

Boston College Center for Work & Family

E X E C U T I V E B R I E F I N G S E R I E S

# **Exploring the Complexities of Exceptional Caregiving**

*This presentation is a companion to the Boston College Center for Work & Family Executive Briefing Series. It is designed to be customized by your organization. Please feel free to cut and paste these slides into your own format, and to use the questions provided as a guide to develop your own presentation. If you do not have a copy of the full Briefing, please email: [cwf@bc.edu](mailto:cwf@bc.edu).*

# Who Is a Caregiver?

Anyone who provides unpaid assistance to someone else who is, in some degree, incapacitated and needs help:

- Husband who has suffered a stroke
- Wife with Parkinson's disease
- Mother-in-law with cancer
- Grandfather with Alzheimer's disease
- Son with traumatic brain injury from a car accident
- Child with muscular dystrophy
- Friend with AIDS

—*Family Caregiver Alliance*

# Why Care About Caregiving?

- 1 in 5 adults is a caregiver
- 1 in 5 households with children cares for a child with special needs
- 1 in 2 men and 1 in 3 women will be diagnosed with cancer
- 1 in 10 people over 65 and 1 in 2 people over 85 will develop dementia

# Caregiving Is More Complex

- Increasing life spans
- Changing family structure and lifestyle
- Having children later in life
- Geographically dispersed families
- Children with severe disabilities living at home
- Multi-generational caregiving

# What Is Exceptional Caregiving?

*Exceptional Caregiving describes caregiving situations that have emerged from societal shifts that 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, exceptional caregivers are feeling the squeeze — between family and career, guilt and ability, time and distance, and finances and responsibilities.*

# What Distinguishes Exceptional Caregiving?

## Typical Child Care

- Constant care that diminishes
- Extraordinary input of time and energy
- Easier as time goes by
- Few interruptions are emergency-driven
- Child grows increasingly independent
- Requires some lifestyle adjustments
- Challenges and successes are easily shared
- Heightened exposure to celebrating achievements

## Exceptional Care

- Constant care that escalates
- Extraordinary input of time and energy
- Harder as time goes by
- Many interruptions are emergency-driven
- Individual grows increasingly dependent
- Requires numerous lifestyle adjustments
- Challenges are rarely shared; successes are fewer
- Heightened exposure to illness and death

# Who Are the Caregivers?

- 1 in 5 adults is a caregiver
- 33.9 million adults provide unpaid care to someone aged 50+
- 9% to 13% of households with one or more persons aged 30 to 60 are comprised of dual-earner, sandwiched-generation couples
- 8.9 million caregivers (20% of adult caregivers) care for someone aged 50+ who has dementia
- 9 million children younger than 18 (12.8% of all children) have special health care needs
- 6% of adult caregivers provide care for an ill or disabled spouse

## Exceptional Caregivers on the Job

| <i>Work adjustments made by caregivers</i> | <i>All caregivers</i> | <i>Caregivers with the most intense responsibilities</i> |
|--|-----------------------|--|
| Arrive late, leave early, take time off    | 57%                   | 83%  |
| Take leave of absence                      | 17%                   | 41%  |
| Reduce work hours                          | 10%                   | 37%  |
| Quit work                                  | 6%                    | 35%  |
| Turn down promotion                        | 4%                    | 14%  |

## Time Spent on Caregiving

- Average time spent on caregiving: 21 hours per week
- As cognitive impairment worsens, time spent increases substantially
  - For persons with severe dementia, informal caregivers spend 46 hours per week providing care
- 40% of caregivers have been providing assistance for 5 or more years

# Special Case: Caring for Children With Special Needs

- 1 in 5 households with children and 1 in 12 U.S. workers have a child with special needs
- Ceridian LifeWorks Services reports that 10-15% of all requests for assistance involve some aspect of raising a child with special needs
- LifeCare® has seen a 25% increase in special needs cases since 2003 when they provided 23,000 special needs referrals
- In 2006, the Working Mother “100 Best” application included questions – for the first time – about support for children with autism

## **Special Case: Caring for People With Alzheimer's**

- 1 in 10 people over 65 and 1 in 2 people over 85 will develop dementia
- Annual cost of Alzheimer's to U.S. businesses: >\$61 billion
- 20% of adult caregivers provide care for someone with dementia
- 50% of Alzheimer's caregivers are employed full-time

## Special Case: Cancer and Careers

- 1 in 2 men and 1 in 3 women will be diagnosed with cancer
- 59% of men and 61% of women diagnosed with survivable cancer will continue to work during treatment
- Employees with cancer (or employee caregivers) want to remain engaged at work as much – and as normally – as possible

# Business Solutions

- Flexibility
  - Flexible work arrangements
  - Leaves of absence
  - Paid sick time to care for dependents
- EAP & Work-Life Services
  - Resource and referral
  - Backup dependent care
  - Geriatric case management
  - Respite care reimbursement
  - Caregiver support groups
- Benefits
  - Comprehensive healthcare
  - Disability insurance
  - Long-term care insurance
  - Flexible spending accounts
- Information & Education
  - Manager training
  - Lending library
  - Newsletter
  - Online resources
  - Seminars and caregiver fairs

# Business Solutions

- **PricewaterhouseCoopers** changed their health plan to cover speech, occupational and physical therapies for children with developmental delays
- **Toyota Motor Sales, USA, Inc.** employees are offered 3 hours of elder care case management per year, including in-home assessments, facility reviews, post-hospitalization assessments and on-going care coordination
- **Pearson Inc.** established *Prepare to Care* – a proactive elder care planning program that offers free consultations at the workplace with a Geriatric Care Manager

## **Business Solutions**

- **Canadian Union of Postal Workers** supports members with young or adult children with special needs through toll-free access to special needs advisors, a newsletter, educational materials, and subsidies for:
  - Child care and provider training
  - Respite care
  - Recreation programs
  - Transportation
  - Uninsured medical expenses

# Business Solutions

*“I had a newborn baby, a 10-year-old daughter and a 13-year-old stepdaughter when my father-in-law died and my mother-in-law [was diagnosed with] Alzheimer's disease...and she came to live with us.*

*Eventually she needed full-time supervision...I found myself taking her and my young son to respective day care centers many miles apart every morning before...work.*

*As the disease progressed, I had to feed and bathe her. In the morning, I'd get her ready, and often she would tear off her diaper and get back into her pajamas, and we'd have to start all over again...I was a nervous wreck by the time I got to work.*

*With the help of my company, I was able to flex my hours and find the community services and counseling we needed. As a result, this difficult situation turned into one that was workable and a win-win all the way around.”*

— Raytheon employee

Since this time, **Raytheon** has further enhanced its support for caregivers, offering company-paid in-home safety and health assessments, and care planning with certified geriatric specialists.

*“There are only four kinds of people in the world:  
Those who currently are caregivers;  
Those who have been caregivers;  
Those who will be caregivers;  
Those who will need caregivers.”*

— Rosalynn Carter