

Step Out of the Spin Cycle

What to Know About Quitting Your Job to Provide Care and
Learn About the Team Approach to Caregiving

Rebekah Keizer - MA, BCC



RKLifecoach, LLC

rklifecoach.com



FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

101 Montgomery Street, Suite 2150

San Francisco, CA 94104

800.445.8106 | 415.434.3388

caregiver.org

Objectives

- ❖ Outline the impact on the family for both caregiver and care receiver, of the caregiver working or not working
- ❖ Layout the steps to consider when making the decision that is best for everyone
- ❖ Provide tips for forming a team to provide the needed care for the care receiver

Introduction

- ❖ Survey by the National Center for Caregiving: Estimates that by 2020, 1 in 3 US Households will be caring for an elderly relative (3)
- ❖ More than half of employed caregivers work full-time (56%). On average, employed caregivers work 34.7 hours a week. (4)
- ❖ One national survey found that 1 in 5 (19%) retirees left the workforce earlier than planned because of the need to care for an ill spouse or other family member. (13)

The Impact of Working While Caregiving

Financial

- ❖ Working until retirement- being able to accumulate the maximum social security, retirement pension, and 401K or 503B income for own retirement
- ❖ Able to maintain current health insurance from job
- ❖ Security of having and maintaining a job that can be held until retirement whether caregiving or not
- ❖ Able to financially provide for various care and medical expenses for the care receiver

Financial

- ❖ More financial flexibility for the future of the caregiver
- ❖ Less financial strain in the present
- ❖ More money is spent on care while the caregiver is working- homecare, adult day care (5)

Emotional and Social

- ❖ Have an outlet outside of caregiving that provides meaning and purpose (16)
- ❖ Receives social interaction at work and a break from the rigors of providing care (18)
- ❖ See that it is not all up to them but they have an opportunity to see the impact of the care others provide and in turn the care receivers learn to depend on the care of others, other than their loved one

Emotional and Social

- ❖ Care receivers develop relationships with others
- ❖ Continue to grow and build skill in your field (10)
- ❖ Caregivers look to the expertise of knowledge of people and resources they might not have entertained before
- ❖ Workplaces often offer EAP programs which offer psychological, legal, and informational support to family caregivers

Emotional and Social

- ❖ Parent or care receiver being “unhappy” complaining about want their loved one to care for them and receiver care in their home.(5)
- ❖ Less time for caregiver and care receiver to spend together

Caregiver Health

- ❖ Avoid: burnout, financial strain, health consequences, caregiver isolation that come with being the primary caregiver for a loved one (14)
- ❖ Have needed health insurance to care for health needs

Care for the Care Receiver

- ❖ Workplaces often provide resources to help caregivers and care receivers, including access to resource lists, subsidized care, or subsidized support services (17)
- ❖ Caregivers learn skills in your career that help provide even better care for a loved one (18)
- ❖ The care divided out, so that the care receiver is receiving care from others that have specialized skills in the care that they need
- ❖ One example of this is being at adult day care or in a retirement facility with a specialized activity director that is educated on stimulating a care receiver with their specific needs

The Impact of Quitting Work for Caregiving

Financial

- ❖ Money can be saved that would be used for hands on care during work by other providers and used for other needs or desires instead
- ❖ Don't need worry about having the needed PTO or sick leave to take time off for appointment and care(13)

Emotional and Social

- ❖ 70% of working caregivers suffer work-related difficulties due to their dual roles.(4)
- ❖ Don't have to worry about the quality of care received by outside sources (14)
- ❖ It is easier to handle a crisis that comes up in having the time to devote to it (3)
- ❖ The caregiver does not have to endure the sadness or complaining of the care receiver from them not being there as much

Caregiver and Care Receiver Health

- ❖ More time to devote to care and medical appointments without rearranging the schedule
- ❖ Being there for meetings and services- seeing first hand what is happening with their care(14)
- ❖ Less strain from feeling pressed for time to get everything done

Care of the Care Receiver

- ❖ They are able to receive more hands on care from the caregiver
- ❖ The caregiver does not have to worry as much about the quality of care provided by other caregivers
- ❖ The caregiver and care receiver are able to build more of a relationship together

Steps to Making the Decision That is Best for Everyone

- ❖ <http://www.rklifecoach.com/wp-content/uploads/2019/08/Steps-to-Making-the-Decision-AND-Building-a-Care-Team.pdf>

Struggle

What is the struggle that is causing a need for change?

Talk

Talk with the care receiver and family that play a major role in their life. Let them know the struggle and potential options. (1)

Assess

Assess the options for change from small to big.

Know Yourself

Given your needs and relationship with the care receiver what are you able to do?

Experiment

Try out some small changes first and see the impact(11)

Evaluate

To see what worked, what didn't work, and what more needs to be done

The Team Approach is Vital for the Caregiver

- ❖ Whether you are working or not working, caregiving cannot be done alone. It is important to develop a team that can work together to provide the best care possible.



Team Approach: Building a Team

- ❖ Take a look around. Who are the people involved in the care of your loved one and supporting you. **These are your team.**
- ❖ First write down your current team. Including the roles that each one of them plays.
- ❖ Your team is going to be the people that provide support, time, information, care, and encouragement.
- ❖ Now think about gaps in the needs that are being met. What are these? What team members can you bring on to help in these areas?
- ❖ Are there things that you are doing as a caregiver that others could take off your plate so you could concentrate on the areas of care and relationship that are more important with your care receiver?
- ❖ <http://www.rklifecoach.com/wp-content/uploads/2019/08/Steps-to-Making-the-Decision-AND-Building-a-Care-Team.pdf>

Team Approach: Services for the Care Receiver

In Facility Care

- Independent Living, Assisted Living, Memory Care, Nursing Care. Either as a long term or respite care option.

In Home Care

- Medical homecare, Non-medical homecare, Services for laying out medications, transportation, shopping/errands, therapies

Care in Another Location

- Adult Day Care Services, Senior Center, Care in a friend

Medical Care

- Doctors, Nurses, Pharmacists, Therapists, Care Manager

Alert and Response Bracelets

- Medical Alert Bracelet, Safe Return Bracelet, Emergency Button Bracelet

Financial Programs

- Programs to pay for care, Medicaid, long term care insurance, grants or special scholarships

Services in home or facility

Nail care, Salon/Hair care, Visiting Physicians, House cleaning, lawn service, Telephone or Visiting therapist or coach, volunteer visitors, Pet care

Team Approach: Services for the Caregiver

Employer

- Talk to boss and HR person about situation

Company Resources

resource lists, EAP program- legal, emotional, care manager support, subsidized care, respite care, support groups, and community services (7)

Flexible Work Schedule/Time

Flex or compressed schedules, job sharing, less/part time hours, telecommuting, or changing work locations. Using sick days to care, donated time off, time off without pay, FMLA (18)

Care Services

- Care manager, assistance with paperwork, information and referral, volunteer organizations

Support Services

- Caregiver Support Groups, Therapist, Coach, Pastor

Support People

- Family member, friends, neighbors, church

Household Services

Accountant, errand service/grocery delivery, legal assistance, pet care, lawn service, cleaning

Communication With the Team

- ❖ Have regular meetings with primary stake holders and decision makers. Keeping them updated
- ❖ Utilize organizational tools to help you keep track of care provided, the schedule, and contact information
- ❖ If a conflict comes up:
 - ❖ Take a step back and evaluate before reacting
 - ❖ Consult someone with expertise to help evaluate options
 - ❖ Talk it through use “I” statements to share how you are feeling or experiencing the situation
 - ❖ Recognize that within teams there will be different expectations, personalities, and communication styles

Summing up

- ❖ The decision to work or quit working as a caregiver is not black and white. Both carry significant impact on the health and wellbeing of, you as a caregiver and on the care receiver
- ❖ Neither decision should be assumed to be the right one until you investigate more and learn about your options
- ❖ There are many options for forming a work schedule and support that can relieve stress on you as a working caregiver
- ❖ A team approach is an important way to ensure that you the care receiver have your needs met

Sources

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- ❖ (16)<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5926991/>
- ❖ (17) Passages in Caregiving by Gail Sheehy
- ❖ (18) Juggling Life Work and Caregiving by Amy Goyer

Resources:

Books

- ❖ Passages in Caregiving by Gail Sheehy
- ❖ Juggling Life Work and Caregiving by Amy Goyer
- ❖ Working Daughter: A Guide to Caring for Your Aging Parents While Making a Living by Liz O'Donnell
- ❖ Share the Care: How to Organize a Group to Care for Someone that is Seriously Ill by Cappy Capossela and Sheila Warnock, et al.

Resources:

Apps/Software/Online Tools:

- ❖ Tyze.com: communicate with and coordinate care services with family and friends
- ❖ LotsaHelpingHands.com or CareCalendar.com: organize help for friends and family
- ❖ CaringBridge.com: provide updates to friends and family about someone
- ❖ AARP Caregiving: App to track and coordinate care
- ❖ Carezone: App to track and coordinate care

Nationwide Organization Resources

- ❖ Area Agency on Aging
- ❖ Alzheimer's Association
- ❖ American Cancer Society
- ❖ American Heart Association
- ❖ Administration on Aging
- ❖ Geriatric Mental Health Foundation
- ❖ Family Caregiver Alliance
- ❖ National Alliance for Caregiving

Thank you! Any Questions?

Rebekah Keizer rebekah@rklifecoach.com



About FCA

Family Caregiver Alliance offers education, services, research, and advocacy based on the real needs of caregivers. Founded in the late 1970s, FCA is the first community-based nonprofit organization in the United States to address the needs of families and friends providing long-term care for loved ones at home.

National Center on Caregiving (NCC) was established by FCA to advance the development of high-quality, cost effective programs and policies for caregivers in every state. NCC sponsors the Family Care Navigator, a state-by-state resource locator designed to help caregivers find support services in their communities.

Bay Area Caregiver Resource Center — operated by FCA for the six-county San Francisco Bay Area — provides support to family caregivers. FCA's staff of family consultants through education programs and direct support offer effective tools to manage the complex and demanding tasks of caregiving.

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Acerca de FCA

Family Caregiver Alliance ofrece servicios educativos, de investigación, y abogacía basados en las necesidades reales de los cuidadores. Fundada a finales de 1970, FCA es la primera organización comunitaria sin fines de lucro en los Estados Unidos, dedicada a atender las necesidades de familias y amigos que brindan cuidado a largo plazo a seres queridos.

National Center on Caregiving (NCC) fue establecido por FCA para promover el desarrollo de programas y políticas de alta calidad y efectivas en costo que beneficien a los cuidadores en cada estado. NCC es patrocinador del Family Care Navigator, un localizador de recursos disponibles en los estados, diseñado para ayudar a los cuidadores a encontrar servicios de apoyo en sus comunidades.

Bay Area Caregiver Resource Center — operado por FCA para los seis condados en el Área de la Bahía de San Francisco — ofrece apoyo a cuidadores. El equipo de consultoras familiares de FCA provee herramientas efectivas para sobrellevar las complejas y demandantes tareas de ser cuidador a través de programas educativos y apoyo directo.

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