

Information and Assistance/Options
Counseling
Resource Guide:
Caregivers for
People with Dementia and Other
Caregivers

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Introduction:

According to the National Association for Area Agencies on Aging, “Research shows that nearly 90 percent of people age 65 and older want to age in place (i.e., stay in their homes and communities) for as long as possible. But to do so, many older adults rely on family or friend caregivers for support. The wide range of services provided by unpaid caregivers, such as transportation, food preparation, housekeeping and personal care enable older adults to live with dignity and independence. Most people who serve as caregivers do not self-identify as caregivers, however. Instead they consider the care they provide as “what you do for someone you care about or love.”

But serving as a caregiver may exact a heavy toll—emotionally, physically and financially—for the person assuming this role. The average age of a caregiver is 48, a time in many people’s lives when they are still raising a family and actively employed. Add the role of caregiver to the mix and many people feel unprepared and overwhelmed.

Area Agencies on Aging (AAAs) around the nation provide direct support to caregivers, primarily through the [National Family Caregiver Support Program](#) (Title III E of the Older Americans Act), which was created in 2000. Services include respite care (temporary supervision of the care recipient to provide rest for the caregiver, which is the most requested service); individual counseling and support groups; caregiver education classes/training; and emergency assistance.

AAAs also play a crucial information and referral role, connecting families with local providers who can help them create a caregiving plan, address specific challenges, or identify support services.” Caregivers usually do not know what they are seeking when calling an agency, so AAA staff can aid caregivers to explore a spectrum of issues so the caregiving family can make informed decisions in their situation.

These training materials were compiled by a workgroup of Idaho’s AAA Information and Assistance Specialists (I&A) and ICOA as an objective of the Creating Dementia Capable Systems project during 2019. The project was funded by grant # 90ADSG000101 to the Idaho Commission on Aging from the U.S. Administration on Community Living. The content is meant as a basic training for new AAA I&A and other employees or volunteers, who may work with caregivers and the public. Most of the materials can also be shared with caregivers as resources.

What is Dementia and Alzheimer’s Disease?

Learn about dementia and be able to refer people to the free learning modules and tools on the Idaho Commission on Aging website and other resources.

- Complete [Dementia Skills Training Modules on the Idaho Commission on Aging website](#)
- Review Alzheimer’s Disease and Caregiving Fact Sheet Alzheimer’s Disease <https://www.caregiver.org/alzheimers-disease-caregiving> This is an excellent resource. Good information about the disease, caregiving, and approaches for all stages of the disease. Answers the question, “What things should I be planning for at this time?” You can order copies of this publication and print from the online version.
- [Idaho Department of Health and Welfare ADRD website](#)

What is long-term care (LTC)?

Be able to help People with Dementia (PWD) and families understand the LTC system; help them identify options and develop a plan. Help them understand that things will change and that they can contact you for more assistance as changes occur.

Review the information on the Genworth website. <https://www.genworth.com/aging-and-you/finances/what-is-long-term-care.html>

Study the Residential Care Options tip sheets <https://www.caregiver.org/residential-care-options-five-tip-sheets> You can print these 5 tip sheets from this website.

- Housing Options
- The Right Time
- Choosing the Right Place
- Caregiving Doesn't End When Your Loved One Moves
- Visiting Someone in Dementia or Memory Care

What are in home services and options?

Be able to describe in home services and options in the community that apply to PWD and family. These include: Personal care service (also referred to as attendant care/services or home care aide), homemaker, respite (paid and volunteer options if available), home delivered meals (through the AAA or arranged with community help like churches, family, or friends). Be able to help the PWD and caregiver talk with family, friends, and others about helping with respite and managing other caregiving tasks.

Services defined:

[Homemaker](#)

Home Health Care vs. Home Care non-medical

<https://www.aplaceformom.com/planning-and-advice/articles/home-health-vs-home-care>

Home Health Care paid by Medicare

<https://www.medicare.gov/what-medicare-covers/whats-home-health-care>

Palliative and Hospice Care explained

<https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>

Be able to talk with caregivers about the importance of and difficulties with family caregiver management of these services. Review the [John Hopkins Medicine Guide for Caregivers](#), which will inform you of the breadth of responsibilities associated with caregiving.

[Respite](#)

[ABC's of Respite](#)

Providing and Receiving Respite Care Safely During the COVID-19 <https://archrespite.org/national-respite-guidelines-for-covid-19>

Be able to talk with caregiving families about the value of sources or respite:

- 9 Steps to Respite Care for Family Caregiver of Persons with Dementia
<https://archrespite.org/consumer-information/family-caregiver-fact-sheets>
- Respite Services: [Enhancing the Quality of Daily Life for Caregivers and Care Receivers](#), booklet by Dale Lund
- [Setting Goals to Maximize Your Respite Time](#), worksheet for caregivers

What kinds of events should PWD and families plan for?

What should those plans include?

- Going to the hospital
<https://www.nia.nih.gov/health/going-hospital-tips-dementia-caregivers>
- Discharge home from the hospital or another facility <https://www.caregiver.org/hospital-discharge-planning-guide-families-and-caregivers>
- Contingency planning for absence of family caregiver due to illness, injury, travel or death
<https://www.caregiving.com/2009/02/be-prepared-create-your-contingency-plan-before-you-need-it/>

How do PWD and families pay for services?

Be able to help people know their payment options and the likelihood of their eligibility for those options. Know where to refer families for eligibility determinations.

What is Home Care?

Private insurance

Know about public and personal options to pay for services.

The Basics <https://acl.gov/ltc> There is information on this website about several related topics. This is good resource to which to refer families.

Review a long-term care planning checklist so you know what is entailed when talking with families.

Here is an example: <https://acl.gov/ltc/basic-needs/pathfinder>

- Know eligibility for AAA services.
- Know about programs available to Veteran's and local contacts. Review *AARP Military Caregivers Guide*
<https://www.aarp.org/content/dam/aarp/caregiving/2019/05/military-caregiving-guide-aarp.pdf>
VA Financial Benefits https://www.va.gov/GERIATRICS/pages/VA_Financial_Benefits.asp
and VA Health Benefits <https://www.va.gov/health-care/>

Webpage of dementia specific information provided by VA

https://www.va.gov/geriatrics/Alzheimers_And_Dementia_Care.asp

- Know general eligibility for Idaho Medicaid and refer people who are likely eligible or soon to be eligible to Idaho Department of Health and Welfare.

- This "Long-Term Care Medicaid" video was developed by Idaho Legal Aid. It was produced in both English and Spanish and is meant to be a very simple overview of long-term care Medicaid in Idaho. The purpose of this video is to dispel some of the myths that often prevent seniors from applying for this valuable program.
<http://www.idaholegalaid.org/node/2560/elder-law-video>
- Refer to current Idaho Department of Health and Welfare Medicaid eligibility requirements or arrange in-service with your Regional Medicaid office or Center for Independent Living.
- Know the difference between Medicaid and Medicare. <https://www.genworth.com/aging-and-you/finances/limits-of-medicare-medicaid.html>
- Know about compassionate allowance for certain chronic conditions, including early onset Alzheimer's disease <https://www.ssa.gov/compassionateallowances/index.htm>
- Know the resources for arranging care for private pay individuals. How to identify and hire a provider agency and how to manage and hire an individual in home service worker. Your knowledge should include Certified Family Homes.
 - [Personal Care Agreements](#)
 - [Background Checking: Resources That Help](#)
 - [Caregiving at Home: A Guide to Community Resources](#)
 - [Emergency Preparedness Checklist for Caregivers](#)
 - [Hiring In-Home Help](#)
 - [Holding a Family Meeting](#)
 - [Working Successfully with Home Care Services](#)
- Certified Family Homes
 - Examples of websites where families can search for in home service providers:
<https://hiremycare.org/>
<https://www.caring.com/>

What are helpful resources for caregivers caring for a PWD at home?

Review these and add resources as you learn about them.

- Thinking of quitting your job for caregiving:
 - [Work and Eldercare](#)
 - <https://www.dhs.wisconsin.gov/publications/p01174.pdf>
- [Caregiver Tip Sheets: Keeping Home Safe](#) (Web page) Alzheimer's Greater Los Angeles.
This web page contains a series of plain language tip sheets on various topics related to Alzheimer's and related disorders, in English and Spanish.
- *A Guide for Families: Keeping the Person with Memory Loss Safer at Home*
https://www.va.gov/Geriatrics/docs/HOME_SAFETY_BOOKLET_March_2019.pdf

- [Video caregiving: A Visual Education Center for Family Caregivers](#) (Video) Terra Nova Films.
This website includes videos about caregiving for people living with Alzheimer's disease. The videos address several topics including how to cope with the disease, communication, driving, and activities for people living with Alzheimer's disease. Website requires Adobe Flash Player.
- [Taking Care of YOU: Self-Care for Family Caregivers](#) (Web page) Family Caregiver Alliance.
This web page provides information for caregivers on caring for one's own health while caring for others. The web page includes tools on continuing self-care by learning how to reduce personal stress, set goals, communicate constructively, seek solutions, and how to ask for and accept the help.
- Training available on YouTube through UCLA and ICOA Caregiver Training videos.
<https://www.uclahealth.org/dementia/caregiver-education-videos>
<https://aging.idaho.gov/stay-educated/>
- Know resources to which you can refer families for training and information about caregiving for someone with dementia. Here are a few resources for review:
 - <https://order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide>
 - <http://www.actonalz.org/dementia-curriculum>
 - <http://www.hcinteractive.com/CARES>
 - [Caregiving at Home: A Guide to Community Resources](#)
 - [Medications: A double-edged sword](#)

How do family members or other informal caregivers get paid for caregiving?

Know about Certified Family Homes (CFH) and other methods for being paid as a caregiver.

- [How to Get Paid for Being a Family Caregiver in Idaho](#)
- Review *How to Get Paid for Being a Family Caregiver?* <https://www.caring.com/articles/payment-for-family-caregiver/>

Generally, what are the legal issues and resources around long-term care and caregiving, and dementia?

Review Legal and Financial Planning for People with Alzheimer's Disease: The website below includes the following information:

- Legal, Financial, and Healthcare Planning Documents
- Advance Healthcare Directives for People with Alzheimer's
- Advance Directives for Financial and Estate Management
- Where Can I Get Help with Legal and Financial Planning?
- Advance Planning Advice for People with Alzheimer's
- Legal and Financial Planning Resources for Low-Income Families

<https://www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers>

<https://www.idaholegalaid.org>

<https://healthandwelfare.idaho.gov/services-programs/birth-marriage-death-records/advance-directives-and-registry-services>

Other resources include:

- *Legal Plans: considerations for helping a person living with dementia plan for the future*
<https://www.alz.org/media/Documents/alzheimers-dementia-legal-plans-b.pdf>
- *Living with Dementia: Advance Planning Guides (FOUR guides) for Persons with Dementia and Caregivers*
 - [Health Care Planning](#): This guide will help you plan for your future health care need
 - [Planning for Care](#): This guide will help you plan for the care and services you may need
 - [Financial Planning](#): This guide will help you plan how to manage your money and property
 - [Making Decisions for Someone with Dementia](#)

To learn more about Advance Care Planning (ACP) specifically for families of People with Dementia go to Honoring Choices Idaho <https://honoringchoicesidaho.org/guides/> Review the *Dementia and ACP Guide* and the *Being the Health Care Agent for Someone with Dementia Guide*. Look around the website so you can refer people to it. Guides and other resources on the site are available in Spanish.

Finding the Right Fit: Decision-Making Supports and Guardianship

The National Center for State Courts has a new training that provides a broad overview of decision-making supports and guardianship. The training is designed to educate individuals about ways to help someone who may need assistance in making decisions with informal supports, legal options, and/or adult guardianship. Finding the Right Fit is not specific to state laws or rules, but rather provides information and guidance on finding the right kind of supports for someone's needs.

<https://eji.courtims.org/catalog/info/id:140>

What are the Idaho resources to effectively refer people?

Know your way around these websites so you can refer people appropriately.

- Idaho Legal Aid <https://www.idaholegalaid.org/>
- Idaho Volunteer Lawyers Program <https://isb.idaho.gov/ilf/ivlp/>
- Mediation services <https://www.idahomediationassociation.org/Find-a-Mediator>