to continue having care responsibilities for the next five years compared with less than half of caregivers of people without dementia (49%) (Alzheimer's Association, 2018).
- Alzheimer's caregivers confront overwhelming challenges on a daily basis that have a negative impact on their work and family lives. The estimated economic value of the care provided by unpaid Alzheimer's caregivers was greater than \$232 billion in 2017 (Alzheimer's Association, 2018).
- 60% of caregivers of people with Alzheimer's or another type of dementia were employed in the past year while providing help, working an average of 35 hours per week while caregiving.
- 57% of employed Alzheimer's or dementia caregivers report sometimes needing to go in late or leave early, compared with 47% of non-dementia caregivers.
- 9% gave up working entirely, compared with 5% of non-dementia caregivers.
- 18% reduced their work hours due to care responsibilities, compared with 13% of non-dementia caregivers (Alzheimer's Association, 2018).

According to the Family Caregiver Alliance, an informal or family caregiver is "anyone who provides [unpaid] assistance to someone else who is, in some degree, incapacitated and needs help: for example, a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a grandfather with Alzheimer's disease; a son with traumatic brain injury from a car accident; a child with muscular dystrophy; a friend with AIDS."

What Distinguishes Exceptional Caregiving?

To illustrate the distinguishing characteristics of exceptional caregiving of adults, elders, and children, the chart below compares it to the care provided while raising a typically developing, healthy child.

In 1900, the average life expectancy at birth was 47 years and only 4% of the population was aged 65 or older. Today, the average life expectancy at birth is 78.7 years and the percentage of the population aged 65 or older has risen to 15%.

By 2035, adults ages 65 and older are projected to outnumber children under the age of 18 for the first time in U.S. history.

— U.S. CENSUS BUREAU, 2018;
WORLD BANK, 2015;
POPULATION REFERENCE BUREAU, 2016

Typical Child Care	Exceptional Care
Constant care that diminishes over the years	Constant care that escalates over the years
Extraordinary input of time and energy	Extraordinary input of time and energy
Easier as time goes by	Harder as time goes by
Few interruptions are emergency-driven	Many interruptions are emergency-driven
Child grows increasingly independent	Individual grows increasingly dependent, or never develops independence
Requires some caregiver and family lifestyle adjustments	Requires numerous caregiver and family lifestyle adjustments
Challenges and successes are easily shared in casual conversations with friends and colleagues	Challenges are rarely shared in casual conversations except with the closest of friends and colleagues; successes are fewer and farther between
Caregiving creates heightened exposure to the satisfaction and joy of celebrating lifetime achievements	Caregiving creates heightened exposure to illness, hospitalization, and even death

Additional Challenges of Exceptional Caregiving

Navigating the healthcare system

Researching and making complex legal and financial decisions

Locating and applying for federal and state programs

Understanding the rights of children with disabilities in the school system

Understanding the rights of people with disabilities in the workplace

Depending on others for information, support, and services

Affording the cost of care

Obtaining a flexible work schedule

Having time for self and respite

The Exceptional Caregiver on the Job

- 60% of caregivers—24 million individuals—are employed (56% full-time and 41% part-time) while providing care (AARP Public Policy Institute, 2016; National Alliance for Caregiving and AARP, 2015).
- 70% report that caregiving responsibilities have affected their work. Those with the most intense care responsibilities report much higher levels of work adjustments (National Alliance for Caregiving and AARP, 2015) including:
 - Reduced work hours or took a less demanding job (25% of individuals with intensive caregiving responsibilities, 10% of those caregiving 20 hours or less per week)
 - Gave up work entirely (12%, 4%)
 - Retired early (8%, 3%)
 - Turned down promotion (4%, 14%) (National Alliance for Caregiving and AARP, 2015)
- Parents of children with developmental disabilities are less likely to remain in paid employment and more likely to work part-time, to earn less money, and to reduce work hours when compared with parents of typically developing children (Rosenzweig et al., 2008).
- Caregivers age 50 and older who leave the workforce to care for a parent lose, on average, nearly \$304,000 in wages and benefits over their lifetime (AARP Fact Sheet 2012).

“Since co-authoring the original briefing 10 years ago, the complexity of exceptional caregiving and its demands on employed caregivers remain. At the same time, awareness of the impact of caregiving on individuals, society and the workplace has increased. In 2018, the bi-partisan RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act was signed into law to develop and maintain a national strategy to recognize and support family caregivers. And more employers are providing enhanced caregiver support through expanded health insurance coverage for treatments such as Applied Behavior Analysis (ABA) for autism, paid caregiving leaves of absence, subsidized in-home and center-based backup care for dependent adults, customized websites and consultations for navigating special education and health care, employee resource groups for caregivers, and more.”

— LINDA ROUNDTREE
ROUNDTREE CONSULTING LLC

Cancer and Careers

73% of cancer patients and survivors want to work, and 69% agreed that work aids in treatment and recovery (Cancer and Careers, 2015). Work is a way for cancer patients and survivors to feel normal and maintain their identity; however working as a patient or survivor comes with challenges (Cancer and Careers, 2015).

Employees with cancer (or employee caregivers) want to remain engaged at work as much and as normally as possible; however, they are often overwhelmed with insurance claims and responsibilities.

- They need time off for treatment without losing pay
- They need flexible schedules with intermittent part-time or work-at-home options

Whether employees are dealing with their own cancer or caring for loved ones, employers represent vital lifelines. Employers can support employees and their families in many ways, including:

- Offering alternative options to continue employment
- Maintaining compensation and/or offering paid time off
- Providing access to resources
- Helping navigate health insurance
- Training managers on how to support employees and workgroups
- Providing flexibility and encouraging managers to offer options
- Sustaining professional development opportunities

Benefits of these accommodations for employers include:

- Retaining a valued employee (90%)
- Increasing the employee's productivity (72%)
- Avoiding the costs of training a new employee (60%)
- Increasing the employee's attendance (55%) (cancerandcareers.org)

For more information and resources visit
<http://www.cancerandcareers.org/>

Caregiving for Children with Special Needs

More families – one in five households with children – are raising children with chronic physical, developmental, behavioral or emotional conditions that require special health care services (Health Resources and Services Administration, 2018). This is due to the growing incidence of some conditions such as autism, attention deficit hyperactivity disorder (ADHD), and asthma, as well as the improved survival of children with conditions such as cystic fibrosis and congenital heart disease. Seven in ten caregivers of children with special needs indicate they were employed at some point while they were caregiving (National Alliance for Caregiving and AARP, 2009).

- 20% of youth ages 13-18 live with a mental illness. 11% of youth have a mood disorder; 10% a behavior or conduct disorder; 8% an anxiety disorder (National Alliance on Mental Illness, 2018).
- Attention deficit hyperactivity disorder (ADHD) is characterized by inattention, hyperactivity, and impulsivity. An estimated 9% of children ages 3-17 have ADHD (National Alliance on Mental Illness, 2015).
- Suicide is the third leading cause of death in youth ages 10-24. 90% of those who died by suicide had an underlying mental illness (National Alliance on Mental Illness, 2018).
- Type 1 Diabetes in children requires consistent care and daily management of the condition (Mayo Clinic, 2017). During 2011-2012, an estimated 17,900 children and adolescents younger than age 20 were newly diagnosed with type 1 diabetes in the United States (CDC National Diabetes Statistics Report, 2017).

“There is much talk about Exceptional Caregiving but very little as it relates to The Invisible 9%; the approximate 9% of the workforce who is caring for a child or other dependent with special needs. These dedicated employees are often invisible relative to their unique issues because many fear to disclose. Many purposely don’t place photos of their child with special needs on their desk, don’t participate in Take Our Daughters and Sons to Work Day or other business-related events. When these parents do disclose, issues related to employee health benefits, job mobility, promotion, and others begin to surface which are often misunderstood.”

— NADINE VOGEL, CEO, SPRINGBOARD CONSULTING, LLC

“Because of my employer’s flexible work environment, I was able to return to work and still diligently take care of and manage my daughter’s chronic disease (Type 1 Diabetes). Having that flexibility allows me to respond to the unpredictability of her disease and enables me to field daily phone calls from school nurses and from my daughter, as well as attend doctor’s visits regularly. A flexible work culture can ease the stress of managing chronic illnesses, knowing that you are supported and can take the time needed to respond to family health issues.”

— FISCAL SPECIALIST AND WORKING MOM

Time Spent on Caregiving

- On average, caregivers provide 20 hours of care per week. 13% of family caregivers are providing 40 hours or more of care a week (National Alliance for Caregiving and AARP, 2009).
- 55% of current family caregivers expect to continue to have some caregiving responsibility in the next five years (National Alliance for Caregiving and AARP, 2015).

Family Responsibilities Discrimination

Family Responsibilities Discrimination (FRD), also called caregiver discrimination, is employment discrimination against workers based on their family caregiving responsibilities. While most family responsibilities discrimination plaintiffs are women, men are increasingly facing family responsibilities discrimination in the workplace as they care for their families.

Family responsibilities discrimination affects employees of every income level and in every industry. Cases have included those in low-wage jobs (grocery clerks, nurses’ aides), pink-collar jobs (administrative assistants, teachers), blue-collar jobs (police, firefighters), and professional/managerial jobs (lawyers, doctors, executives).

— CENTER FOR WORKLIFE LAW

Workplace Support

Flexibility is perhaps the most important workplace tool needed by all exceptional caregivers to help them remain employed and productive. Caregivers face the challenge of juggling responsibilities and often create patchwork arrangements to provide care – the more intense the care, the more juggling. For those caregivers in the workforce, some work only when children are in school, elders are in day care, or when other caregivers are available. Couples may stagger work shifts to ensure continuity of care between household members. Still others arrange to work from home occasionally or on a regular basis, often with flexible hours and in-home help.

Even with the ability to make adjustments on the job, caregivers may still struggle in the workplace due to barriers created by unsupportive supervisors and co-workers. As a result, they may be reluctant to disclose their caregiving situations for fear of stigma, blame, or discrimination. Employee assistance programs can help by facilitating training for supervisors and co-workers to help them understand the impact of caregiving on the workplace and how they can help.

This Briefing includes a variety of best practice scenarios. The following is a list of benefits and work-life initiatives that can help support exceptional caregivers:

Flexibility <ul style="list-style-type: none">• Flexible schedules• Reduced work schedules• Telecommuting• Leaves of absence• Paid sick days to care for dependents	Benefits <ul style="list-style-type: none">• Comprehensive medical and dental plans• Disability insurance• Long-term care insurance• Healthcare Flexible Spending Account• Dependent Care Assistance Plan (DCAP)
EAP and Work-Life Services <ul style="list-style-type: none">• Resource and referral services• Emergency and backup dependent care• Dependent care and respite reimbursements• Geriatric case management• End-of-life support information• Caregiver networks or support groups	Information and Educational Materials <ul style="list-style-type: none">• Manager training• Online resources• Lending library• Newsletter• Seminars• Caregiver fairs

NORTHROP GRUMMAN

Northrop Grumman: Cancer and Caregiving

Northrop Grumman Corporation is committed to supporting employees coping with cancer, and also providing help for their caregivers and family members.

- Northrop Grumman highlights the most valuable cancer resources on the Benefits & You and Employee Assistance Program (EAP) websites. These websites provide updated and comprehensive cancer related information year round.
- EAP case management to include consultations, counseling, work-life services and assistance with workplace accommodations as needed.

- Webinars designed to inform employees and managers regarding the latest cancer resources and treatments. Additional customized webinars on the subject of cancer can also be provided upon request.
- Workplace transition support is available to assist employees returning to work from treatment of cancer, or from caring for a family member
- Advocacy and support through the Employee Assistance Program and the Women's Employee Resource Group

Northrop Grumman is a National Sponsor of the Relay for Life, establishing a long-term commitment to support research, patient assistance and services to those who are fighting cancer.



The EY organization is committed to creating a culture that allows their people to bring their best selves to their work and personal lives. That means providing critical support and resources to their people who are caregivers too. EY defines caregivers broadly, giving people who are outside of the traditional family unit an opportunity to participate in these groups and benefit from the resources.

The Today's Families Network (TFN) provides support, mentoring, networking and advocacy for all families in many stages and circumstances. Additionally, for caregivers with more specific needs, we offer a Parents Network for Families of Children with Special Needs, a Caregivers Circle for people caring for adult loved ones, and a First Responders group for the friends and family members of police, fire, military or other frontline providers.

The Ernst & Young LLP employee assistance and resource and referral program, EY Assist, provides a wide range of services to support families—including the national campaign, We Care—to address the stigma of mental illness and addictions. We Care provides opportunities to share the impact of personal challenges, including caring for loved ones with an addiction or mental health issue.



Bristol-Myers Squibb

Employees at Bristol-Myers Squibb Company (BMS) work passionately to advance science for patients with serious diseases. As of January 1st, 2018, U.S. employees are being given expanded paid time off – up to eight weeks paid leave – for critical life events including caregiving for seriously ill family members and the care of newborn, foster or adoptive children. BMS' inclusive new family care leave program broadens the definition of family to include all types of caregivers and family members of all ages who need care. This generous and inclusive family-friendly benefit is part of the company's commitment to meeting the needs of its diverse workforce through an innovative, market-leading approach.

Flexibility is a key feature of the program. Employees can use their paid leave all at once or in intervals throughout the year, based on their personal situations and consistent with the policy terms. The BMS program helps the company achieve its commitment to attracting and retaining the best talent to help discover, develop and deliver innovative medicines that help patients prevail over serious diseases.

Raytheon

Raytheon supports their employees' well-being through a number of programs, services and resources specific to caregiver support:

Flexible Work Arrangements

- Employees have the opportunity to work with their managers to identify changes in work schedules (remote, change of start/end time)

Employee Resource Groups

- Raytheon has 9 employee groups to support employees, including the Raytheon Alliance for Diverse Abilities (RADA)

FMLA

- Offers unpaid leave for care of a family member up to 480 hours

Health Advocate

- Available for employees and family members to assist with challenges with medical plan/claims/finding a doctor/etc.

Bright Horizons

- Subsidized Child, Adult and Eldercare back-up services and discounted rates for full-time centers
- CareDirect – Access to database of caregivers with free background checks
- New Parents have 10 additional days of back-up care available in the first year (applies to adoptive families as well)

LifeResources-EAP Worklife Program

- Onsite EAP across Raytheon; telephonic and web-based support available 24/7
- Eldercare Facilities Interview Guide, Nursing Home Checklist, Aging Parents Kit and Free in-home eldercare assessment
- Parent resource kits: baby, toddler, school years, teenage years
- Special needs navigator for parents of children with disabilities
- Monthly caregivers webinar series

Conclusion

Right now someone you know – a friend, a family member, a neighbor, a co-worker – is an Exceptional Caregiver. They may be struggling silently to balance the needs of their loved ones with the needs of their families and their jobs, while trying to maintain some level of self care. When forced to choose between caregiving and work, caregivers may take time off or leave their jobs altogether. Caregivers should not have to choose. Employers can offer support by providing flexibility, comprehensive healthcare plans and access to financial and informational resources. We will all face these issues – in our families, our communities, and our workplaces in some way – if not now, in the future. Employers who are able to support their employees through these caregiving challenges will retain valued workers and help ease some of their stresses, leading to higher loyalty and engagement.

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Many thanks to Northrop Grumman for their generous sponsorship of this briefing.

A Publication of the Boston College Center for Work & Family

About this Series

Written for an executive level audience, the Boston College Center for Work & Family Executive Briefing Series addresses topical and strategic issues of particular relevance to the current business climate. The series highlights research findings, data trends and best practices in a concise format, aiming to foster action-oriented dialogue within organizations. Each issue features an accompanying PowerPoint presentation that captures key points and includes a section for practitioners to customize and add organization-specific data.

About the Center

Since its founding in 1990, the Boston College Center for Work & Family (BCCWF) has been a leader in helping organizations create successful workplaces that support and develop healthy and productive employees. We provide a bridge linking the academic community to leaders in employment settings who are committed to promoting workforce effectiveness. With 100 employers as our corporate partners, the Center for Work & Family positively impacts the lives of nearly 4 million employees through research, education and contributing a leading voice to conversations on contemporary issues around work and life.



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