

A Provider's Guide to Caring for the Caregiver

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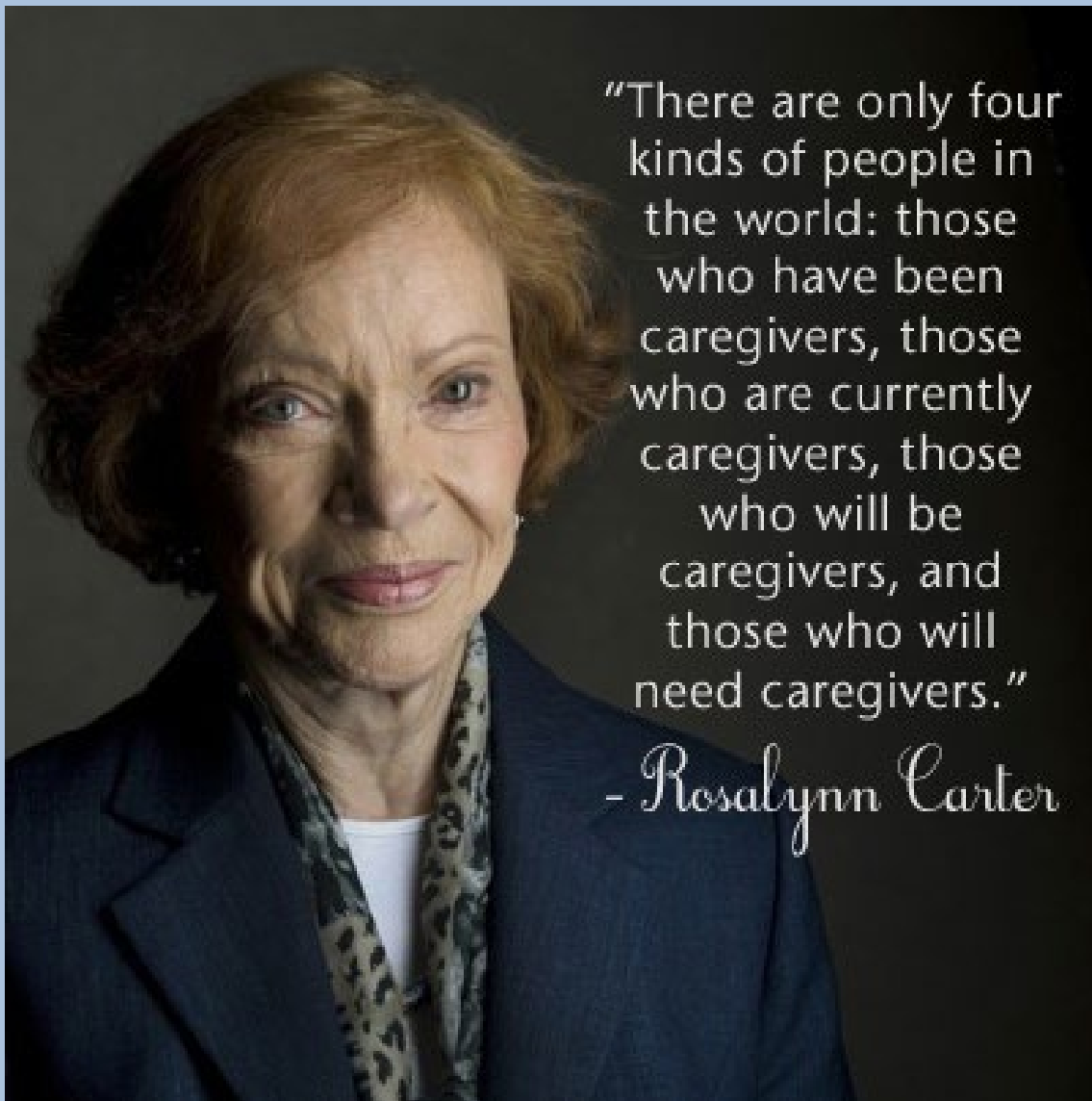
Program Manager - Caregiver Support Program & ADRD Program

OBJECTIVES

- ❑ Understand the challenges and needs of the family caregiver
- ❑ View care partners/caregivers as a valuable resource and seek to incorporate them into the care team
- ❑ Understand the role you play in setting patients/caregivers up for success by connecting them to resources/supports
- ❑ Overview of community supports for caregivers

“...caregiving remains an activity that occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations.”

~Caregiving in the U.S. 2020



"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, and those who will need caregivers."

- Rosalynn Carter

CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*



NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**

More Americans are caring for more than one person.



More family caregivers have difficulty coordinating care.



More Americans caring for someone with Alzheimer's disease or dementia.

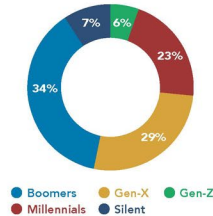


More family caregivers report their own health is fair to poor.



23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?



45%
HAVE HAD AT LEAST ONE FINANCIAL IMPACT



UTAH'S CAREGIVERS

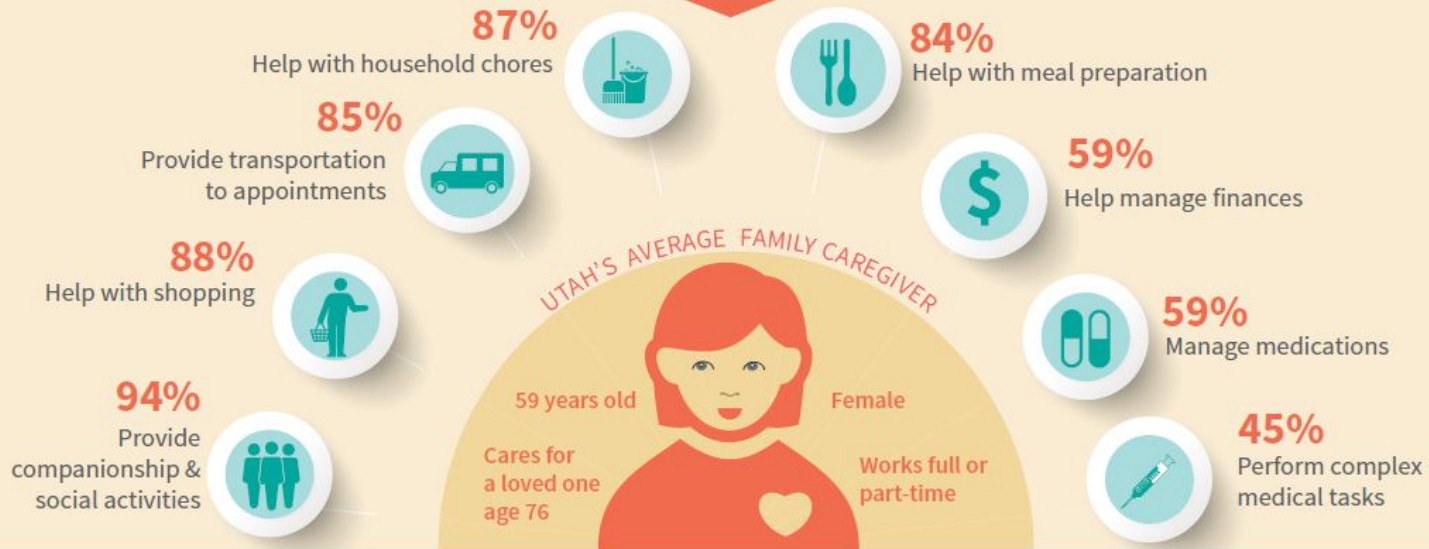
In Utah, approximately **1 in 5** adults provide unpaid caregiving services to their family and friends.

UTAHNS ARE FAMILY CAREGIVERS

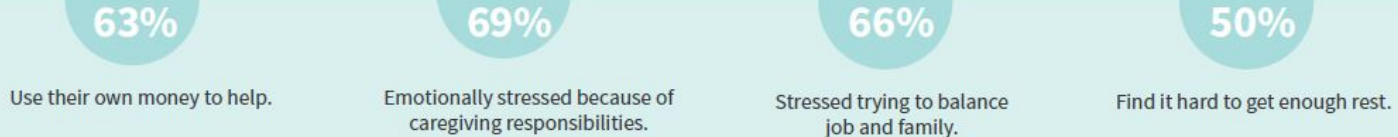
Across Utah family caregivers take on big responsibilities helping their parents, spouses, and other loved ones stay at home. AARP recently surveyed 801 Utah registered voters age 40-plus about caring for their families. Here's what we learned:



Utah family caregivers often have huge responsibilities. They:



Utah family caregivers believe it's important to help their loved ones live independently at home, but they also face challenges:



Source: September 2018 Survey of 801 Utah Registered Voters Aged 40-plus. Margin of error is ± 3.5%

I  Caregivers

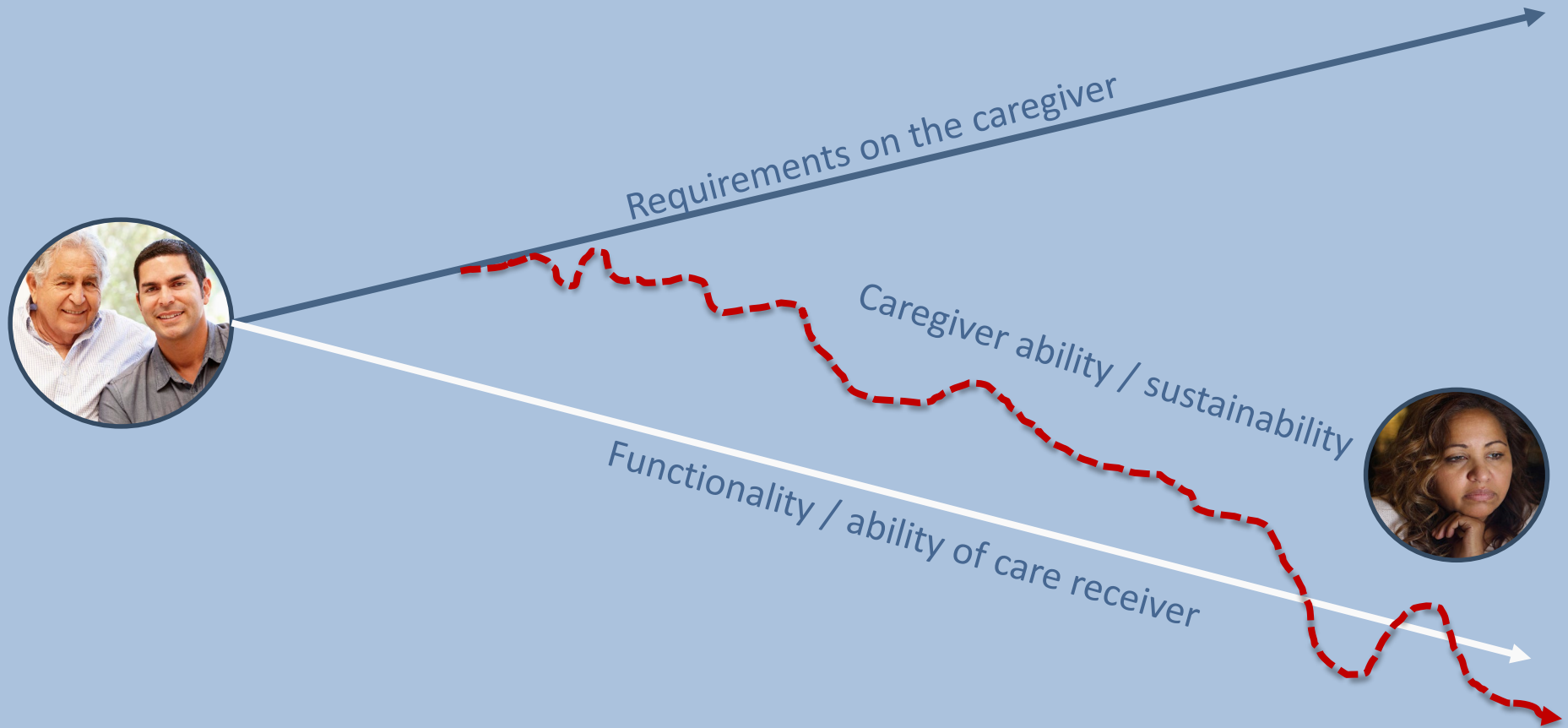
AARP Real Possibilities

UTAH FAMILY CAREGIVER SUPPORT PROGRAM

Greatest difficulties faced as a caregiver:

- 86% creates stress
- 62% doesn't leave enough time for myself
- 37% doesn't leave enough time for my family
- 43% creates or aggravates problems with my health
- 30% creates a financial burden
- 34% creates an impact on employment

THE CAREGIVING CONTINUUM



EFFECTS OF CAREGIVER STRESS ON THE CARE RECEIVER

When family caregivers are in **distress/crisis** the care receiver is affected as well

- Increased institutionalization rates
- Exacerbated behavioral and psychological challenges
- **Increased risk of abuse**

“When one needs care,
two need help.”

~Nancy Madsen Wilkerson



CAREGIVERS ARE VITAL TO BETTER CARE

- Partner with family caregivers because they:
 - Often **know their loved one better** than anyone else
 - Know their own capacity and limitations in providing care safely in the home
- Utilizing family caregivers results in **better care, better health and quality of life for patient; lower costs; easier and more meaningful work**



NOVEMBER 2021

Caring For The Caregiver: Incentivizing Medical Providers to Include Caregivers as Part of the Treatment Team

About the National Alliance for Caregiving

NAC's mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers. Our work aims to support a society which values, supports, and empowers family caregivers to thrive at home, work, and life. As a 501(c)(3) charitable non-profit organization based in Washington, D.C., we represent a coalition of more than 60 non-profit, corporate, and academic organizations; nearly 40 family support researchers with expertise in pediatric to adult care to geriatric care; and more than 50 advocates who work on national, state and local platforms to support caregivers across the United States. In addition to our national work, NAC leads and participates in a number of global meetings on caregiving and long-term care, working closely with peer organizations from more than a dozen nations. Learn more at www.caregiving.org.

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WHAT FAMILY CAREGIVERS NEED

Caregivers' highest priority concerns include the following domains:

- Caregiving education and training
- Respite care; and
- A range of financial considerations including:
 - Having workplace flexibility
 - Direct pay for being a caregiver and
 - Changes in tax policy to benefit caregivers



What Family Caregivers Need: Findings from Listening Sessions

By Eileen J. Tell, Mph
Pamela Nadash, PhD
Marc A. Cohen, PhD
May 17, 2021



COMMUNITY SUPPORTS AND RESOURCES

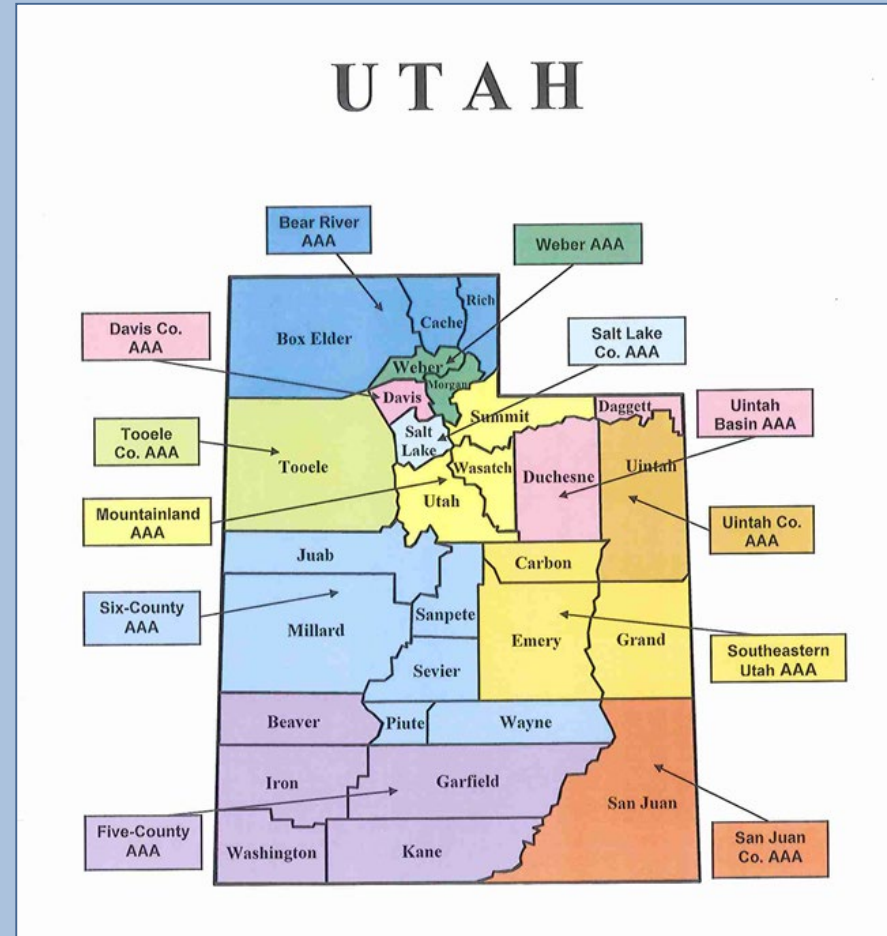


AREA AGENCIES ON AGING (AAA)

To promote positive aging and assist seniors in maintaining health, independence, and quality of life

- Information and resources
- Advocacy
- Plan, coordinate, and provide services

Find your local AAA:
<https://eldercare.acl.gov/>



AAA SERVICES

- Information & Resources
- Nutrition; Meals on Wheels
- Medicare Insurance Counseling
- **Caregiver Support Program**
- In-Home Services Programs
- Evidence-Based Health Programs
- Long-term Care Ombudsman
- Transportation
- Senior Centers
- And so much more ...



To find your local AAA: <https://eldercare.acl.gov/>

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

- Caregivers of Older Adults – adult family member (18+) or other informal caregiver
 - provides support to an individual with Alzheimer’s disease or a related disorder (any age)
 - provides support to an older individual (60+)
- Older Adult Caregivers – caregiver who is 55+
 - provides support to an adult age 18-59 with a disability (may be a parent)
 - provides support to a child under 18 and is not a parent (i.e. grandparents or fictive relatives)

CAREGIVER SUPPORT PROGRAM

Core Services

- * Information about available community resources
- * Assistance in gaining access to supportive services
- * Counseling & Case Management
- * Support groups
- * Caregiver Education/Training
- ** Respite care (relief for caregivers, i.e. in-home services, supervision for loved one)
- ** Supplemental services (Emergency Response System, grab bars, incontinence supplies, etc.)

* Available to general public

** Meet eligibility criteria

ELIGIBILITY CRITERIA FOR RESPITE & SUPPLEMENTAL SERVICES

No low income requirement;
based on stress index for caregiver.

Care receiver unable to perform 2 ADLs
w/o substantial assistance

OR

require substantial supervision due to cognitive impairment.

FAMILY CAREGIVER SUPPORT PROGRAM

As a result of receiving caregiver services:

- 85% able to provide care for a longer period of time than would have been possible without these services
- 76% have delayed placement in an assisted living or nursing home
- 89% able to be more self-reliant

ADDITIONAL IN-HOME SERVICES

- **The Alternatives Program:** (TAP) provides non-medical in-home services for older adults at risk of nursing home placement.
- **Medicaid Aging Waiver:** (AW) provides non-medical in-home services to low income seniors 65+ who are on Medicaid. Health must meet SNF admissions guidelines.
- **New Choices Waiver:** (NCW) provides Medicaid recipients residing in institutional settings w/ the option of receiving supportive services in their own home or in other community-based settings (i.e. assisted living facilities).
- **Veteran-Directed Home & Community-Based Services:** (VD-HCBS) provides Veterans of all ages the opportunity to receive self-directed services they need. Must be at risk of SNF placement and are interested in directing their own care or designating a personal representative.

ALZHEIMER'S ASSOCIATION

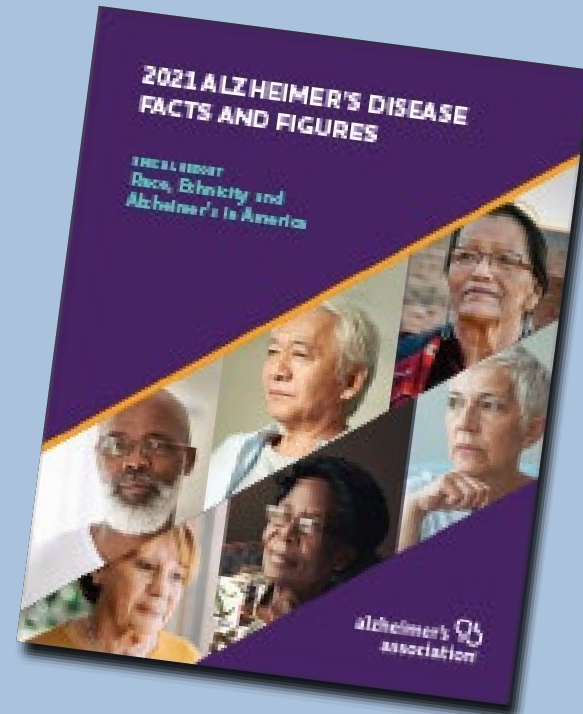
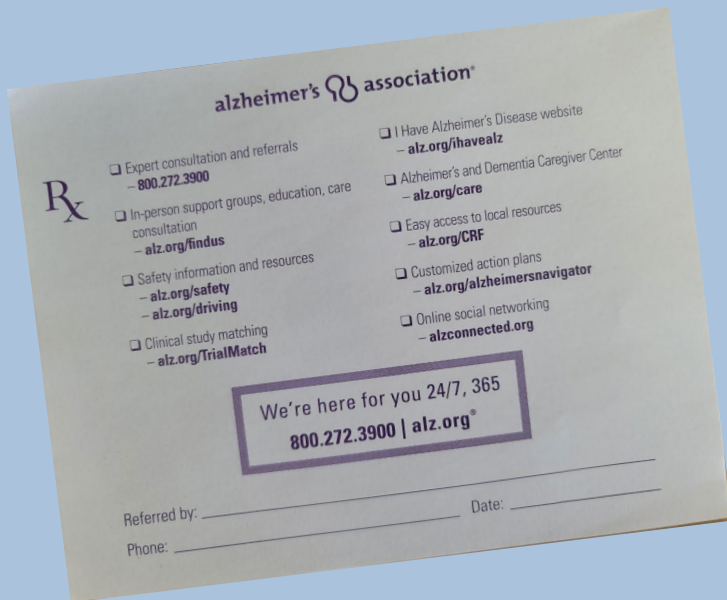
- Information about and referral to community resources
- Support groups
 - Individuals in the early stages of dementia
 - Family caregivers
- Caregiver education programs (online & in-person)
- Educational material

24/7 Helpline: 800-272-3900

www.alz.org

alzheimer's 
association

ALZHEIMER'S ASSOCIATION



24/7 Helpline: 800-272-3900
www.alz.org



VA CAREGIVER SUPPORT PROGRAM

- Resource and Referral: assistance navigating VA services
- Counseling
- Education, Training, and Support
- May also qualify for:
 - In-Home Care
 - Respite Care
 - Equipment & Supplies

VA Caregiver Support Line: 855-260-3274

www.caregiver.va.gov

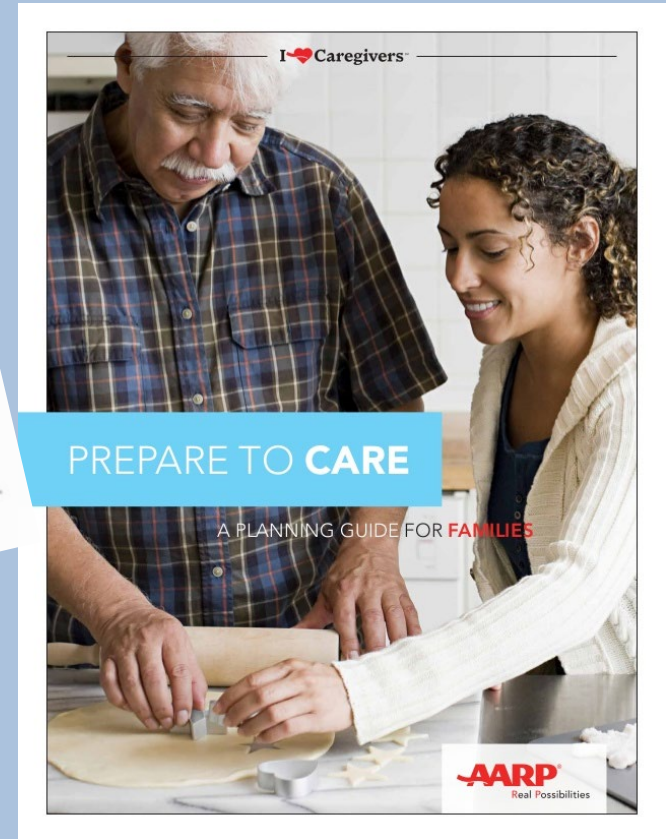
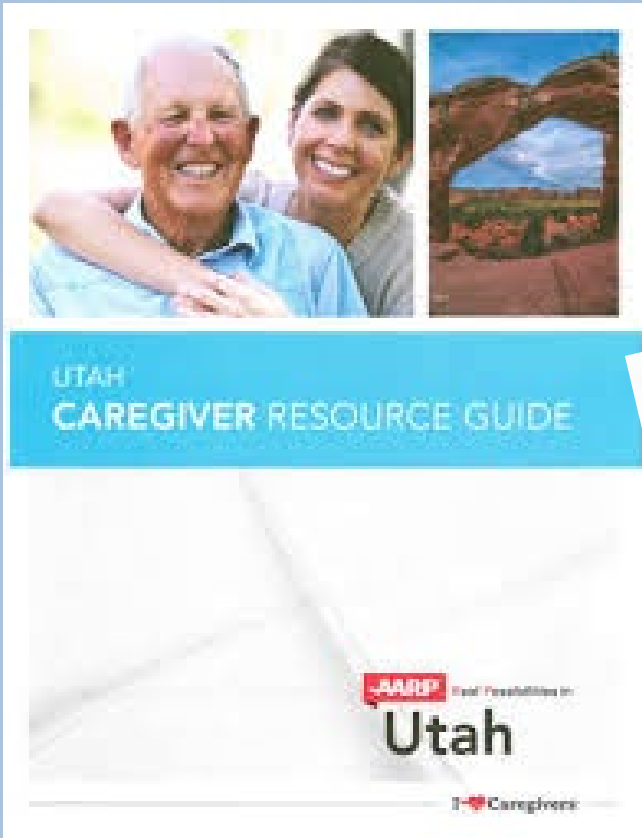


HOW THE VA IS INCORPORATING FAMILY CAREGIVERS

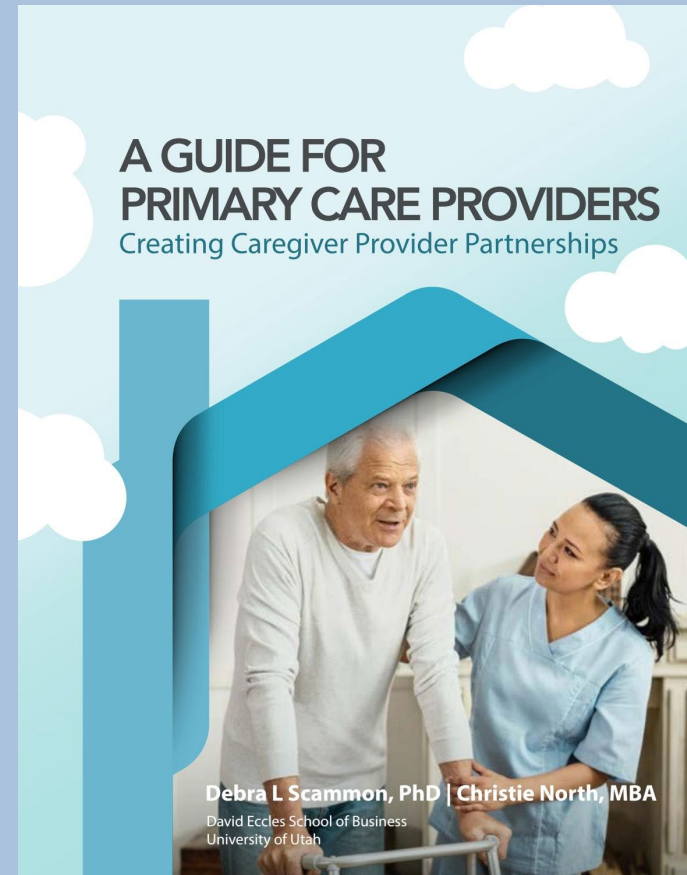
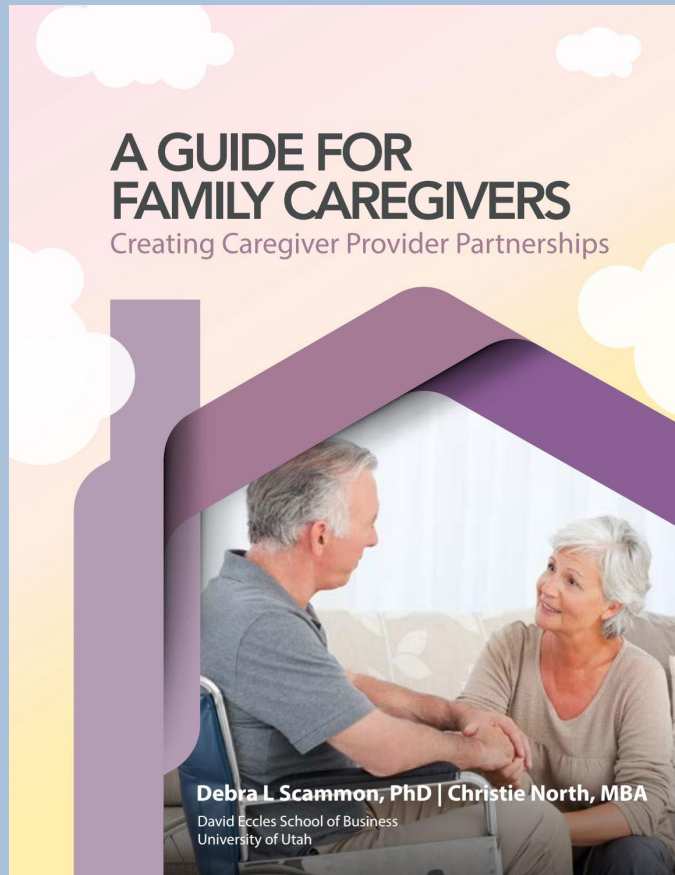


<https://campaignforinclusivecare.elizabethdolefoundation.org/about/>

AARP PUBLICATIONS



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



https://ucoa.utah.edu/_resources/documents/CreatingCaregiver_r126_Digital.pdf
https://ucoa.utah.edu/_resources/documents/ProviderGuide_Digital.pdf

WHAT CAN PROVIDERS/HEALTH SYSTEMS DO

- **Bring care partners/caregivers into the conversation as early as possible**
- Not everyone identifies as a “caregiver”
 - Ask “who else needs to be involved in these meetings/discussions?”
- Ensure your **intake process** has the option to **list a family caregiver** or someone who supports their care
- Ensure your entire team recognizes the important role caregivers play so they don’t get lost along the way

WHAT CAN PROVIDERS/HEALTH SYSTEMS DO

- Speak with the caregiver to **understand their challenges**
- Ask questions such as:
 - What can I help you with at home that you are not able to accomplish?
 - What else do you have on your plate?
 - What stresses do you have at home that you are struggling with?

WHAT CAN PROVIDERS/HEALTH SYSTEMS DO

- Connect caregivers to resources in their local area
- Have **information packets/one-pagers** ready to go to hand to family caregivers
- Follow up that those resources are helpful



utah department of
human services
AGING AND ADULT SERVICES

TAKEAWAYS

- Care partners/caregivers are a valuable resource
- You and your team play a vital role in connecting patients/caregivers to resources and encouraging their self-advocacy
- Without being directed to community resources/supports, caregivers will struggle/fail
- **Eldercare.acl.gov** will get you to an Area Agencies on Aging near you, which will get you, your patients/clients, and their care partners to all other resources

CONTACT INFORMATION

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<https://daas.utah.gov/>



To find your Area Agency on Aging:
<https://eldercare.acl.gov>

For additional supports & resources, Utah Commission on Aging:
www.utahaging.org

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