

# Caring For Those You Care About



It usually starts small or with a phone call – perhaps running a few errands, preparing some hot meals or getting the news that your mother or father fell. Or sometimes the change is more dramatic or sudden.

Maybe you don't even see yourself as a "caregiver" yet. You may live in the same house, in a nearby town, or even in another state. The care involved may range from modest tasks to heavy-duty, round-the-clock assistance.

Whatever the situation, AARP Oregon wants you to know that you're not alone (there are hundreds of thousands of Oregonian family

caregivers) and that there are many local, state and national resources that can help.

In this special caregiving edition you will hopefully find some valuable tips and resources to help you and the ones who need you.



## Caregiving by the Numbers

**420,000**  
Number of Oregonians serving as unpaid caregivers.

**1,080**  
Average hours of care a year each.

**\$4.6 billion**  
Estimated value of family caregiving in Oregon alone.

Source: June 2007 AARP Public Policy Institute study, "Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving."



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

— Rosalynn Carter

## Family Caregiving Q&A



Vicki L. Schmall, PhD, is a gerontologist and president of Aging Concerns in West Linn. A Professor Emeritus of Oregon State University, she served as the Gerontology Program's Director and as a Gerontology Specialist for over 20 years.

### What are the top three issues facing caregivers today?

On an individual caregiver level, the top issues will vary, but overall it's probably balancing work, family, and caregiving responsibilities, having access to well-trained, dependable caregivers and community services, and maintaining the caregiver's own health and well-being.

### Stress is a major factor for caregivers. What are some ways to handle it?

Stress is inherent in caregiving, and it's unrealistic that stress can be totally avoided. Family caregivers are frequently referred to as "hidden patients." Research shows caregiving can take a physical, social, emotional, and financial toll. To ward off emotional and physical exhaustion:

- **Take care of yourself and take breaks.** Breaks are not selfish and are as important to health as diet, rest and exercise.

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- Questions and Answers with a Caregiving Expert
- Free Nov. 17 Caregiving Forum
- Caregiving Profiles with Tips, Lessons Learned
- Quick List of Caregiving Resources
- New Caregiving Guides
- Get Involved and Share Your Story, Tips

- **Maintain contact with friends** and involvement in outside activities.
- **Ask for help.** This is A SIGN OF STRENGTH, not a sign of failure.
- **Focus on what you have done well.** Too often, caregivers focus only on what they have not done or feel they have done poorly.

### Six out of 10 workers are caregivers. What can employers do to support caregivers?

The workplace can play a vital role in an employee's ability to coordinate work and caregiving responsibilities. Besides having a family-friendly work culture, employers can provide:

- **Job flexibility.** Flexible schedules help employees juggle competing demands, reduce stress and work-family conflicts, and decrease work interference.
- **Supervisor support.** Sensitivity, flexibility and ability to direct employees to assistance can be a tremendous benefit.
- **Caregiver-oriented benefits.** Ranging from resources and referral listings to hosting on-site support groups and offering flexible spending accounts.

It's also important that businesses create ways to make sure employees are aware of available benefits and feel comfortable using them.

### What are the five best resources every caregiver should know about?

Caregivers' needs vary, but in general it boils down to these:

- **Family and Friends.** They can often be one of the strongest sources of support, but don't assume they know when you need help.
- **Geriatric care managers.** If a caregiver lives at a distance, has competing responsibilities, or simply does not have time or resources to find needed services, this person can be extremely helpful.
- **Adult Day Centers.** These are for older adults who cannot live independently and need a supervised environment. Programs are usually available on a weekday or hourly basis. They enable caregivers to continue work while caregiving, or just provide a break.
- **Respite Care.** Even a short break from daily demands can help preserve a caregiver's well-being. The care receivers also benefit. Respite may be provided at home or in a community setting, by paid staff or volunteers, and can be for part of a day, evening, overnight or for an extended time.
- **Caregiver support groups.** These are an opportunity to talk and share with others and get practical suggestions for dealing with difficult situations. They can be general, or geared for those caring for someone with specific medical condition like cancer, stroke, Parkinson's, or Alzheimer's.

*Editor's note: For the complete interview, please visit [www.aarp.org/or](http://www.aarp.org/or) and select the "Caregiving" article.*

### Alzheimer's Caregiving



Mark Donham helps his wife Christine remember their adventures.

For 45-year-old Mark Donham and his bride of 14 years, 51-year-old Christine "Chris" Donham, Alzheimer's and its devastating effects have been all too familiar.

Chris, a one-time women's apparel buyer for Nordstrom, inherited a rare gene that causes early onset of the disease – the only hereditary form of Alzheimer's with diagnoses two decades earlier than most. Her mother died of it at age

53 while Chris was in her 20s. She then watched her sister progressively worsen until she passed away at only 49. Armed with those losses and knowledge, Chris regularly participated in medical testing and learned to live each day as a gift. She and Mark also made it sure to plan ahead – saving, purchasing long-term care insurance and getting their finances in order.

With this preparation and the early signs becoming more obvious, Mark quit his job as a successful sales representative in 2006 to be with Chris full-time. Their first adventure was a cross-country motorcycle trip from Oregon to New York City, where they first met and fell in love. They visited all their friends, family and favorite and new places along the way – capturing their memories in photos. Their pictures, curled at the edges, now adorn their Lake Oswego home, where Mark uses them as comforting reminder to Chris and to himself.

For Mark, the trip also was a very important way to keep friends and

## Free Caregiving Forum

Thinking Ahead: Help Your Aging Loved Ones and Keep Your Wits

If you currently provide some care for an aging loved one, or expect to do so in the next few years, join AARP Oregon and the Tri-County Caregiving Coalition to learn about the information, services, and resources available to help you in your community.

**Saturday, Nov. 17 – 8:30 a.m. to 2 p.m.**  
**Crowne Plaza, Lake Oswego**

*There is no cost to attend, though registration is required as space is limited. Free breakfast and lunch will be served.*

Call today to 877-926-8300 toll-free to reserve your spot.

# lies Share their Stories and Lessons Learned

## Sandwich Generation Caregiving

family involved and help avoid the potential isolation they had both read about. His advice: “people may think they don’t know what to say or do, but just being there, listening or just staying in touch is so huge.”

As the disease steadily marches in, taking away Chris’ sense of place and time, faces and history and increasing dependence with many daily tasks like eating, bathing and dressing, Mark says his faith and attitude “being able to accept, adapt and embrace these changes” are essential as he braces for the worst to come.

Now a board member of the Oregon Chapter of the Alzheimer’s Association working to raise awareness and funds to combat the disease, Mark offers two other pieces of counsel to those who may be caregiving for a loved one. Know how and when to take care of yourself. Consider attending a support group - you’ll realize that you’re not alone, and also gain tips to help figure out the challenges and opportunities.

With her 12-year-old son Wiley and 79-year-old parents, Joyce Beedle of Portland is what’s known as the “sandwich” caregiver. A growing phenomenon for the boomer generation, more adults are serving two very different caregiving roles on each end of the age spectrum.

Joyce first experienced this role stretch while she was five months pregnant and on through Wiley’s birth and preschool years when her 95-year-old grandmother came to live with her family.

“Nothing like a baby and diaper bag in one arm and my other arm wrapped through grandma’s as we’d go to her doctor appointments,” she recalls.

Five years later, Joyce and her family took on caregiving duty again when her mother was diagnosed with cancer and faced grueling chemotherapy and operations. A 5th grader at the time, Wiley would play his cello to soothe the household.

“The intergenerational bond and the dramatic healing impact I’ve seen first-hand between the ‘young’ and ‘old’ is something I wouldn’t trade for anything. I would never have chosen the path, but I believe it was the only way to the precious connections we have now,” Joyce says.

Her mom in remission now, caregiving duties ebb and flow.

An author and registered nurse specializing in aging and dementia, Joyce teaches family caregiver classes, but says it’s often hard to take her own advice despite what she knows cascades of caregiving research and studies have shown.

“You really have to overcome feeling like there’s always more that can and must be done, trying to do it all so you don’t let anyone down; it just isn’t possible,” she explains.

“It is critical to recharge your battery, to know when you are being stretched too thin, to tap the numerous resources available, and to be able to be able to ‘air out.’ Air



Wiley practices his cello while Joyce and grandparents “look on.”

out physically - I walk or bicycle - air out emotionally - laugh, cry, get mad or sad, whatever - and to air out verbally - have someone you can download with and who can just listen.”



Mary Ann Hard prepares to visit her mom in Alabama.

## Long-Distance Caregiving

Mary Ann Hard’s life changed dramatically two years ago when her 78-year-old mother’s Parkinson’s disease progressed - and she began long-distance caregiving.

Hard juggles a full-time job as a lifespan respite coordinator for Clackamas County, spending time with her husband and two teenage sons sandwiched

being available for her mother, who lives several states and time zones away in Alabama.

Despite the miles, Hard is there for her mother. They speak twice a day, once in the morning and once in the evening. Hard also visits her three times each year, most recently to help her move, despite concerns about the impact it could have by leaving her social support system and doctors.

“She was longing for more independence, and even though it might be more difficult for her in some ways, she wanted one last experience of calling the shots.”

Hard has noticed that her relationship with her mother has changed, but also that the experience has made her a more appreciative and compassionate person.

“I can be more easily frustrated because I feel powerless to help because of the distance. If I hear she is having a problem, it’s particularly difficult to let that go without thinking about her all day,” she says. “At the same time, even a single hug from my sons makes me grateful.”

What helps span the distance is sharing responsibilities with her brother and sister. Her sister lives close, taking care of her mother’s prescriptions and grocery shopping. Her brother - who has a hard time watching his mother age - gives primarily financial support.

Hard says her best piece of advice to potential caregivers is to ask their parents what they want their quality of life to be as they age, *before* they reach the point of needing caregiving. “We took it for granted that it was going to happen,” she said.

# Be Informed. Get Involved. Make a Difference.

Caregiving and the impact it has on loved ones, families, employers, the economy and on the health and long-term care system is significant. There are many facets to this issue and many ways to get informed or involved.

- I would like a list of "Free Caregiving Publications".
- I'd like to share my caregiving story or tips.
- I am interested in receiving AARP Oregon's free quarterly newsletter with state and community-specific news, information and activities.
- I'd like to keep informed on AARP Oregon issues and activities in my community as well as advocacy and legislative alerts, including on caregiving issues.
- I am interested in volunteering for AARP Oregon.
- I am interested in learning more about efforts to fix health care and strengthen the long-term system in Oregon.
- I am interested in learning more about Divided We Fail, AARP's new initiative to break partisan gridlock and ensure health and long-term financial security for all. (Check out [www.dividedwefail.org](http://www.dividedwefail.org)).

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

E-mail: \_\_\_\_\_

*Contact information is strictly confidential and will not be shared externally or sold.*



Return to: AARP Oregon  
9200 SE Sunnybrook Blvd.  
Suite 410  
Clackamas, OR 97015

Or call or e-mail your  
information to:  
**866-554-5360 toll-free**  
**oraarp@aarp.org**

## Two new free caregiving resource guides

AARP has developed two new free resource guides that can help in your caregiving journey.

"**Prepare to Care**" is a five-step guide designed to create a specific caregiving plan. It includes information on how to get started, questions to ask and where to find basic resources.

"**Resources on Caring for your Aging Relative or Friend: A Guide for Employees and Employers**" looks at a range of caregiver challenges, with a focus on balancing work and caregiving. Each section is followed by Oregon-specific resources as well as others that can help.

To get your free copies, contact AARP Oregon at 866-554-5360 toll-free or via e-mail at [oraarp@aarp.org](mailto:oraarp@aarp.org).



## Faith in Action – One Featured Resource



Caregivers in many Oregon communities can turn to Faith in Action (FiA), a program where volunteers of many faiths come together to provide cost-free informal caregiving services to seniors and those with disabilities.

An initiative of the Robert Wood Johnson Foundation, there are eight FiA programs in Oregon: Northwest Portland Ministries (NWPM), Sherwood, Newberg, Corvallis, Albany, Hood River, Bend, and Tillamook. Services are free and provided without regard to gender, race, income or religious affiliation.

## Caregiver's Resources

No matter if you are a long-distance caregiver, a working caregiver, a caregiver for both your own children and another family member, or a future caregiver, everyone should know about the resources available to make caregiving a little easier and a little less stressful.

**AARP Caregiver Circle**  
[www.aarp.org/caregiving](http://www.aarp.org/caregiving)

**Alzheimer's Association, Oregon Chapter**  
800-733-0402 or [www.alzheimers-oregon.org](http://www.alzheimers-oregon.org)

**Area Agencies on Aging**  
[www.oregon.networkofcare.org](http://www.oregon.networkofcare.org)

**Benefits Quicklink**  
[www.aarp.org/quicklink](http://www.aarp.org/quicklink)

**Clackamas County Social Services Division**  
503-650-5724 or [www.co.clackamas.or.us/socialservices/respite.htm](http://www.co.clackamas.or.us/socialservices/respite.htm)

**Eldercare Locator of the U.S. Administration on Aging**  
800-677-1116 or [www.eldercare.gov](http://www.eldercare.gov)

**Faith in Action**  
[www.faithinactionoregon.org](http://www.faithinactionoregon.org)

**Family Caregiver Alliance**  
800-445-8106 or [www.caregiver.org](http://www.caregiver.org)

**Legacy Health System Caregiver Services & Information and Referral**  
503-413-7706 or [www.legacyhealth.org/body.cfm?id=767](http://www.legacyhealth.org/body.cfm?id=767)

**Loaves and Fishes**  
503-736-6325 or [www.loavesandfishesonline.org](http://www.loavesandfishesonline.org)

**Multnomah County Aging & Disability Services**  
503-988-3646 or [www.co.multnomah.or.us/ads/ads\\_main.shtml](http://www.co.multnomah.or.us/ads/ads_main.shtml)

**National Alliance for Caregiving**  
[www.caregiving.org](http://www.caregiving.org)

**National Association of Professional Geriatric Care Managers**  
520-881-8008 or [www.caremanager.org](http://www.caremanager.org)

**Office of the Oregon Long Term Care Ombudsman**  
800-522-2602 or [www.oregon.gov/LTCO/index.shtml](http://www.oregon.gov/LTCO/index.shtml)

**Oregon Department of Human Services – Seniors and Peoples with Disabilities Division**  
800-282-8096 or [www.oregon.gov/DHS/spwpd/caregiving/home.shtml](http://www.oregon.gov/DHS/spwpd/caregiving/home.shtml)

**Oregon Health & Science University Caregiving Support**  
[www.ohsu.edu/healthyaging/caregiving/](http://www.ohsu.edu/healthyaging/caregiving/)

**Oregon State University Caregiving Publications**  
<http://extension.oregonstate.edu/fcd/aging/extpubs.php>

**Providence Health & Services, Services for Older Adults and Caregivers**  
[www.providence.org/resources/oregon/PDFs/Aging/Senior\\_Services\\_Directory.pdf](http://www.providence.org/resources/oregon/PDFs/Aging/Senior_Services_Directory.pdf)

**Ride Connection**  
503-528-1720 or [www.rideconnection.org/index.htm](http://www.rideconnection.org/index.htm)

**Washington County Department of Disability, Aging & Veterans Services**  
503-640-3489 or [www.co.washington.or.us/deptmts/aging/aging.htm](http://www.co.washington.or.us/deptmts/aging/aging.htm)

Delanie Delmont of NWPM says their program supplies about 1,000 door-to-door rides each week to medical appointments, grocery stores, banks and other destinations in the metropolitan area. They also provide a variety of one-on-one assistance, or even just someone to talk to.

FiA programs can be especially helpful for long-distance or working caregivers who are not available to provide regular, constant care or transportation.

For additional information, visit [www.faithinactionoregon.org](http://www.faithinactionoregon.org).