

The SHRIVER REPORT

Welcome to A Woman's Nation. Women are half the workforce, raise our children and care for our elderly. Now there's a new pressure on this Woman's Nation: Alzheimer's disease. We have learned:

- Women are at the epicenter of the Alzheimer epidemic. Two-thirds of the people over 65 who have Alzheimer's (3.3 million of the estimated 5.1 million) are women. And among the 11.2 million Alzheimer and dementia caregivers in the United States, 60 percent (6.7 million) are women. That is 10 million American women who either have Alzheimer's or are caring for someone with the disease.
- More than half of all Americans now know someone with the disease. Almost 30 percent of Americans now have a family member with Alzheimer's.
- To know Alzheimer's is to fear it: 9 out of 10 Americans who know someone with the disease are concerned that they or someone close to them will get it.
- The annual per-patient cost of Alzheimer's is now \$56,800, the lion's share of it borne by families. Unpaid family caregivers spend \$4 billion a year on their own health care due to the stress and strain of caregiving. The overall cost of Alzheimer's to American government, business and families is a whopping \$300 billion per year and growing.
- Nearly 40 percent of Alzheimer caregivers say they had no choice but to become the caregiver. About 40 percent of women said they're doing the caregiving because they're the only women in their families.
- By large margins, working women find it easier to find good child care than elder care. And 46 percent of working women say they've wanted time off from the job for Alzheimer's care and couldn't get it.
- Depression, cardiovascular disease, diabetes and insulin resistance have all been linked with an increased risk of Alzheimer's.
- Spouses of people with Alzheimer's and other dementias are six times more likely to develop dementia themselves.
- At the same time the federal government is spending about \$6 billion on cancer research and about \$4 billion on research into cardiovascular disease this coming year, it's investing less than \$500 million in Alzheimer research.
- There's no cure yet, but there is hope. Scientists say advances in early diagnosis like biomarkers may point the way to treatments that could slow or stop the progression of Alzheimer's disease.



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A Woman's Nation Takes on Alzheimer's

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A Woman's Nation Takes on Alzheimer's

A Study by Maria Shriver and
the Alzheimer's Association

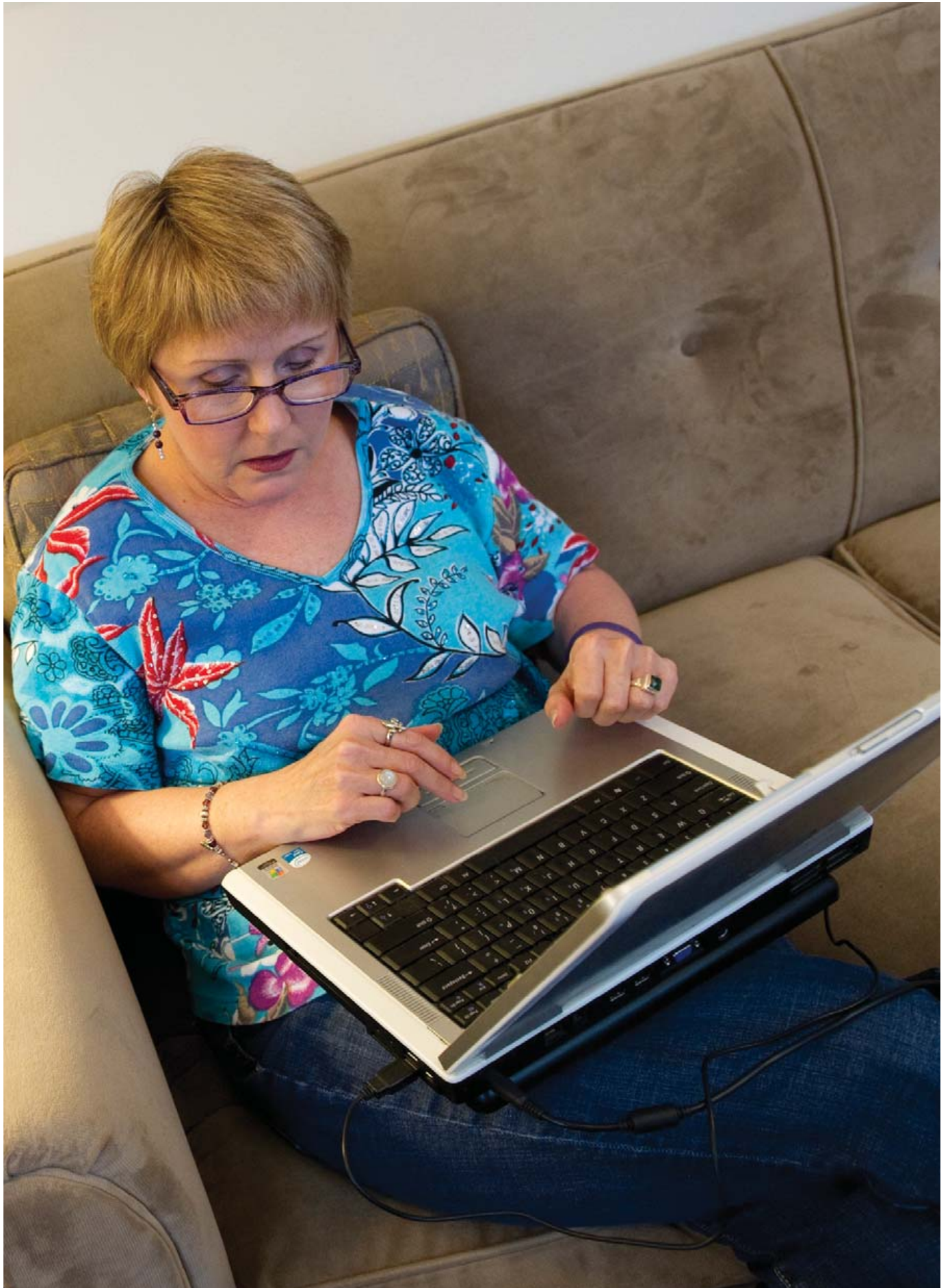
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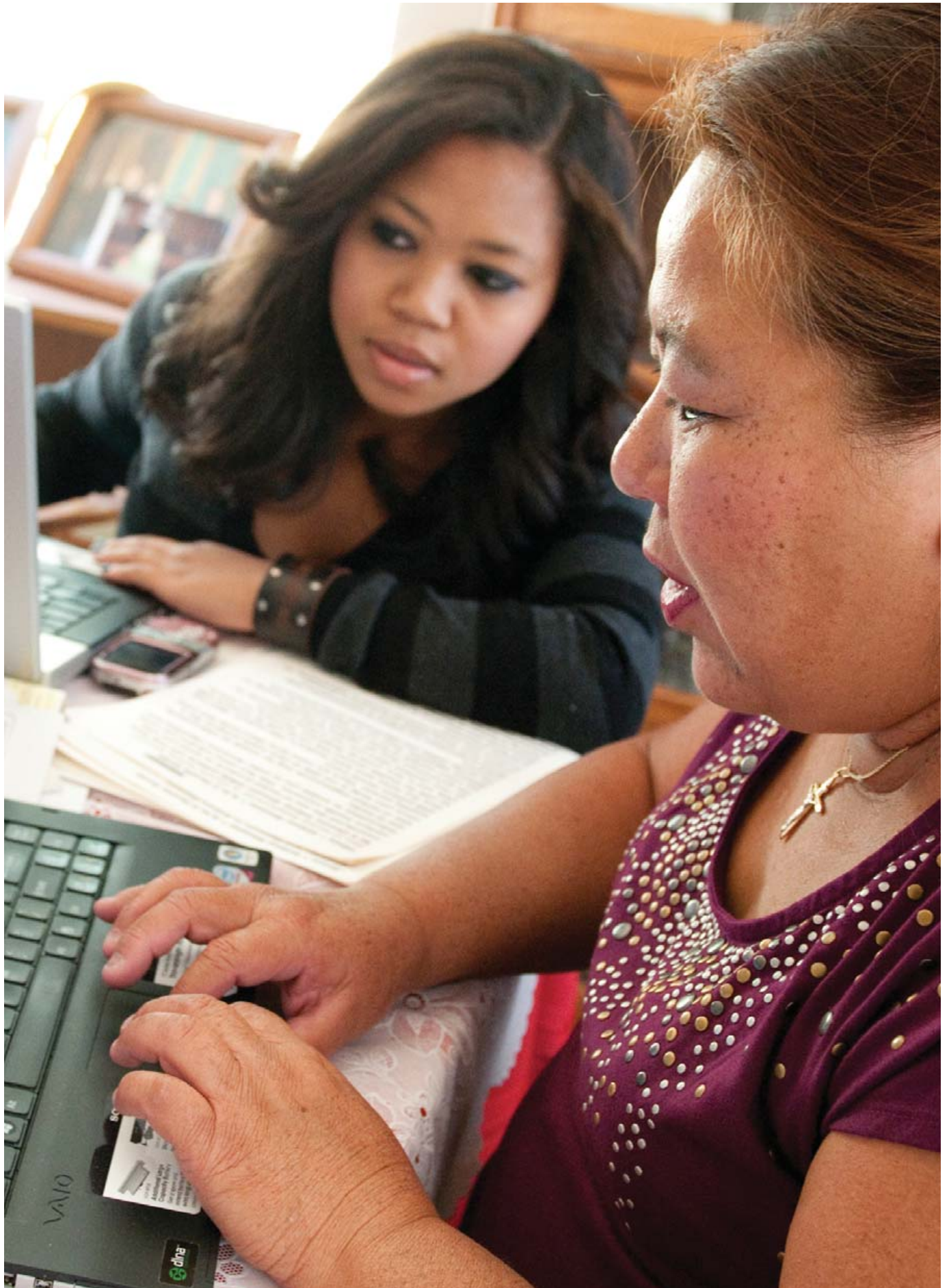
Are We Prepared?
What's the Workplace Impact?

Chapter 5

Alzheimer's, Women and the American Work Force

- Working women get even less support for elder care than they do for child care. By large margins, they find it easier to find good child care than elder care. And 46 percent of working women say they've wanted time off from the job for Alzheimer care and couldn't get it.
- Workers providing Alzheimer care most crave flexibility in their work hour and schedules, as well as better or more Alzheimer care options for their loved ones living with the disease.
- 40 percent of caregivers care for a relative who would fall outside the allowable family members for whom a caregiver can take leave under the Family and Medical Leave Act (FMLA).
- A significant majority of working caregivers of people with Alzheimer's—64 percent—reported the need to come in late, leave early or take time off as a result of their caregiving responsibilities. Another 20 percent reported that they needed to take a leave of absence to care for their family member with Alzheimer's disease.
- Workers providing care to a family member with Alzheimer's disease or other dementias were 31 percent more likely than other caregivers to reduce hours or quit if their family member had the disease but was not experiencing behavioral symptoms, and 68 percent more likely than other caregivers to reduce hours or quit if their family member was also experiencing behavioral symptoms.





CHAPTER 5

*What's the Workplace Impact?**By Ann O'Leary*

Justice Sandra Day O'Connor, who retired from the Supreme Court in 2006, publicly reflected that she had wanted to stay on the court longer but needed to leave her job to provide care and comfort to her husband who was dying of Alzheimer's disease.¹ Former President Ronald Reagan retreated from public life and his ongoing work in 1994 when the progression of Alzheimer's disease made it impossible to continue his efforts.²

While these are the most high-profile cases of the impact of Alzheimer's disease on workers—both those caring for family members with Alzheimer's and those suffering from the disease themselves—such stories play out every day in the lives of many Americans. This chapter will:

- Explore how millions of workers are caught between the dual demands of work and providing care for a relative with Alzheimer's disease.
- Explain how too few workers have access to workplace policies and practices that support Alzheimer's caregivers, and how workplace policies for those living with the disease are nonexistent or underdeveloped.
- Show the trend of rising number of workers being diagnosed with Alzheimer's disease while still in the workplace.
- Recommend solutions for addressing the impact of Alzheimer's in the workplace.

Alzheimer caregivers in the workplace

Alzheimer's disease will have an increasing impact on our workers and workplaces due to the dramatic demographic shift our population and our work force is experiencing. This demographic shift will require more workers to provide care for their family members who are living longer.

The U.S. Census Bureau predicts that the 65-and-older population will more than double from nearly 35 million in 2000 to over 71 million in 2030, going from 12 percent to nearly 20 percent of the population.³ With more Americans living longer and the aging of the baby boomers, the incidence of Alzheimer's and other dementias is expected to increase because it is a disease that primarily impacts adults 65 years of age and older. By 2050, researchers predict that as many as 16 million individuals age 65 and older will be living with Alzheimer's disease, triple the number living with the disease today.⁴

Caregiving falls largely to those who must combine work in the paid labor force with being unpaid caregivers of family members.

This increase in the number of older Americans living with Alzheimer's—combined with a movement to deinstitutionalize elder care and a decrease in the government's commitment to pay for in-home care services for the elderly and disabled—means that more family members will be called upon to provide unpaid care and assistance to loved ones with Alzheimer's.⁵

As the demand for unpaid family care increases for individuals with Alzheimer's, fewer family caregivers will be available to provide the care. While, as mentioned, the population of Americans 65 and older is expected to nearly double by 2030, the population of typical caregivers—adult children ages 45 to 65—is expected to only increase by 25 percent in this same time period.⁶

The math just doesn't add up in terms of the ratio of caregivers to older Americans. In addition, most caregivers today must combine care with work, which makes caregiving all that more stressful. Today, women are half of all workers, and two-thirds of families are made up of dual-worker couples or single working heads of households.⁷ This means caregiving falls largely to those who must combine work in the paid labor force with being unpaid caregivers of family members.

So while many women are no longer at home full-time, the vast majority of caregivers are still women. Sixty percent of all Alzheimer caregivers are women—6.7 million women. Of these women, 56 percent are working.⁸ A 2010 study from the Families and Work Institute on working elder caregivers finds that all working caregivers of elderly family members are equally divided between men and women.⁹ However, this does not appear to hold true for care providers of family members with Alzheimer’s disease—a 2009 survey established that of the working Alzheimer care providers, 62 percent were women.¹⁰

What’s more, today’s generation of Alzheimer caregivers face unique challenges. With many women giving birth later in life, 37 percent of today’s female caregivers are caring for both a family member with Alzheimer’s disease and children under 18 years of age still living at home.¹¹ Many families also now live farther apart, and as a result, the Alzheimer’s Association estimates that somewhere between just under 1 million to just over 1.5 million caregivers are providing “long-distance caregiving.”¹²

The impact on work for Alzheimer caregivers

*My professional life all but stopped. Finding doctors for him and getting him to appointments and coordinating escalating medical needs swallowed entire days.*¹³

While this sentiment was written by Jonathan Rauch, a journalist who was caring for his father who suffered from Parkinson’s disease, it very well could have been written by my own mother. My mother quit her job last year—just six months shy of turning 66, the age to qualify for full Social Security benefits—because she could no longer manage the care needs of her mother who was suffering from dementia yet trying to stay in her own home. A doctor’s appointment rescheduled at the last moment. A fall. A paid-care provider who called in sick. An angry incident between my confused grandmother and the care provider. Each of these episodes sent my mother into further career crisis. Unable to manage her work and satisfy the needs of her employer, she finally just felt she had to call it quits and retire early.

My mother is not alone. The impact of providing care to a family member with Alzheimer’s disease or other dementias causes severe strain on one’s ability to work effectively. According to the working elder caregiver study from the Families and Work Institute, a majority of working caregivers of the elderly (54 percent) report interference between caregiving and work, and one in five current caregivers report experiencing a negative impact at work as a result of this interference.¹⁴ The Alzheimer’s Association’s new Women and Alzheimer’s poll found that a significant majority of working caregivers of people with Alzheimer’s—64 percent—reported the need to come in late, leave early or

take time off as a result of their caregiving responsibilities.¹⁵ Another 20 percent reported that they needed to take a leave of absence to care for their family member with Alzheimer's disease.¹⁶

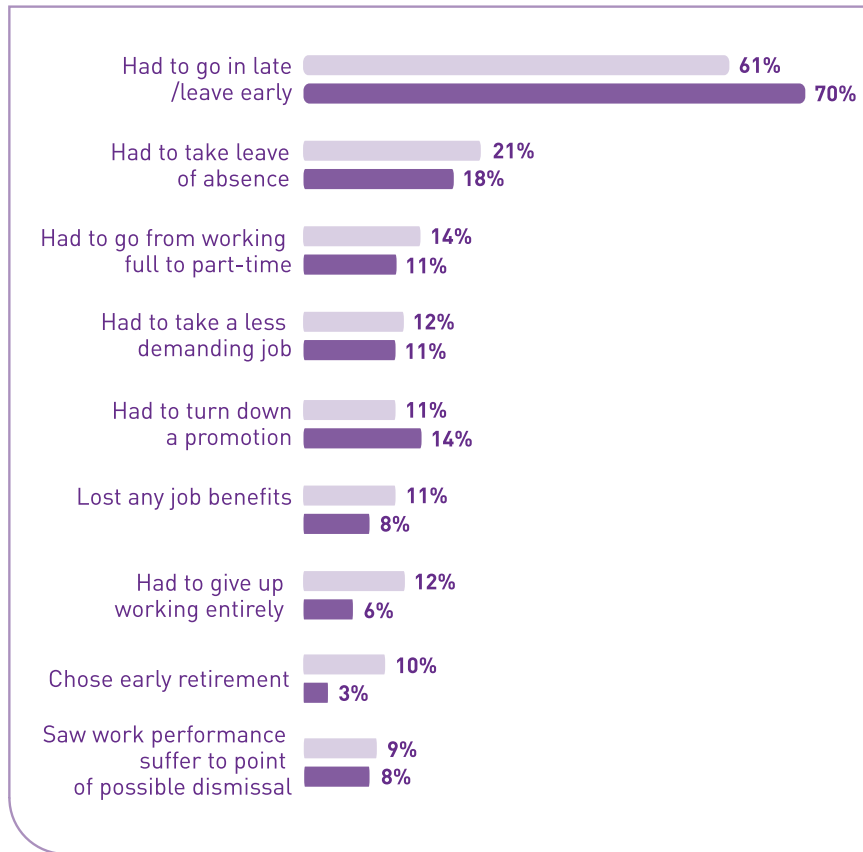
More than 60 percent of working caregivers of people with Alzheimer's reported the need to come in late, leave early or take time off as a result of their caregiving responsibilities.

Some, like my mother, found it impossible to stay in the labor force at the same level. The Alzheimer's Association Women and Alzheimer's poll found that more than a third (34 percent) of women caregivers of people with Alzheimer's had to give up their job.¹⁷ This number is much larger than overall estimates for elder caregivers. According to the 1999 MetLife Juggling Act study, 16 percent of working caregivers quit their jobs.¹⁸ A 2009 survey conducted by the National Alliance for Caregiving and the AARP found that among all caregivers, 10 percent had to quit work or take early retirement.¹⁹ The larger percentage of Alzheimer caregivers quitting their jobs is consistent with other research contrasting Alzheimer caregivers with other elder caregivers. Another study found that caregivers providing care to a family member with Alzheimer's disease or other dementias were 31 percent more likely than other caregivers to reduce hours or quit if their family member had the disease but was not experiencing behavioral symptoms, and 68 percent more likely to reduce hours or quit than other caregivers if their family member was also experiencing behavioral symptoms.²⁰

Workplace policies for working caregivers

These numbers make one thing very clear: Working caregivers of family members with Alzheimer's disease need time and resources to deal with the challenges of providing care and working. The overwhelming majority—61 percent—need flexibility in their work schedules and time off to provide care. While we don't know the exact reasons that over one-third of working women who are Alzheimer caregivers are quitting their jobs, we do know that certain workplace policies help caregivers stay employed while taking the time needed to care for their loved ones.

With nearly half of all workers expecting to be providing family care for an elder in the next five years, according to the working elder caregiving study by the Families and Work

FIGURE 1 : The effect of caregiving on work:

Source: Alzheimer's Association Women & Alzheimer's Poll, 2010 Caregivers: ■ Women ■ Men

Institute, these policies are important for all elder caregivers. But the difference between Alzheimer caregivers and other elder caregivers is that the disease often requires the provision of family care for many years. Forty-three percent of caregivers of people with Alzheimer's disease have been providing care for one to four years compared to 33 percent of other elder caregivers.²¹ In addition, Alzheimer's is an unpredictable disease, particularly at the early stages. The longevity and unpredictability put a greater burden on working caregivers for the time and financial resources necessary to fully support their family members.

This section will explore the state of existing policies to support workers with Alzheimer caregiving responsibilities by examining federal laws and government programs. It then will highlight voluntary employer practices, including best practices offered by employers to aid workers in balancing work with caring for a family member with Alzheimer's.

Government policies to aid working caregivers

According to the newest Alzheimer's Association poll, workers caring for elder family members most crave flexibility in their work hour and schedules, as well as better or more Alzheimer care options for their loved ones living with the disease.²²

Flexibility for working caregivers

Flexibility is the number-one wish of elder caregivers—flexibility to set hours, reduce their schedules or change the location of their workplace—or combine flexibility alternatives to make work fit with their needs while providing care to their family member with Alzheimer's disease.²³

Workers caring for elder family members most crave flexibility in their work hours and schedules, as well as better or more Alzheimer care options for their loved ones living with the disease.

We know from the Families and Work Institute's National Study of Employers that most employees have scant access to workplace flexibility—particularly the flexibility needed by caregivers of family members with Alzheimer's. Most Alzheimer caregivers report the need to come in late or leave early. Yet only 37 percent of employers report that they periodically allow most or all employees to change start and quitting times, and only 10 percent allow most or all employees to change starting or quitting times on a daily basis.²⁴ Other caregivers report the need to reduce hours, yet only 13 percent of employers allow most or all of their employees to move from full-time to part-time and back again while remaining in the same position or level.²⁵

To date, there is no law requiring employers to offer flexible or predictable work schedules and these numbers show that not very many businesses voluntarily offer flexibility. In the previous *Shriver Report* and a follow-up report titled *Our Working Nation*, Heather Boushey and I recommended that Congress require employers to set up a process to allow employees the right to request flexible or predictable schedules. This would spark conversations about the needs of employers and employees and protect workers with the right to ask for flexibility.²⁶ The ability to set up a system of flexibility is particularly important for caregivers of people with Alzheimer's who may need to set up flexible schedules—and possibly revise them—over many years as they balance work and long-term care.

Time off to provide family care

Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) is a powerful tool for family members caring for loved ones with Alzheimer's. It allows for covered workers to take up to 12 weeks of unpaid leave per year, which can be taken through reduced schedules or intermittent leave, to care for a spouse or parent with Alzheimer's disease.²⁷ This provides important flexibility to allow workers to take job-protected leave in order to provide the continual, long-term family care that Alzheimer's disease often demands. Twelve weeks of leave taken intermittently or as a reduced schedule allows workers to be creative. For example, a worker could take FMLA leave for one day a week for the entire year or for 1.5 hours per day for the entire year to provide care to a family member with Alzheimer's. Or, as another example, a family member providing long-distance care could take three days off at 20 different times in the year to provide care to a spouse or parent with Alzheimer's disease.

Forty percent of Alzheimer caregivers are providing care to a relative not covered under the Family and Medical Leave Act.

However, the law falls short in several key respects for working caregivers of family member's with Alzheimer's.²⁸ First, the definition of family is limited to care for children, parents and spouses. This means that a worker cannot take leave to care for a parent-in-law, a grandparent or another relative with Alzheimer's disease. Yet according to the newest Alzheimer's Association poll, 40 percent of caregivers are providing care to a relative who would fall outside the allowable family members for whom a caregiver can take leave under the FMLA, including grandparents, siblings, in-laws, aunts and uncles.²⁹ The FMLA also only covers about half of all U.S. workers due to eligibility requirements for workers and size requirements for employers.³⁰ Because FMLA does not cover these caregivers, they are at the mercy of their employer when they need to take leave for work to provide care.

Second, the law allows employers to require their workers to substitute any of their accrued paid vacation leave, personal leave or family leave for FMLA leave. This means that some worn-out working caregivers only get leave to care for their family member with Alzheimer's disease and have no time left over for a vacation day to restore their own energy and health, or a sick day to recover from their own illness. This limitation is particularly troubling given the finding from the newest Alzheimer's Association poll

showing that 68 percent of women Alzheimer caregivers report emotional stress, and 51 percent report physical stress from caregiving.³¹

Finally, the FMLA is unpaid, a financial burden that is particularly challenging for caregivers who must miss work or reduce their hours, sometimes for years, as they care for their ailing relative with Alzheimer's.

Income and retirement savings replacement

The newest Alzheimer's Association poll also showed that the majority of working Alzheimer caregivers, 55 percent, were the primary breadwinners of the household, which means that quitting or reducing hours with no wage replacement would cause a severe strain on the family.³²

Paid family leave

Two states—California and New Jersey—have programs that provide wage replacement for workers taking leave to care for a family member with Alzheimer's disease. Both programs allow six weeks of wage replacement if your employer provides leave, and allow it to be taken on an intermittent basis.³³ President Obama proposed a 2011 budget that includes funding to allow new states to develop paid family leave programs and to expand the reach of the programs in existing states.

The majority of working Alzheimer caregivers are the primary breadwinners of their household.

The need for income replacement while Alzheimer caregivers are temporarily out of work caring for their ill family members is crucial, as demonstrated by Brent Fulton's chapter on the economic impact of Alzheimer's disease. These programs are an important first step, but they could be strengthened. For starters, California and New Jersey should boost efforts to spread the word to workers about these programs. Currently, awareness is very low that these programs are available and can be used for caregiving. For example, in a 2007 survey, only 28 percent of Californians knew about the California paid family leave program.³⁴

Furthermore, these paid-leave programs offering wage replacement should be coupled with FMLA protection—requiring employers to allow workers to take leave and to pro-

vide them the same job upon their return. Right now, state paid-leave programs allow many more workers to qualify for the leave than to qualify for FMLA. That means many workers are unable to access the paid-leave program because their employers won't give them the time off to provide the care in the first place.

Social Security credit

In addition to lost wages, working caregivers—particularly women who may have taken time away from the workplace to care for children—lose the ability to earn credits to qualify for Social Security when they take time off to provide care for a relative with Alzheimer's disease. While Social Security provides some protection for married women by allowing women to receive 50 percent of their husband's Social Security benefits, it leaves too few women with little resources in retirement. Rep. Nita Lowey (D-N.Y.) has introduced a bill that would allow workers to earn Social Security credits for up to five years when providing unpaid care for an average of 80 hours a month.³⁵ This proposal would help workers—who are disproportionately women—take leave to provide care while not sacrificing their own retirement security to do so.

Financial support to provide paid caregivers

In-home health and support services

While time off to provide direct family care is essential, it is often not enough. Family members with Alzheimer's disease often need round-the-clock attention. To ensure fewer work disruptions, working caregivers need support for paid home healthcare services. In fact, the newest Alzheimer's Association poll found that workers most wanted more or better care options for their loved ones.³⁶ Care options, outside family caregivers, can provide great relief to family members and allow caregivers to stay in the work force. In one study of government expenditures for formal residential and home-help for the elderly, researchers found that an increase in paid elder caregiving increased the labor force participation rates of women by relieving their informal care burden.³⁷ Unfortunately, state budget cuts threaten paid caregiving services by withdrawing state Medicaid funds for such services.³⁸

Dependent care tax credit

In addition to the financial burden of missing work to provide care, many working caregivers of Alzheimer's disease spend their own resources to provide care while they are at

work. Unlike funding paid for child care, Alzheimer and elder caregivers receive no tax relief for the funds that they spend in this way. Heather Boushey and I previously recommended that Congress consider expanding the Child and Dependent Tax Credit, or create an independent caregiving credit, to allow workers to receive some tax relief for caregiving expenses even when the person in need of care doesn't live with the caregiver and is not entirely financially dependent.³⁹

Business policies to aid working caregivers

Businesses do not need to wait for government action to provide their workers with the policies discussed above. In fact, many do so on their own. The most common workplace policies offered by employers to accommodate employee elder caregiving needs include time off to provide care without losing one's job (75 percent of employers), eldercare resource and referral services (31 percent) and dependent care savings accounts (23 percent).⁴⁰

As discussed earlier, the provision of time off and flexibility is very uneven for workers. Too few have the protection afforded by our existing laws, and too few businesses offer these benefits on their own accord. The essay by Cathleen Benko and Anne Weisberg offers one promising model of how to provide needed flexibility for workers across their careers, a model built on rewarding employees on their career results.

One of the most promising resource and referral workplace practices to support working caregivers caring for a family member with Alzheimer's is an employer-provided geriatric care manager. Research has shown that employers that provide intensive geriatric care manager services—individualized services to employees to help with care planning from arranging adult daycare or assisted living services to answering questions about the progression of the disease to helping explain insurance coverage—had positive outcomes for their employees and their business.⁴¹ Their employees were more on-task and healthier over time.⁴² For example:

- IBM offers its employees six hours per year of paid elder services such as care management in the form of a geriatric nurse or social worker who conducts home assessments, develops a home care plan and researches the availability, costs and quality of alternative housing.

- Time, Inc., provides a medical-decision support program that gets employees in touch with a medical researcher and a physician who share the latest research about diseases such as Alzheimer's.⁴³

Much more can be done by the government and private employers to provide the needed supports—from time off to informational and financial resources—to aid caregivers of family members with Alzheimer's disease. The long-term and unpredictable nature of Alzheimer caregiving takes dedicated and ongoing negotiations between employers and employees to ensure that the needs of both parties are met. A way to ensure that these conversations take place would be to require businesses to allow employees the job-protected right to request flexibility.

Workers with Alzheimer's disease

The challenges associated with the millions of working caregivers who are balancing work and care have had the largest impact on workplaces to date. But workers with Alzheimer's disease will become an increasing presence in the work force in the years ahead, creating new challenges that workplaces are not yet prepared to handle.

Two sets of workers face Alzheimer's disease while still working. First, workers who have younger-onset Alzheimer's disease—Alzheimer's diagnosed before the age of 65—are most likely to still be in the work force because workers under 65 years of age have a higher work force participation rate in the general population than older workers. Up to 130,000 individuals with younger-onset Alzheimer's disease could face this diagnosis while still working.⁴⁴

Second, individuals over the age of 65 who have Alzheimer's disease could still be working when they receive their diagnosis. Currently, the number of individuals over 65 who have Alzheimer's disease while still working could be as high as 464,000 but could increase to as high as 848,000 by 2050 because older workers are staying in the work force longer.⁴⁵

Aiding workers with Alzheimer's disease

Alzheimer's disease ultimately forces individuals to withdraw from the work force. But the path to leaving the work force can be a difficult one—both for workers and for employers. This section will outline the challenges that workers and employers face as a result of ill-fitting laws and social policies, and a lack of model practices to aid employers.

Workers may begin experiencing symptoms of Alzheimer's disease—short-term memory loss, language problems and loss of knowledge, difficulties in planning and organization, impaired decision making and accompanying anxiety and depression⁴⁶—long before knowing what is wrong or receiving a diagnosis. This problem is especially true for individuals with younger-onset Alzheimer's disease, as colleagues, family members and even medical professionals often don't expect Alzheimer's in a person who is in his or her 40s or 50s; thus, a diagnosis can take months or even years.⁴⁷ Employers may be faced with a worker who was once a reliable and strong member of the work force becoming increasingly unable to perform, and the employer may not have the tools to discuss the problem with the worker in a constructive way. In many instances, neither the employer nor the worker knows the nature of the problem, but they do recognize that the worker can no longer perform and, as a result, in two-thirds of the cases the employer fires the worker or the worker voluntarily quits, often causing great financial hardship to the worker and his or her family.⁴⁸

Americans with Disabilities Act

Alzheimer's disease does not fit neatly into our main law protecting people with disabilities for workplace discrimination, the Americans with Disabilities Act (ADA). Title I of the ADA prohibits employers from discriminating against qualified applicants or employees with disabilities and requires employers to provide necessary reasonable accommodations to enable qualified workers with disabilities to participate in and enjoy equal employment opportunities. However, a number of barriers exist for workers with Alzheimer's disease to access their rights under the ADA.

First, workers must recognize that they have a disability, defined as substantial limitation in performing a major life activity, in order to request and receive accommodations. When symptoms arise, it may take time before the worker recognizes that there is a problem and, even then, as noted earlier, the road to diagnosis is often a long one. In fact, according to a study conducted for the U.S. Preventative Services Task Force, two-thirds of primary care physicians misdiagnose the disease in their younger patients.⁴⁹

While an exact diagnosis of Alzheimer's disease is not necessary to receive an accommodation, the employee must nonetheless establish that she has a medical condition that is limiting her ability to perform a major life activity and that it cannot be corrected with a mitigating measure.⁵⁰ Requesting and receiving an accommodation for symptoms arising from Alzheimer's disease without a correct diagnosis could be challenging. For example, if an employee is misdiagnosed with depression and given medication to miti-

gate the depression, the employee may try to continue working and ask for no accommodation with the hopes that the medication would correct the problem.

The delay in asking for accommodation and continuing frustration by the worker who is not getting better could ultimately lead to a termination of employment. As one worker aptly stated, “By the time I was given a diagnosis, I had had several years of failing at my job, been forced to retire, become penniless. Had I had a diagnosis, (my employer) would have been legally bound to give me a lesser job. What a waste!”⁵¹

Second, if and when a worker receives the diagnosis, he or she must still be qualified for the job and able to conduct it with reasonable accommodations. At least one court has noted that there are no reasonable accommodations for Alzheimer’s disease: “If the plaintiff did, indeed, have Alzheimer’s disease, the defendants would not be liable pursuant to the ADA for their decision to terminate his employment because no reasonable accommodation would have been possible.”⁵² This may be true for many workers with Alzheimer’s disease because by the time they receive the diagnosis, their cognitive impairment is so great that they may be unable to perform their job even with accommodations.⁵³

The Equal Employment Opportunity Commission (EEOC) puts out guidance for employers and employees to ensure that workers who have specific diseases—including epilepsy, diabetes, cancer and intellectual disabilities (previously known as mental retardation)—are not discriminated against and receive appropriate accommodations.⁵⁴ No such guidance exists to aid employers of workers who have degenerative cognitive disabilities, such as Alzheimer’s and other dementias. Such guidance could be particularly helpful for employers who suspect that their employee has Alzheimer’s disease but do not know how to approach their employee to offer support and guidance. The EEOC should consider putting out guidance that helps employers and employees with each stage of Alzheimer’s disease in the workplace—the detection of the problem; the diagnosis of the disability; the accommodation, where still possible, of workers who would like, and are able, to remain in the work force; and the aid for employees who ultimately must transition out of the work force when they can no longer perform their job even with reasonable accommodations.

Given the potential for a rising numbers of workers who may receive such diagnosis while in the work force, this guidance would have a tremendous impact on employers and employees dealing with Alzheimer’s—both in providing accommodations while the individual is still able to work and in aiding employers in how to help employees to effectively transition out of the workplace. In addition, guidance on accommodations could aid those workers in staying on the job for a little longer, which benefits both the employer

and the employee. For the employer, it can allow the worker to pass on their institutional knowledge before losing their memory and can ensure that a replacement worker is well trained.⁵⁵ For the employee, it can mean additional income and more time in which the person remains engaged in the work that may have defined her before the disease struck.

Social Security Disability Insurance

For all workers with Alzheimer's disease, they will ultimately need to stop working, and when they do, they will need financial support to replace their income from their job in order to sustain themselves and their family.

Workers who are permanently disabled qualify for Social Security Disability Insurance (SSDI). In March 2010, the Social Security Administration (SSA) expanded its list of Compassionate Allowances, which allow individuals with certain diseases and medical conditions to quickly qualify for disability insurance, to include early-onset Alzheimer's disease (also known as younger-onset Alzheimer's disease, with both terms referring to those individuals diagnosed under the age of 65).⁵⁶ This change will mean that workers with early-onset Alzheimer's disease who previously may have had to wait years to qualify for SSDI—awaiting the progression of the disease yet unable to work—will be able to qualify within a matter of months.

Employers and workers need more information both about workplace accommodations for individuals with Alzheimer's disease who are still able to remain in the workplace and about the availability of SSDI for workers no longer able to work due to early-onset Alzheimer's disease. The EEOC and the SSA should team up to provide joint guidance to employers and workers on both ADA workplace accommodations, as well as the availability of qualifying for SSDI through the Compassionate Allowances program.

Model employer practices

With little guidance from the government on what to do when faced with an employee who has increasing cognitive decline, employers are left on their own to determine how to support their employees. Often, with no experience in doing so, they simply fire the employee as the employee becomes progressively unable to work. But there are steps that can be taken. First and foremost, employers should be encouraged to urge their employees to seek medical attention when they notice cognitive decline in the workplace. Once a diagnosis is made, the employer should actively work with employees in either creating

an accommodation plan or accessing both private disability insurance available through the employer and, once they leave the workforce, SSDI.

Conclusion

Alzheimer's disease already impacts workplaces across the country due to the millions of workers who are combining work with unpaid care of a family member or friend with Alzheimer's disease. Our laws and the voluntary practices of businesses have room to be improved—to expand the reach of paid leave, job-protected leave, workplace flexibility and resources for caregivers—in order to help caregivers remain financially stable and effectively able to work and provide care. Alzheimer's disease may also soon have a larger impact on workplaces that employ workers living with the disease. The challenges of providing appropriate accommodation and transition plans are real, and the government should do more to ensure that employers and employees understand the rights of employees diagnosed with Alzheimer's disease.

ENDNOTES

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- 44 Approximately 65 percent of all individuals age 55 to 64 are still in the workforce. If individuals with early-onset Alzheimer's disease, 200,000 total, were in the workforce at the same rate, 130,000 would be in the workforce when they received the diagnosis. However, this number would quickly drop upon onset of disabling cognitive impairments. Only 22 percent of workers with such impairments remain in the workforce, which would be approximately 28,600 individuals with early-onset Alzheimer's. Figures derived from Health and Retirement Survey of 2000 as reported in Alzheimer's Association, *Early Onset Dementia: A National Challenge, A Future Crisis* (2006).
- 45 Only 300,000 to 500,000 individuals between the ages of 65 and 74 have Alzheimer's disease and this number is not projected to increase by 2050. The number of individuals 75 to 84 with Alzheimer's disease is 2.4 million in 2010 and is expected to double to 4.8 million by 2050. See L.E. Hebert and others, "Alzheimer's Disease in the U.S. Population," p. 1121. In 2007, the work participation rate of individuals who were 65 and older was 16 percent. See Bureau of Labor Statistics, "Spotlight on Statistics, Older Workers, July 2008, Chart Data," available at http://www.bls.gov/spotlight/2008/older_workers/data.htm#chart_02 (last accessed September 2010). Work participation rates are not broken down further by older age categories. Work participation rates are continuing to climb for older Americans, but given that we don't have the breakdown of the participation rate of our oldest workers, I conservatively estimate a constant rate of 16 percent workforce participation for those in the 65 and older category and derive the high numbers by taking 16 percent of the numbers of individuals with Alzheimer's disease in the 65 to 84 categories.
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