

Welcome!

November 18, 2019
2:00 pm ET/11:00 am PT



**What You Need to Know
About Quitting Your Job to Provide Care:
Developing a Plan to Maximize Independence
in Providing and Receiving Care**

Guest Speaker:
Rebekah Keizer, MA, BCC
Caregiver Coach
RKLifecoach, LLC

Hosted by:

The ALS Association

National Office-Care Services

Ph: 800-782-4747 cknoche@alsa-national.org



What You Need to Know About Quitting Your Job to Provide Care:

Developing a Plan to Maximize Independence in Providing and
Receiving Care



Rebekah Keizer MA, BCC

Caregiver Coach

RKLifecoach, LLC

rklifecoach.com

Objectives

- Outline the impact on the family for both caregiver and care receiver, of the caregiver working or not working
- Share keys to making a plan for care that involves the team approach to maximize independence for the caregiver and care receiver
- Layout available resources to adapt to your situation and need

Introduction

- Approximately 5,000 people are diagnosed with ALS each year. (20)
- Sixty-one percent of caregivers work outside the home. Of those caregivers who work outside the home, 37% work more than 30 hours per week. (19)
- 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 on the Family for Both Caregiver and Care Receiver:

The caregiver working or not working

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

- 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, skilled nursing 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

- Care receivers develop relationships with others
- Continue to grow and build skill in your field (10)
- Caregivers look to the expertise and 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

- Parent or care receiver being “unhappy” and wanting 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 is divided out, so that the care receiver is receiving care from others that have specialized skills in the care that they need

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 to 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>

Keys to Making a Plan for Care: Using the Team Approach to Maximize Independence



Keys to Making a Plan for Care: Building a Team

- Remember your loved one with ALS is your primary team member
- 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?

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, Hospice, Services for laying out medications, transportation, shopping/errands

Care in Another Location

- Senior Center, Adult Day Care, Church people, Care from friend or Family

Medical Care

- Doctors, Nurses, Pharmacists, OT/PT/ST, Care Manager, Respiratory Therapists, Nutritionist

Alert Bracelets & Adaptive Equipment

- Medical Alert Bracelet, Safe Return Bracelet, Emergency Button Bracelet, Assessments to determine equipment most useful, Home automation, Cameras

Financial Programs

- Medicare (limited), Programs to pay for care, VA Aid and Attendance, 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

Available Resources to Adapt to Your Situation and Needs



Home Automation

- Amazon Echo- [Article](#)
- Phillips Hue Lighting Systems
- Smart Plugs
- Cameras
- Smart Thermostats
- These are just some of the devices available help activate and control household, lights, thermostats, electronics, entertainment equipment independent of arm/hand movement.
- More information: [Contact your local ALS Association](#)- for home automation resources and guidance.

Adaptive Medical Equipment

[Talk: How DME/Assistive Technology Benefits Caregivers](#)

- Communication-Electronic Communication Aids
- Ambulation Aids- wheelchairs
- Transfer Devices
- Toileting Devices
- Showering Devices
- Hospital Beds
- Accessibility
- Eating and drinking devices
- Transportation

- **Apps/Software/Online Tools:**

- Care Connection (alsa.lotsahelpinghands.com): a central place to coordinate help and care from friends and family
- Tyze.com: communicate with and coordinate care services with family and friends
- 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

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

Links to Care Plan and Caregiver Support Plan Worksheets

- [Care Plan](#)
- [Caregiver Support Plan](#)

• **Nationwide Organization Resources:**

- ALS Association
- ALS Foundation for Life
- Veterans Affairs
- Area Agency on Aging
- Alzheimer's Association
- Administration on Aging
- Geriatric Mental Health Foundation
- Family Caregiver Alliance
- National Alliance for Caregiving

Resources:

Books

- Navigating Life with Amyotrophic Lateral Sclerosis by Mark B. Bromberg and Diane Banks Bromberg
- 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.

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 and the care receiver have your needs met

Sources:

- (1)<https://www.aginginplace.org/do-i-have-to-quit-my-job-to-be-an-elderly-caregiver-for-my-parents/>
- (2)<https://www.agingcare.com/articles/is-aging-in-place-always-the-best-option-for-seniors-185858.htm>
- (3)<https://www.agingcare.com/articles/caregiving-issues-and-work-95637.htm>
- (4)<https://www.caregiver.org/caregiver-statistics-work-and-caregiving>
- (5)<https://www.agingcare.com/articles/should-you-quit-your-job-to-care-for-your-elderly-parent-150227.htm>
- (6)<https://www.aarp.org/caregiving/life-balance/info-2017/tips-for-working-caregivers.html>
- (7)<https://www.aarp.org/caregiving/life-balance/info-2017/work-benefits-rights.html>
- (8)<https://www.caregiver.org/balancing-career-and-caregiving>
- (9)<https://www.aarp.org/caregiving/life-balance/info-2017/balancing-demands-ag.html>
- (10)<https://www.reuters.com/article/us-caregivers-quittingjobs/think-before-you-quit-your-job-to-care-for-mom-idUSBRE84T15520120530>
- (11)<https://www.forbes.com/sites/carolinecenizalevine/2015/10/17/should-i-leave-my-job-to-take-care-of-my-elderly-parents/#78c6a0307783>
- (12)https://www.huffpost.com/entry/caregivers-caregiving-quit-jobs_n_5c3e16c6e4b01c93e00e1843
- (13)<https://www.ncbi.nlm.nih.gov/books/NBK396402/> (Families Caring for An Aging America)
- (14)<https://www.agingcare.com/articles/should-you-quit-your-job-to-care-for-your-elderly-parent-150227.htm>
- (15)<http://www.caringnews.com/en/171/1/472/Should-You-Quit-Your-Job-to-Care-for-a-Loved-One.htm>
- (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
- (19) The ALS Association Care Services Survey-January 2019
- (20) <http://www.alsa.org/about-als/facts-you-should-know.html>

Thank you! Any Questions?

Rebekah Keizer

rebekah@rklifecoach.com