

Public Health Insider - The Caregiving Conundrum: Complex Challenges and an Uncertain Future

Panelist-Recommended Resources from the
Webcast



Oregon State University
Alumni Association

U.S. Department of Health and Human Services

Family Caregiver Alliance

- A listing of all facts and tips is available online [here](#).
 - [Holding a Family Meeting](#)
 - [Hiring In-Home Help](#)
 - [Residential Care Options](#)
 - [Making End-of-Life Decisions: What Are Your Important Papers?](#)
 - [Understanding Palliative/Supportive Care: What Every Caregiver Should Know](#)

Aging Life Care Association

(formerly the National Association of Professional Geriatric Care Managers)

Medicare and Medicaid (MediCal in California)

Meals on Wheels America

National Adult Day Services Association

National Hospice and Palliative Care Organization

Information for families and caregivers, including downloadable Advance Directives for every state

National Volunteer Caregiving Network

Visiting Nurses Association of America

National Alliance for Caregiving

- <https://www.caregiving.org/>

Resources (taken from NAC website)

- Virtual toolkit on prescription drug assistance for eligible Medicare Part D beneficiaries
- <https://www.caregiving.org/extra-help-virtual-toolkit/>

National Family Caregiver Support Program

<https://www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

The National Family Caregiver Support Program (NFCSP), established in 2000, provides grants to States and Territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.

Eldercare Locator

<https://eldercare.acl.gov/Public/Index.aspx>

Are you a family caregiver in need of information or assistance? Are you interested in learning more about the programs and services that may be of assistance to you or your loved one? The Eldercare Locator, a public service of the U.S. Administration on Aging, is the first step to finding resources for older adults in any U.S. community. Just one phone call or Website visit provides an instant connection to resources that enable older persons to live independently in their communities. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers.

Next Step in Care

<http://www.nextstepincare.org>

Next Step in Care provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.

Lotsa Helping Hands

www.lotsahelpinghands.com

Lotsa Helping Hands is a free caregiving coordination web service that provides a private, group calendar where tasks for which a caregiver needs assistance can be posted. Family and friends may visit the site and sign up online for a task. The website generates a summary report showing who has volunteered for which tasks and which tasks remain unassigned. The site tracks each task and notification and reminder emails are sent to the appropriate parties.

Caring.com

www.caring.com

Caring.com is the leading online destination for family caregivers seeking information and support as they care for aging parents, spouses, and other loved ones. Caring.com offers helpful content, advice from leading experts, a supportive community of caregivers, and a comprehensive directory of eldercare services. Caring.com's carefully researched and expert-reviewed content includes advice from a team of more than 50 trusted leaders in geriatric medicine, law, finance, housing, and other key areas of healthcare and eldercare.

- Caring.com's [Steps & Stages](#) offers a free guide to Alzheimer's care. Expert advice and practical tips provided in a Custom Care Guide and e-newsletter help family caregivers learn what to expect, what to do, and how to cope with Alzheimer's.
- Caring.com also publishes findings from research with family caregivers at <http://www.caring.com/about/news>.

WISER (Women's Institute for a Secure Retirement)

Financial Steps for Caregivers: What You Need to Know About Money and Retirement is designed to help you identify financial decisions you may face as a caregiver. The decision to become a caregiver can affect both your short-term and long-term financial security, including your own retirement. For more information on planning for a secure retirement, please visit <http://www.wiserwomen.org>.

National Transitions of Care Coalition

www.NTOCC.org

- The last concern most individuals have when they or their loved ones are dealing with a health situation is ensuring effective communication between their doctors, nurses, social workers, and other health care providers. However, poor communication between well-intentioned professionals and an expectation that patients themselves will remember and relate critical information that can lead to dangerous and even life-threatening situations. NTOCC has brought together industry leaders who have created resources to help you better understand transitional challenges and empower you as part of the caregiving team.

Caregiver Action Network

<http://www.caregiveraction.org/>

Resources from the Caregiver Action Network, including a Peer Forum, a Story Sharing platform, the Family Caregiver Tool Box, and more. CAN also provides support for rare disease caregivers at <http://www.rarecaregivers.org>

U.S. Food and Drug Administration, Office of Women's Health

Tips for Caregivers

FDA Office of Women's Health understands caring for a loved one can be rewarding but challenging. FDA's Tips for Caregivers website provides tools to help caregivers manage the care of their loved ones. The website provides tips for caregivers of older adults, young children, teens, and people with special needs. The website also highlights 7 tips for all caregivers to know. FDA Office of Women's Health also provides information on women and clinical trials. To learn more, visit: fda.gov/womeninclinicaltrials

Other Key Resources

- [Resources for Caregivers-2007 Edition \(PDF\)](#)
- [Aging Parents & Common Sense – 5th Edition \(PDF\)](#)
- [Aging Parents & Common Sense Resource Directory \(PDF\)](#)
- [Supports for Single Parent Caregivers Literature Review \(PDF\)](#)
- [Caring Today, Planning for Tomorrow \(PDF\)](#)
- [Planning for Your Retirement and Long-Term Care \(PDF\)](#)

Alzheimer's & Dementia Caregiving

Are you caring for a loved one with Alzheimer's or another form of dementia? These resources may be helpful to you.

Alzheimer's Association

The Alzheimer's Association works on a global, national and local level to provide care and support for all those affected by Alzheimer's and other dementias. They offer help through a professionally staffed [24/7 Helpline](#) (1.800.272.3900), face-to-face support groups and [educational sessions](#) in communities nationwide, and comprehensive online resources and information through the [Alzheimer's and Dementia Caregiver Center](#).

Alzheimer's Foundation of America

The Alzheimer's Foundation of America offers a national, toll-free helpline (866-232-8484) staffed by licensed social workers, educational materials, a free quarterly magazine for caregivers and "AFA Partners in Care" dementia care training for healthcare professionals. For more information about AFA, call 866-232-8484, visit www.alzfdn.org.

The Association for Frontotemporal Degeneration (AFTD)

AFTD promotes and funds research into finding the cause, therapies and cures for frontotemporal degeneration. They also offer information, education and support to persons diagnosed with an FTD disorder, and for their families and caregivers. To learn more about AFTD, visit www.theaftd.org.

The Lewy Body Dementia Association (LBDA)

LBDA works to raise awareness of Lewy body dementias (LBD), promoting scientific advances, and supporting people with LBD, their families, and caregivers. LBD is a complex disease that can present a range of physical, cognitive, and behavioral symptoms. It dramatically affects an estimated 1.4 million individuals and their families in the United States. To learn more, visit www.lbda.org.

[Alzheimers.gov](#) – For the People Helping People with Alzheimer's

Resources from the Administration for Community Living on Alzheimer's disease and other forms of dementia.

National Institute on Aging: Alzheimer's Disease Education and Referral Center

Resources from the National Institutes of Health on Alzheimer's disease and other forms of dementia, including information on clinical trials and current advances in scientific research.

U.S. Department of Veterans Affairs: Dementia Care (including Alzheimer's)

For those caring for a Veteran, resources on dementia care through the VA and information on new research on dementia in Veterans.

Cancer Caregiving

Are you caring for a loved one with cancer? These resources may be helpful to you.

National Cancer Institute

• *Family caregivers may be spouses, partners, children, relatives, or friends who help the patient with activities of daily living and health care needs at home. Many cancer patients today receive part of their care at home. Hospital stays are shorter than they used to be, and there are now more treatments that don't need an overnight hospital stay or can be given outside of the hospital. People with cancer are living longer and many patients want to be cared for at home as much as possible. It is important that the family caregiver is a part of the team right from the start. These resources are about adult family caregivers in cancer.*

Cancer Experience Registry – Caregiver

• The Cancer Experience Registry is a unique online community that allows people facing cancer to share their experiences, identify the issues that impact their lives, take surveys, access resources and learn from each other. It is free, confidential and open to anyone who has been diagnosed with cancer or provides care to a cancer patient.

Cancer Support Community Helpline: 1-888-793-9355 or to chat live at www.cancersupportcommunity.org

• The Cancer Support Community Helpline provides emotional and educational services for all people affected by cancer and their family caregivers.

Cancer Support Community Affiliates & Support Groups for Caregivers

• *The Cancer Support Community Affiliate Network consists of 44 licensed affiliates, 170 locations and a growing number of healthcare partnerships.*

American Cancer Society – Caregivers Page

• A cancer diagnosis affects close friends and family too. Find out what to expect if you become a caregiver for a person with cancer and get tips for making sure that you take care of yourself as well. Resources available include information and support on How to Care for Someone with Cancer, Taking Care of Yourself as a Caregiver, How to Be Supportive to Someone with Cancer, When Your Child has Cancer, and a list of American Cancer Society Support Services and Programs for families who are managing cancer.

Help for Cancer Caregivers

• A collaboration of Anthem, Inc., CancerCare, Caregiver Action Network, Indiana University and Michigan State University, this website provides resources and news on caregiver caregiving.

Caregiving for Persons with Disabilities

[ALS \(Amyotrophic Lateral Sclerosis\) Association](#)

[Autism Society of America](#)

[Autism Speaks](#)

[Brain Injury Association of America](#)

[Easter Seals](#)

[Epilepsy Foundation](#)

[Global Genes](#)

[Muscular Dystrophy Association](#)

[National Alliance on Mental Illness \(NAMI\)](#)

[National Down Syndrome Society](#)

[National MS Society](#)

[National Organization for Rare Disorders \(NORD\)](#)

[The Arc](#)

[United Cerebral Palsy](#)

Family Caregiver Resources for Oregon

<https://states.aarp.org/oregon/caregiver-resources>

General Resources (taken from AARP website)

Supporting Family Caregivers in Your State

- AARP has a website dedicated to providing you with information about how we're advocating for caregivers in your state.

211 (2-1-1 | 866-698-6155 toll-free)

- 211info offers information and referrals to connect people with a wide range of health and social service organizations, including utility, food, health and housing, with a Community Information Center that is supported by a Resource Database team.

Seniors and People with Disabilities (503-945-5600)

- A program of the Oregon Department of Human Services, Seniors and People with Disabilities provides services designed to protect individual independence, dignity and choice. Staff at local offices, with the aid of community partners, can help individuals and families find the right mix of services to meet a person's needs.

Health Resources

Senior Health Insurance Benefits Assistance (SHIBA) (800-722-4134)

- Part of the Oregon Department of Human Services, Office of Aging and People with Disabilities, SHIBA is a statewide network of trained volunteers who educate and advocate for people of all ages who have Medicare. Volunteers help consumers understand their Medicare insurance choices and rights at no charge, and information is confidential.

Oregon Health Authority (OHA) (503-947-2340)

- The OHA includes most of the state's health care programs, including Public Health, Oregon Health Plan (Medicaid), crisis line, addiction services and mental health services. Its focus is on lowering and containing costs, improving quality and increasing access to health care in order to improve Oregonians' lifelong health.

Home- and Community-Based Resources

Aging and Disability Resource Connection (ADRC) of Oregon (855-ORE-ADRC | 855-673-2372 toll-free)

- ADRC is a comprehensive, one-stop statewide resource that provides guidance to connect older adults with a broad range of home-based assistance, local information, and government and community-based services. Individuals can be paired with an information and assistance specialist in the area who can help find resources and refer callers to local services. They also have skilled professional options counselors, who provide assessments to improve quality of life and help with short- and long-term planning.

Financial Resources

AARP Foundation's Benefits QuickLINK

- Find public benefits that can help you pay for food, medicine, health care, utilities and more by using AARP Foundation's Benefits QuickLINK tools.

Oregon Department of Consumer and Business Services (DCBS) (888-877-4894 toll-free)

- DCBS Division of Financial Regulation helps protect your financial well-being, with a dedicated team of consumer advocates who provide assistance and answer questions free of charge.

Legal Resources

Legal Aid Services of Oregon (LASO) and Oregon Law Center (OLC)

- Under the umbrella of OregonLawHelp.org, these nonprofit statewide organizations provide low-income and older clients with access to free legal help in matters of physical safety, food and shelter, and other critical legal needs. The website provides contact information based on location.

Oregon Office of the Long-term Care Ombudsman (800-522-2602)

- The Long-Term Care Ombudsman program is an independent state agency established to protect individual rights, enhance quality of life, improve care and promote the dignity of residents living in Oregon's licensed nursing, residential care, assisted living and adult foster care homes. Ombudsmen investigate and resolve complaints and advocate for improvements in resident care.

Oregon Department of Justice (DOJ) (877-877-9392 toll-free hotline)

- The Oregon DOJ Consumer Protection division helps consumers with complaints, prevents fraud and enforces consumer protection laws.

Workplace/Employer Resources

Supporting Caregivers in the Workplace

- AARP offers valuable resources to help employers create a caregiver-friendly workplace.

Transportation Resources

Aging and Disability Resource Connection of Oregon (ADRC) (855-ORE-ADRC | 855-673-2372 toll-free)

- ADRC is a comprehensive, one-stop statewide resource that connects seniors with a broad range of local information and government and community-based services for Oregonians, including transportation services based on location. You will be connected with an information and assistance specialist in your area who can help you find transportation resources and refer you to services.

Specific Audience Resources

AARP Caregiving Guides

- AARP offers free caregiving guides for specific audiences, including guides for military families and LGBT individuals. The guides, also offered in Spanish and Chinese, are designed to help develop and implement a caregiving plan.

Alzheimer's Association (800-272-3900 24-hour hotline)

- The Alzheimer's Association of Oregon & Southwest Washington Chapter provides education and support for people diagnosed with the disease and for their families and caregivers, including a 24/7 hotline for emergency placement, local resources, tips on wandering issues, communication advice, and behavioral and overall basic information.

National Multiple Sclerosis Society — Oregon Chapter (503-223-9511 | 800-344-4867)

- The society provides services and resources for people affected with MS, including health and wellness, family and relationships, and financial assistance.

Care for Caregivers

Community Connections

- AARP Community Connections is a new website that offers steps to get or give help. You can organize online mutual aid groups to stay connected, share ideas and support those in need.

Create the Good

- Create the Good connects people with volunteer opportunities and project ideas to share their life experiences, skills and passions in their communities.

The Oregon Hospice & Palliative Care Association

- This statewide organization provides information to hospice and palliative care services to ensure that Oregonians have access to high-quality care as they near the end of their life. It offers resources for patients, caregivers and family members.

AARP Resources for Family Caregivers

AARP Family Caregiving Website (en español: aarp.org/cuidar)

- AARP's Family Caregiving website is your one-stop shop for tips and tools to help you care for a loved one. It has valuable information about handling medical issues, health records and advance directives, home safety, financial and legal issues, caregiver life balance and much more.

AARP Family Caregiving Resource Line (877-333-5885 toll-free, en español: 888-971-2013 toll-free)

- Connect with a real person and learn how to access local resources via our toll-free family caregiving hotline.

AARP Family Caregivers Facebook Group

- Join the AARP Family Caregivers Discussion Group on Facebook to connect, ask questions and share ideas with other family caregivers.

Community Resource Finder

- Community Resource Finder, a joint service from the Alzheimer's Association and AARP, is a database of dementia- and aging-related resources powered by Carelike. The online tool makes it easy to find local programs and services.

I Heart Caregivers

- Join the thousands of family caregivers who have shared their experiences through AARP's storytelling initiative, I Heart Caregivers. Your story will help AARP continue to fight for more support for family caregivers.

AARP Online Caregiving Community

- Join our community and connect with other caregivers like you.

AARP HomeFit Guide

- The AARP HomeFit Guide can help individuals and families make their current or future residence age-friendly. It can also help elected officials, policymakers and local leaders learn about and advocate for the types of housing features and designs that communities need so that their residents can live safely and comfortably and thrive.

National Resources for Family Caregivers

- A listing of national agencies, groups and organizations that can connect family caregivers with direct services and supports.