



# Southern Caregiver Resource Center

*Caring for those who care for others*

## **Fact Sheet:** **Thinking of Quitting Your Job to Care for a Loved One?**

### **Read This First!**

If you're a family caregiver facing the often-conflicting demands of a job and caregiving, you're likely, at some point, to find yourself facing a difficult dilemma: In light of the needs of your loved one should you quit your job to provide care?

According to an AARP study of caregivers in the U.S. entitled, *Valuing the Invaluable*, the typical caregiver is a 49-year-old woman caring for her mother. She is also married and employed. All caregivers, whether employed outside the home or not, take on many tasks, including personal care, transportation, food preparation, health care oversight, medications management, companionship, management of financial and personal affairs, and legal and personal advocacy. And although family caregivers are not usually paid, the economic value of this care is truly staggering: In the U.S. it's estimated at nearly \$200 billion a year.

The question is, how do you balance all these essential care responsibilities with the responsibilities of employment? Further conflicts arise if you have

children or additional family responsibilities. There are only so many hours in the day. Yet the long-term, personal, and financial consequences for those who give up their jobs and careers in order to become full-time caregivers can't be underestimated.

### **Tipping Points**

If you're caring for someone with a progressive condition such as Alzheimer's or Parkinson's disease, making this decision can feel even more overwhelming as you anticipate future challenges. Some caregivers point to a specific event or experience that becomes a tipping point in deciding whether to become a full-time caregiver. Here, for example, are some typical situations you might recognize:

- There's a sudden, unexpected change in a loved one's health status, requiring more care.
- You're getting unreliable or inconsistent help from other family members.
- Your loved one is in a potentially dangerous situation, for example, their medications have been mixed up; they wander away from the house; they've fallen; they've

left the stove on; they're vulnerable to phone scams.

- An in-home aide you've hired does not show up for work.
- Your loved one is increasingly isolated as friends have stopped visiting.
- You feel you simply cannot handle the stress of juggling caregiving and your job any longer.

Given these circumstances—but *before* you quit your job—it's very important to have time to fully explore your options. You might even need to take time off or personal leave first to investigate financial and personal implications of remaining in the workforce.

It's also important to know the types of supportive resources in the community that may be available to you. Home delivered meals, transportation services, adult day care, visitor programs, and in-home assistance could help you manage care and allow you to remain in the workforce.

## **Income and Benefits: Long- and Short-term Impacts**

Men and women of middle age are usually at the height of their earning ability and career. They may have worked hard over a period of years to attain their education and to establish their careers and professional lives. They may have achieved seniority at work and become trusted, knowledgeable, and valued employees. Women, more often than men, may have moved in and out of the workforce due to family and caregiving responsibilities. In a recent estimate

([www.caringacross.org/family-caregivers-win-hawaii](http://www.caringacross.org/family-caregivers-win-hawaii)), women caregivers made other types of employment compromises as well, including reducing work hours for an extended period of time, passing up promotions or other opportunities, switching to part-time employment, quitting their jobs, and retiring early.

Time off work means a substantial amount of lost income and savings. The later years of women's work lives can be a time to compensate for income they may not have earned or been able to save earlier.

For anyone in the workforce, giving up a full-time job means more than just foregoing current salary, although that, of course, is the primary concern. It also may mean sacrificing retirement benefits, 401(K) or equivalent contributions (if available), and vesting in other retirement programs. Losing employer-sponsored health insurance is a major consideration.

Significantly, leaving a job also means not paying into Social Security and other benefit programs. When retirement benefits are calculated either in private or public programs, caregiving currently is given no credit of any kind. Work years without any earned income are factored in as "zeros," which significantly reduces final monthly benefit amounts. According to recent Social Security Administration data for newly retired-worker beneficiaries, women average 13 years of zero earnings since age 22. (Note, however, that when applicable, Social Security's spousal and survivor benefits do provide benefits to a spouse who has a lower lifetime history of earned income, which may

help mitigate final benefit amounts.) Another consideration: Even if you are at the minimum age to receive Social Security (62), you will receive less income than if you are able to work for more years, up to age 70. More information is available by contacting the Social Security Administration

More subtle results in terms of retirement for caregivers who leave the workforce could include lack of compounded returns on 401(k) matching contributions, reduced investments and overall savings, and even the inability to finance home improvements that can increase resale value of a home.

When comparing your income with your own expenses and the costs of care, be sure to think carefully about hidden expenses. Consider the cost of living in your area, as well as issues including health insurance, car maintenance, home maintenance, care supplies, respite care, and discretionary spending.

## **Workforce Realities**

It's often quite difficult for women in their 40s, 50s, and beyond to reenter the workforce at their previous full-time level after taking time off for caregiving. Considering the wealth of experience and skills that women in this age group possess, this may seem not only daunting but also unjust. Nevertheless, it's not uncommon and needs to be taken seriously in terms of decision-making. In caregivers' words:

*"I was in senior management and resigned because my husband needed more care. I tried to find part-time work*

*but with no luck. With my high-powered work history no employer will take me 'seriously' for part time work."*

*"I cared for one parent, then the other ... by the time I wanted to return to the workforce in my profession I was unemployable."*

In making a decision about leaving a job or career, it's important to consider your relationship to work and professional life. Caregivers feel a profound sense of duty, responsibility, loyalty, and compassion for their loved ones. At times it may be difficult for caregivers to navigate between their identities and responsibilities as caregivers, and their other sources of meaning and fulfillment. Some questions to ask yourself as you work through this decision:

- If you leave your full-time job, what will you be giving up besides income and benefits?
- How much of your socializing and interpersonal interaction occur at work and work-related activities? Have many important relationships and close connections in your life come from the workplace?
- Does work currently serve as your "respite" from caregiving?
- Has your working life provided you with a great sense of purpose?
- Are your career and your work ethic important examples and models for others in your life, particularly your children or other family members?

- Have you made a comprehensive budget that considers your change in employment status?
- If you receive health insurance through a spouse or partner's employment, do you have a back-up plan if something happens to his/her job?
- How well have you planned for your own retirement?
- Have you considered meeting with a financial planner to determine how leaving the workforce will affect your long-term finances?

## **Medicaid and Caregiver Benefits**

One of the most frequent questions that Family Caregiver Alliance receives is, can I be paid to take care of my loved one? The short answer is it may be possible through Medicaid, but many conditions apply, and there are complicated financial restrictions. It's important to note that at present few options exist in terms of public funds to replace a caregiver's income and salary.

Options that do exist can be changed or rescinded based on the health needs of the person receiving care. In no case are those payments made based on the needs of the caregiver. Medicaid in theory and practice aims to allow people at all stages of life to live at home with as much independence as possible.

Medicaid recipients are encouraged to participate in self-directed plans, in which the care receiver has an overall budget for goods and services that includes caregiving. The caregiver's rate of pay is negotiated to be at least the

state minimum wage, and the role is often filled by a family member or spouse. In California through the Medi-Cal program, this compensated worker role is known as IHSS (In-Home Supportive Services). Such self-directed and consumer-directed programs expanded under the Affordable Care Act; in the current political climate, however, their future is not necessarily secure.

- Medicaid serves lower-income adults and families who do not have significant financial assets. Spousal impoverishment protections under Medicaid, however, may protect a certain amount of assets for the "well spouse."
- Family caregivers are often relieved to know that financial compensation may be available to them through Medicaid; however, this work does not count towards accrual of Social Security credit. In addition, through Medicaid, the share of cost can be high. While it might seem to you as a caregiver that full-time care for your loved one is an obvious necessity, in terms of Medicaid benefits there is no way in advance to confirm the number of hours that will be approved for payment.
- Where you live also makes a difference: Medicaid eligibility and rules differ state-by-state, as does the availability and variety of community services, including adult day care, in-home care, support groups, and other services. You may qualify for Medicaid benefits that you may not be aware of. Consult your

local Area Agency on Aging or use the Eldercare Locator.

- Medicaid-financed caregiving for family members often means a minimum wage job without benefits, including unemployment benefits. Applying to receive compensation for caregiving may involve being on a long wait list.

## Employee Rights and Options

Forty million people in the U.S. are caregivers for loved ones; of those, 24 million are also employed outside the home. Many employers have become increasingly aware of the challenges of these dual roles, and as an employee, you may have options, resources, and legal rights that you may not be aware of.

- Flexible hours are perhaps the most helpful benefit to working caregivers and are the most commonly requested. Flexible schedules may include altering start and end times, working a four-day or four-shift week rather than five days; full-time or part-time telecommuting; and job sharing. These options are becoming increasingly common in many—though certainly not all—fields throughout the country. A recent AARP study reports that 70% of caregivers who were also employed have made some kind of job modification to accommodate caregiving.
- The federal Family and Medical Leave Act (FMLA) mandates that individuals employed by companies with 50 or more employees may take up to 12 weeks of unpaid leave to care for

family members (or 26 weeks to care for an active service member). The FMLA applies to caregiving for parents, children, and spouses, and it protects an employee's job and health insurance benefits. Although employers with fewer than 50 employees are legally not obligated to abide by FMLA requirements, some do follow the guidelines to support individual employees.

- California, New Jersey, Rhode Island, and New York have passed Paid Family Leave (PFL) legislation. This benefit generally covers care for parents, children, spouse or registered domestic partner, and new parents. In California, partially-paid leave may be taken for up to six weeks. California has been pioneering in its PFL legislation, and recent action has extended benefits for lower wage employees in particular, who, beginning in 2018 will receive up to 70% of their wages; those making up to \$108,000 annually can receive up to 60% of their salaries for six weeks of leave. However, PFL does not provide job security, although your job may be protected under other laws.
- Some larger employers may offer long-term care insurance benefits for purchase for employees and their families. Access to a long-term care policy through employee group coverage may be less expensive to you than would be an individual policy, especially if you are over 55 or have pre-existing conditions. Pursuing this benefit option may

be extremely valuable to you now and in the future, but thoroughly review the policy's limits.

- You might also have access to employee benefits that you're not aware of, including supplemental dependent care coverage, which can partially reimburse costs for in-home care or adult day care. A few employers offer subsidized payments for geriatric care managers. Check with your HR or benefits manager.
- Your employer may have other informal resources available, including information on community resources and caregiver support groups.
- The Americans with Disabilities Act (ADA) and some state regulations prohibit employers from discriminating against caregiving employees. This may apply to issues such as promotions and raises, among others.

## Physical and Emotional Demands of Caregiving

Many caregivers are surprised at the demands of full-time caregiving. Caregivers have admitted that they didn't entirely understand what they were taking on, and were not aware of how long their loved one's illness or condition could persist. For individuals with dementia, it's often impossible to know how long care will be needed and at what level.

When assessing the needs of your loved one's and your sense of responsibility to them, it might be difficult to consider your own personal

limitations and quality-of-life concerns. Additionally, caregivers are in the midst of an emotionally demanding situation, and feelings of grief and isolation are common. In-person or online caregiver support groups can be helpful for sharing support and information.

On a physical level, caregiving can be very demanding, especially tasks such as assisting with lifting and moving. While assistive tools and technology are available and can be helpful, the physical risks and challenges are real, especially for older caregivers. Some caregivers report that they underestimated the physical demands of their role, and as needs increased, they were unable to continue to care for their loved one at home, resulting in unanticipated costs of residential care. Caregivers often find it difficult to take care of their own physical health; many suffer from depression. Help and resources are available (see the fact sheet, *Depression and Caregiving*.)

### Some Questions to Consider:

- Are you basically physically healthy? Do you have any health conditions or injuries that would make caregiving difficult? Do you have the patience and stamina to be a full-time caregiver?
- What do you need to do on a daily basis maintain your own health, including time for exercise?
- Are you familiar with assistive tools for care receivers?
- Are you willing to seek out physical and emotional support for yourself?

## Involving Family Members

Many caregivers find it difficult to ask others to help with the work that needs to be done day-in and day-out to care for a loved one. If you're the primary caregiver for a parent, you may wish siblings or other family members were more involved in care. Navigating family dynamics can be challenging, and it may be helpful to call a family meeting in cases where caregiving needs are changing or increasing or if you are considering leaving the workforce. (See the fact sheet, *Holding a Family Meeting*.)

Learning to identify and make use of a broader network of support could make the difference between maintaining your employment or taking on a full-time caregiver role. If you convene a family meeting, you might want to discuss the possibility of receiving financial contributions from other family members for ongoing care costs. You may also want to draft a personal care agreement. Many caregivers report frustration at being the primary or "only" caregiver for a parent or family member among siblings. On the other hand, some caregivers feel that they alone can provide the best or most appropriate care. Identify specific tasks others can do that would be helpful, whether on a one-time or ongoing basis. If someone asks in general how they could help, suggest something specific.

## Conclusion

Caregiving for a loved one is an enormous commitment and responsibility. There are many ways to be a dedicated caregiver to your loved one without giving up your own employment. Make a thorough analysis

of your own financial situation, retirement plan, and community resources that might be available to help. Carefully consider your options and involve family members on your support team.

## Resources

### **Southern Caregiver Resource Center**

891 Kuhn Drive Ste. 200  
Chula Vista, CA 91914  
(858) 268-4432 | (800) 827-1008  
E-mail: [scrc@caregivercenter.org](mailto:scrc@caregivercenter.org)  
Website: [www.caregivercenter.org](http://www.caregivercenter.org)

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial Counties. Services information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

### **Family Caregiver Alliance National Center on Caregiving**

235 Montgomery Street, Suite 950  
San Francisco, CA 94101  
(415) 434-3388 | (800) 445-8106  
Email: [info@caregiver.org](mailto:info@caregiver.org)  
Website: [www.caregiver.org](http://www.caregiver.org)

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

**National Association of Area  
Agencies on Aging**  
[www.n4a.org](http://www.n4a.org)

**Eldercare Locator**  
[www.eldercare.gov](http://www.eldercare.gov)

**National Adult Day Services  
Association**  
[www.nadsa.org](http://www.nadsa.org)

**National Council on Aging**  
[www.ncoa.org](http://www.ncoa.org)

**National Resource Center On Women  
And Retirement Planning**  
[www.wiserwomen.org/index.php?id=38  
&page=National\\_Resource\\_Center\\_on\\_  
Wome...](http://www.wiserwomen.org/index.php?id=38&page=National_Resource_Center_on_Wome...)

**Social Security Administration**  
[www.ssa.gov](http://www.ssa.gov)

## **Fact Sheets**

*Work and Eldercare*

*Hiring In-Home Help*

*Caregiving at Home: A Guide to  
Community Resources*

*Holding a Family Meeting*

*Personal Care Agreements*

*Special Concerns for LGBT Caregivers*

*Caregiver Statistics: Work and  
Caregiving*

*This fact sheet was prepared by Family Caregiver Alliance and written by Kristina Youso, Ph.D., reviewed by Bonnie Lawrence and Kathleen Kelly, ©2018 Family Caregiver Alliance. All rights reserved.*

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