Supporting Care Partners of persons with dementia

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Objectives

- Understand care partner demographics.
- Understand an overview of care partner tasks and how to alleviate stress.
- Understand the challenges faced by care partners including managing their own health, emotional and psychosocial factors and how to help navigate.
- ADL care and support methods for the person with dementia as well as self-care for the care partner.

2025 Care Partner Stats

There are more than 12 million unpaid care partners for those with dementia in the US.

19.2 billion hours of informal care provided is valued at $413 billion.

Total lifetime cost of caring for a person with dementia is $405,262 (in 2024 dollars). 70%, $283,683 of this cost borne by the family as unpaid caregiving hours & out of pocket expenses

Alzheimer's Association. (2025).

Who are care partners?

- Average age 49.5
- Majority are women
- 66% of care partners live with their person with dementia in the community
- Many don't self-identify as a "care partner"
- LGBTQIA+ community

Alzheimer's Association. (2025).

CAPC. (2025).

Common Care Partner Tasks

1. Household tasks
2. Health & Medical Care
3. Emotional, Spiritual and Social Support
4. Activities of Daily Living,
5. Safety, Managing Unmet Needs
6. Advocacy & Care Coordination
7. Surrogate Decision Making

CAPC. (2025).

The Impact of Caregiving

Grief

- Ambiguous Grief
- Denial, anger, resentment, guilt, acceptance
- Relationship changes

Emotional Health

- “Caregiver Burden” & cultural awareness
- Meaningfulness & pride
- Anxiety & stress: constant worry
- Isolation
- **Depression**

Overall Health

- Sleep Deprivation
- Poor eating habits
- Failure to exercise
- Failure to stay in bed when ill
- Postponement or failure to make/keep their own medical appointments

(Family Caregiver Alliance, 2025), (Harrison, 2025), (Arevalo-Flechas, 2013), (Alzheimer's Association, 2025b)

Care Partner Health Concerns: Getting in their own way

Common misconceptions care partners tell themselves:

- If I don't do it, no one will.
- Only I can do things the right way.
- If I do it right, I will get the love, attention, and respect I deserve.
- I promised them I would always take care of them.

Family Caregiver Alliance. (2025).

Questions to ask to assess care partner well-being

Do you see a doctor for your own health needs?

Who gives you support? Is it helpful?

How are you? Really, how are you?

Many care partners find their caregiving role stressful. Can you tell me how you're doing with it?

(CAPC, 2025)

What care partners need from us

Clear, concise communication

- Take education levels into consideration
- They are learning an entirely new language

Information about loved ones medical care

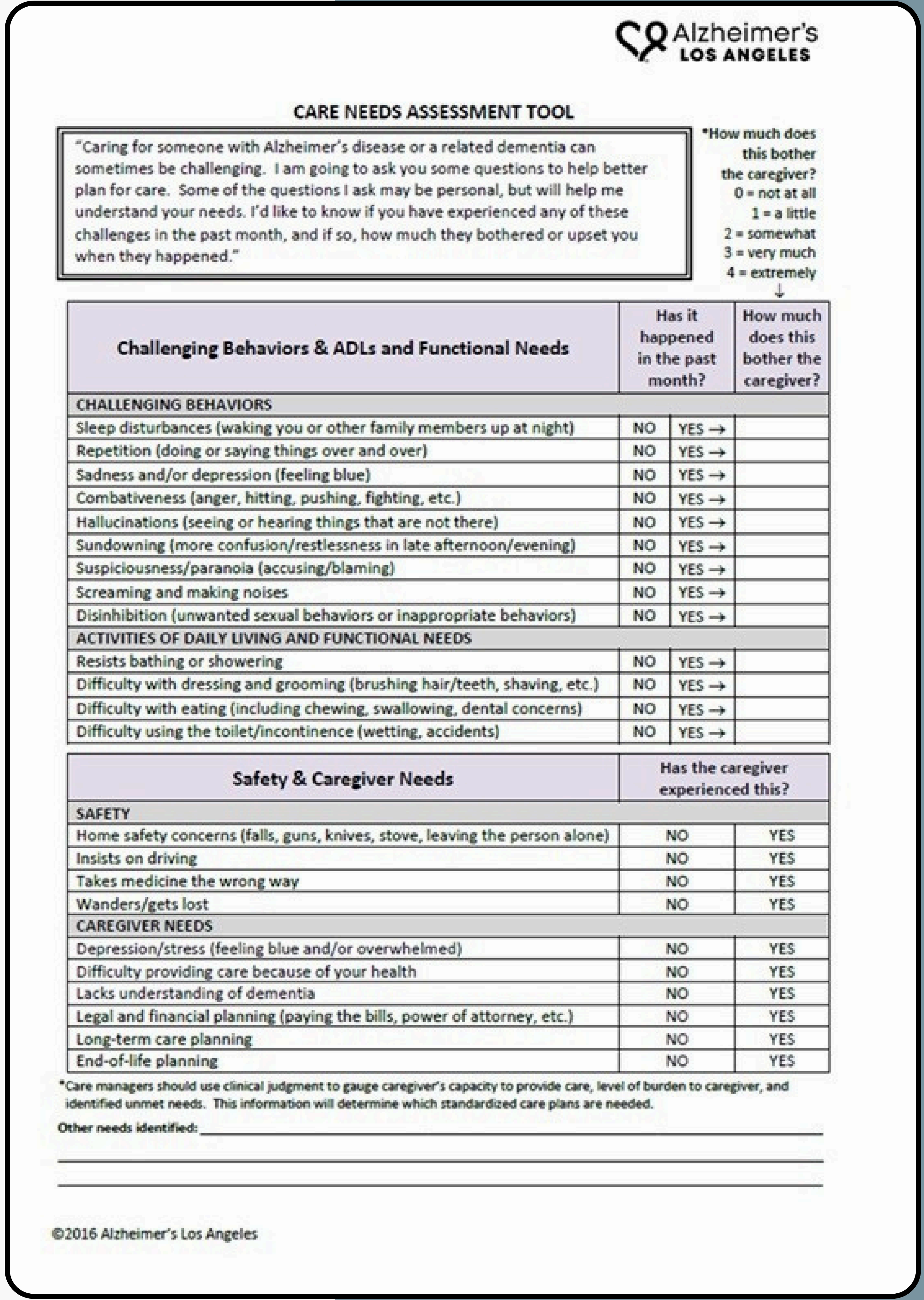
Emotional Support & Validation

- Compassionate honesty

Information about dementia progression

Referrals for services that relieve stress

- Use a care needs assessment tool



Alzheimer's
LOS ANGELES

CARE NEEDS ASSESSMENT TOOL

> "Caring for someone with Alzheimer's disease or a related dementia can sometimes be challenging. I am going to ask you some questions to help better plan for care. Some of the questions I ask may be personal, but will help me understand your needs. I'd like to know if you have experienced any of these challenges in the past month, and if so, how much they bothered or upset you when they happened."

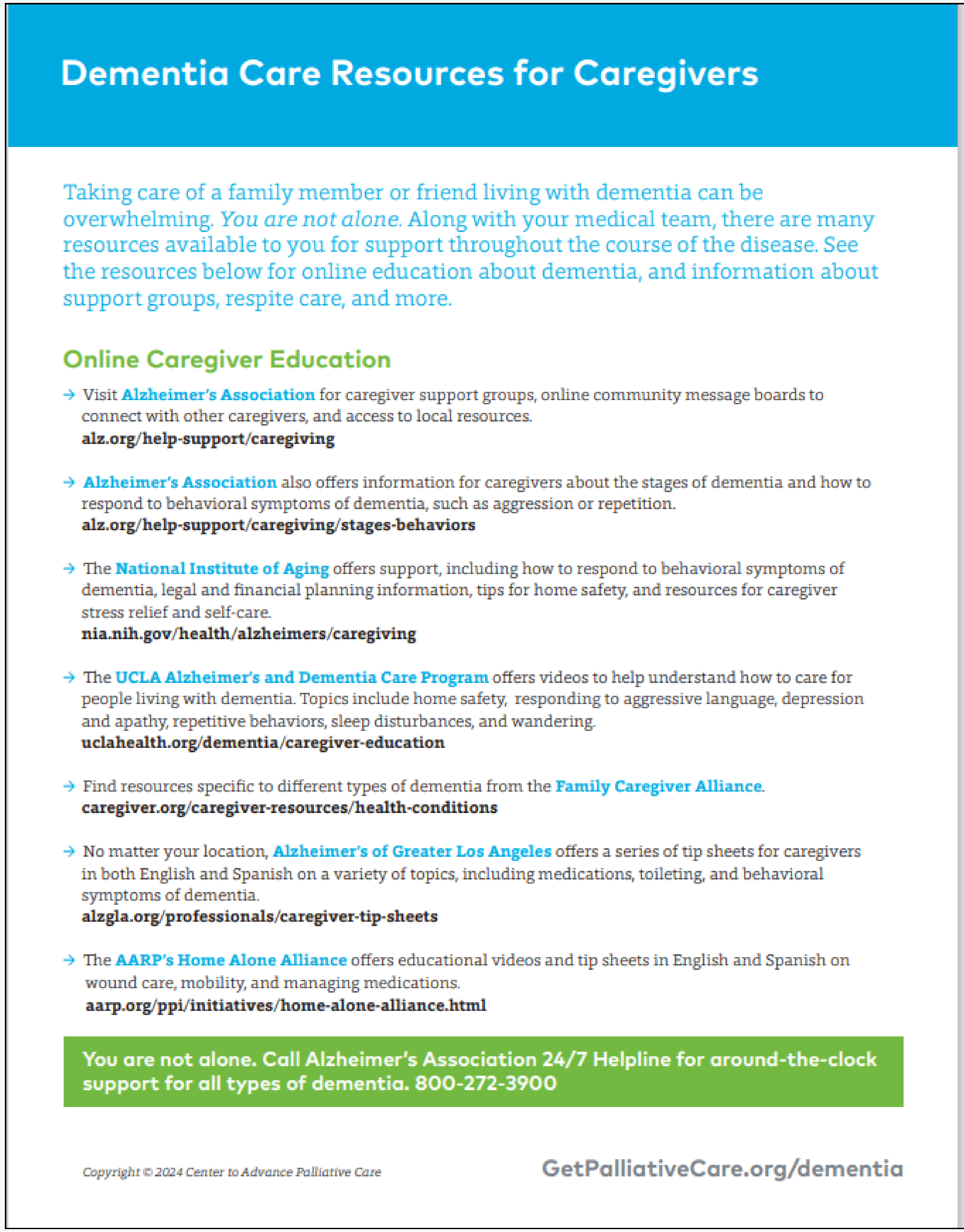
*How much does this bother the caregiver?
0 = not at all
1 = a little
2 = somewhat
3 = very much
4 = extremely
↓

Challenging Behaviors & ADLs and Functional Needs	Has it happened in the past month?		How much does this bother the caregiver?
CHALLENGING BEHAVIORS			
Sleep disturbances (waking you or other family members up at night)	NO	YES →	
Repetition (doing or saying things over and over)	NO	YES →	
Sadness and/or depression (feeling blue)	NO	YES →	
Combativeness (anger, hitting, pushing, fighting, etc.)	NO	YES →	
Hallucinations (seeing or hearing things that are not there)	NO	YES →	
Sundowning (more confusion/restlessness in late afternoon/evening)	NO	YES →	
Suspiciousness/paranoia (accusing/blaming)	NO	YES →	
Screaming and making noises	NO	YES →	
Disinhibition (unwanted sexual behaviors or inappropriate behaviors)	NO	YES →	
ACTIVITIES OF DAILY LIVING AND FUNCTIONAL NEEDS			
Resists bathing or showering	NO	YES →	
Difficulty with dressing and grooming (brushing hair/teeth, shaving, etc.)	NO	YES →	
Difficulty with eating (including chewing, swallowing, dental concerns)	NO	YES →	
Difficulty using the toilet/incontinence (wetting, accidents)	NO	YES →	

Safety & Caregiver Needs	Has the caregiver experienced this?	
SAFETY		
Home safety concerns (falls, guns, knives, stove, leaving the person alone)	NO	YES
Insists on driving	NO	YES
Takes medicine the wrong way	NO	YES
Wanders/gets lost	NO	YES
CAREGIVER NEEDS		
Depression/stress (feeling blue and/or overwhelmed)	NO	YES
Difficulty providing care because of your health	NO	YES
Lacks understanding of dementia	NO	YES
Legal and financial planning (paying the bills, power of attorney, etc.)	NO	YES
Long-term care planning	NO	YES
End-of-life planning	NO	YES

*Care managers should use clinical judgment to gauge caregiver's capacity to provide care, level of burden to caregiver, and identified unmet needs. This information will determine which standardized care plans are needed.

Other needs identified: ____________________



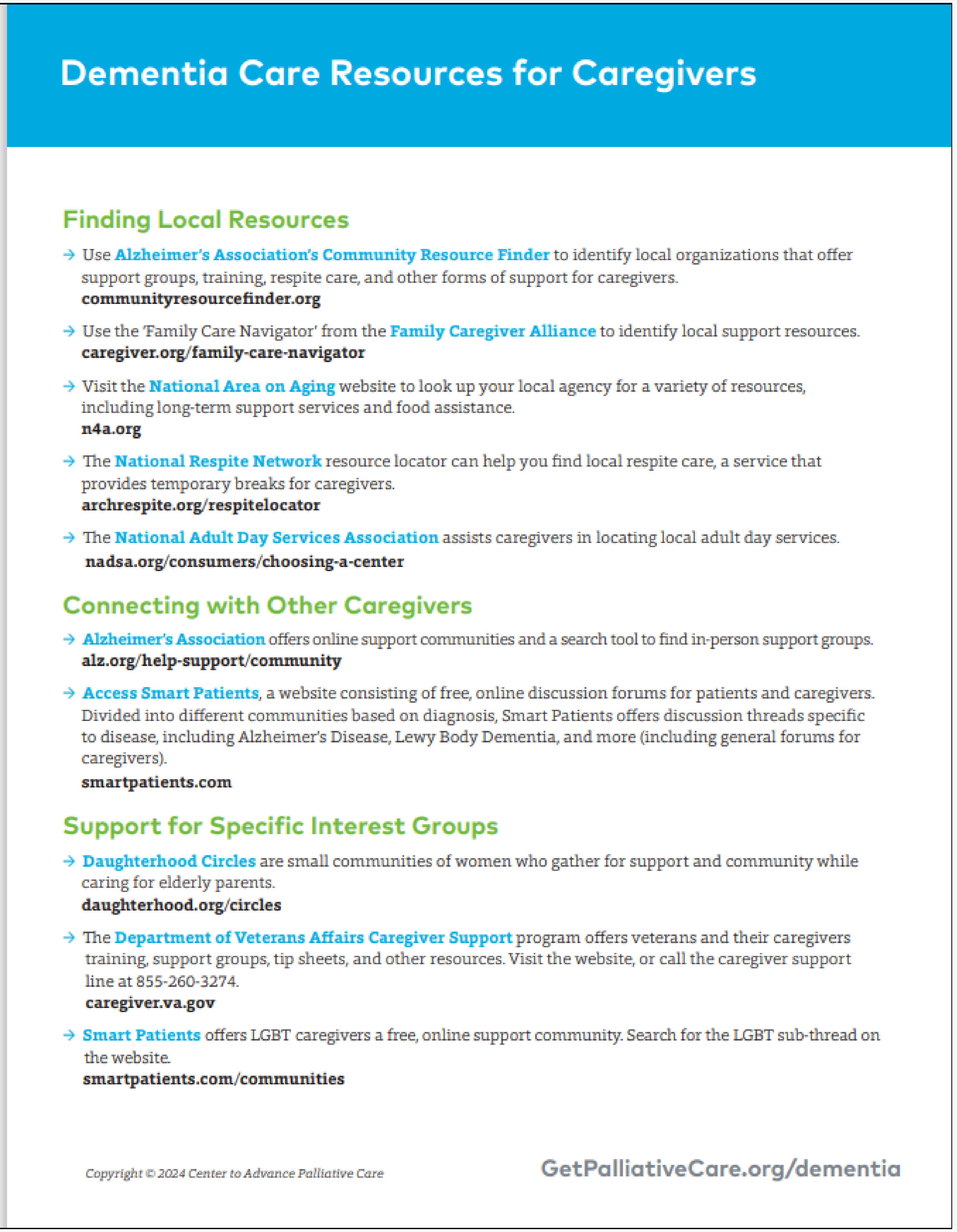
Dementia Care Resources for Caregivers

Taking care of a family member or friend living with dementia can be overwhelming. *You are not alone.* Along with your medical team, there are many resources available to you for support throughout the course of the disease. See the resources below for online education about dementia, and information about support groups, respite care, and more.

Online Caregiver Education

- Visit **Alzheimer's Association** for caregiver support groups, online community message boards to connect with other caregivers, and access to local resources.
  alz.org/help-support/caregiving
- **Alzheimer's Association** also offers information for caregivers about the stages of dementia and how to respond to behavioral symptoms of dementia, such as aggression or repetition.
  alz.org/help-support/caregiving/stages-behaviors
- The **National Institute of Aging** offers support, including how to respond to behavioral symptoms of dementia, legal and financial planning information, tips for home safety, and resources for caregiver stress relief and self-care.
  nia.nih.gov/health/alzheimers/caregiving
- The **UCLA Alzheimer's and Dementia Care Program** offers videos to help understand how to care for people living with dementia. Topics include home safety, responding to aggressive language, depression and apathy, repetitive behaviors, sleep disturbances, and wandering.
  uclahealth.org/dementia/caregiver-education
- Find resources specific to different types of dementia from the **Family Caregiver Alliance**.
  caregiver.org/caregiver-resources/health-conditions
- No matter your location, **Alzheimer's of Greater Los Angeles** offers a series of tip sheets for caregivers in both English and Spanish on a variety of topics, including medications, toileting, and behavioral symptoms of dementia.
  alzgla.org/professionals/caregiver-tip-sheets
- The **AARP's Home Alone Alliance** offers educational videos and tip sheets in English and Spanish on wound care, mobility, and managing medications.
  aarp.org/ppi/initiatives/home-alone-alliance.html

You are not alone. Call Alzheimer's Association 24/7 Helpline for around-the-clock support for all types of dementia. 800-272-3900



Dementia Care Resources for Caregivers

Finding Local Resources

- Use **Alzheimer's Association's Community Resource Finder** to identify local organizations that offer support groups, training, respite care, and other forms of support for caregivers.
  communityresourcefinder.org
- Use the 'Family Care Navigator' from the **Family Caregiver Alliance** to identify local support resources.
  caregiver.org/family-care-navigator
- Visit the **National Area on Aging** website to look up your local agency for a variety of resources, including long-term support services and food assistance.
  n4a.org
- The **National Respite Network** resource locator can help you find local respite care, a service that provides temporary breaks for caregivers.
  archrespite.org/respitelocator
- The **National Adult Day Services Association** assists caregivers in locating local adult day services.
  nadsa.org/consumers/choosing-a-center

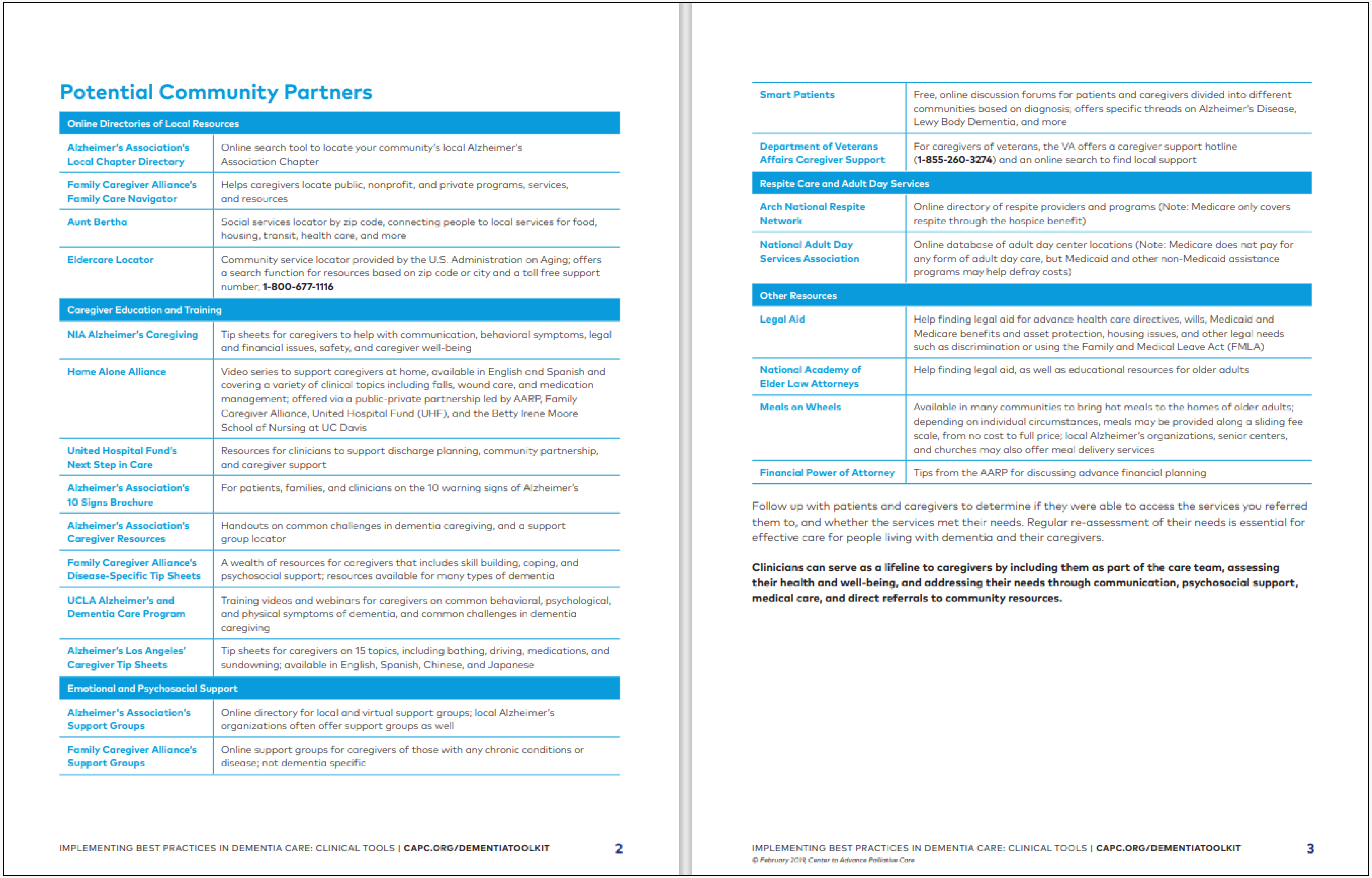
Connecting with Other Caregivers

- **Alzheimer's Association** offers online support communities and a search tool to find in-person support groups.
  alz.org/help-support/community
- **Access Smart Patients**, a website consisting of free, online discussion forums for patients and caregivers. Divided into different communities based on diagnosis, Smart Patients offers discussion threads specific to disease, including Alzheimer's Disease, Lewy Body Dementia, and more (including general forums for caregivers).
  smartpatients.com

Support for Specific Interest Groups

- **Daughterhood Circles** are small communities of women who gather for support and community while caring for elderly parents.
  daughterhood.org/circles
- The **Department of Veterans Affairs Caregiver Support** program offers veterans and their caregivers training, support groups, tip sheets, and other resources. Visit the website, or call the caregiver support line at 855-260-3274.
  caregiver.va.gov
- **Smart Patients** offers LGBT caregivers a free, online support community. Search for the LGBT sub-thread on the website.
  smartpatients.com/communities

(CAPC, 2024)



Potential Community Partners

Online Directories of Local Resources	
Alzheimer's Association's Local Chapter Directory	Online search tool to locate your community's local Alzheimer's Association Chapter
Family Caregiver Alliance's Family Care Navigator	Helps caregivers locate public, nonprofit, and private programs, services, and resources
Aunt Bertha	Social services locator by zip code, connecting people to local services for food, housing, transit, health care, and more
Eldercare Locator	Community service locator provided by the U.S. Administration on Aging; offers a search function for resources based on zip code or city and a toll free support number, **1-800-677-1116**
Caregiver Education and Training	
NIA Alzheimer's Caregiving	Tip sheets for caregivers to help with communication, behavioral symptoms, legal and financial issues, safety, and caregiver well-being
Home Alone Alliance	Video series to support caregivers at home, available in English and Spanish and covering a variety of clinical topics including falls, wound care, and medication management; offered via a public-private partnership led by AARP, Family Caregiver Alliance, United Hospital Fund (UHF), and the Betty Irene Moore School of Nursing at UC Davis
United Hospital Fund's Next Step in Care	Resources for clinicians to support discharge planning, community partnership, and caregiver support
Alzheimer's Association's 10 Signs Brochure	For patients, families, and clinicians on the 10 warning signs of Alzheimer's
Alzheimer's Association's Caregiver Resources	Handouts on common challenges in dementia caregiving, and a support group locator
Family Caregiver Alliance's Disease-Specific Tip Sheets	A wealth of resources for caregivers that includes skill building, coping, and psychosocial support; resources available for many types of dementia
UCLA Alzheimer's and Dementia Care Program	Training videos and webinars for caregivers on common behavioral, psychological, and physical symptoms of dementia, and common challenges in dementia caregiving
Alzheimer's Los Angeles' Caregiver Tip Sheets	Tip sheets for caregivers on 15 topics, including bathing, driving, medications, and sundowning; available in English, Spanish, Chinese, and Japanese
Emotional and Psychosocial Support	
Alzheimer's Association's Support Groups	Online directory for local and virtual support groups; local Alzheimer's organizations often offer support groups as well
Family Caregiver Alliance's Support Groups	Online support groups for caregivers of those with any chronic conditions or disease; not dementia specific
Smart Patients	Free, online discussion forums for patients and caregivers divided into different communities based on diagnosis; offers specific threads on Alzheimer's Disease, Lewy Body Dementia, and more
Department of Veterans Affairs Caregiver Support	For caregivers of veterans, the VA offers a caregiver support hotline (**1-855-260-3274**) and an online search to find local support
Respite Care and Adult Day Services	
Arch National Respite Network	Online directory of respite providers and programs (Note: Medicare only covers respite through the hospice benefit)
National Adult Day Services Association	Online database of adult day center locations (Note: Medicare does not pay for any form of adult day care, but Medicaid and other non-Medicaid assistance programs may help defray costs)
Other Resources	
Legal Aid	Help finding legal aid for advance health care directives, wills, Medicaid and Medicare benefits and asset protection, housing issues, and other legal needs such as discrimination or using the Family and Medical Leave Act (FMLA)
National Academy of Elder Law Attorneys	Help finding legal aid, as well as educational resources for older adults
Meals on Wheels	Available in many communities to bring hot meals to the homes of older adults; depending on individual circumstances, meals may be provided along a sliding fee scale, from no cost to full price; local Alzheimer's organizations, senior centers, and churches may also offer meal delivery services
Financial Power of Attorney	Tips from the AARP for discussing advance financial planning

Follow up with patients and caregivers to determine if they were able to access the services you referred them to, and whether the services met their needs. Regular re-assessment of their needs is essential for effective care for people living with dementia and their caregivers.

Clinicians can serve as a lifeline to caregivers by including them as part of the care team, assessing their health and well-being, and addressing their needs through communication, psychosocial support, medical care, and direct referrals to community resources.

(CAPC, 2024a)

Planning for the Future

Education & Next Steps

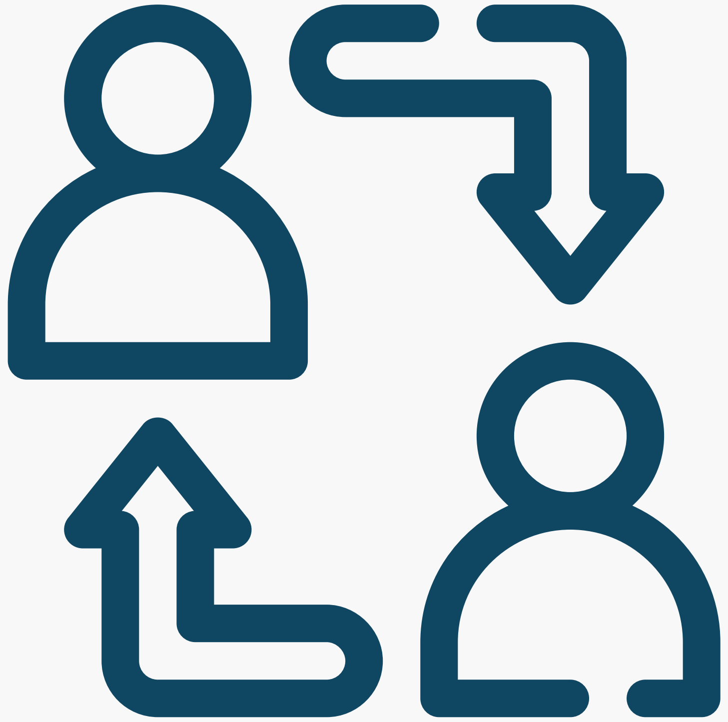
- Disease progression and stages
    - Care plans align with person with dementia's wishes, goals of care and promote highest quality of life
- Financial: navigation tools & resources
- Legal concerns: Competency & DPOA activation
- Care settings: home, PACE, day centers, residential communities

Care Partner Health

Maintain Physical Health

Exercise & Diet

Doctors appointments



Coping and De-Stress

Give yourself grace

Support Groups

Find ways to “release the pressure valve”

Finding Joy

Do things that bring you joy

Keep your sense of humor

Recreation and leisure

Find ways to have fun together

(Alzheimer's Association, 2025a).

Care Partner Support

It takes a village

- Accepting help
- Professional hired care & help
  - Doesn't have to hired care help. Could be cleaning, meal/grocery delivery, lawn care, etc.
- Family, friends, neighbors

Support Groups

- Online or in person: Alzheimer's Association Support Group Search Tool

Family Dynamics

- Differing views and opinions on care
- Accepting the person with dementia's status
- Assigning and dividing roles based on ability
- Guilt

ADL Challenges

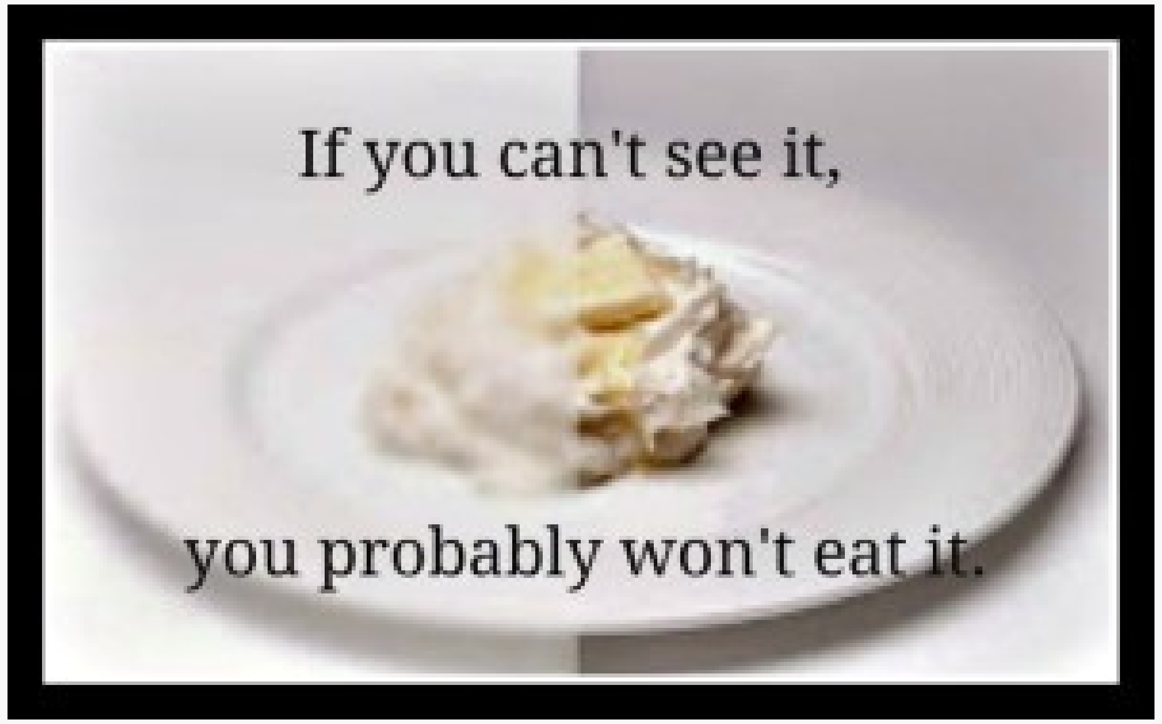
Bathing

- Bathing can be scary and painful
- Play music, prepare bathroom ahead of time
- Encourage dignity and as much independence as possible
- Alternatives to daily showers: sponge baths, dry shampoo

Incontinence

- Causes of incontinence
- Monitor for signs they need the bathroom
- Interventions
- Often challenging for male care partners to navigate

ADL Challenges



Eating & Nutrition

- Offer foods one at a time
- Finger foods
- Color contrast
- Don’t force feed, adapt!
- Limit distractions

Safety

- Wandering
- Safe Storage: Alcohol, guns, medications, substances, chemicals
- Driving

Case Study

Case Study

Pam and her husband Todd have been married for 50 years. Todd, age 75, was diagnosed with Alzheimer's disease 2 years ago and is in the end of the early stages. Todd is still driving but recently has some new scrapes on the car and has trouble navigating to places he's known for years. Pam knows it's time for Todd to stop driving and is dreading having the conversation with Todd. She knows he isn't going to agree or react well.

What are techniques that can be used in this situation?

Thank you

Trillium
INSTITUTE

LIVE WELL. DIE WELL. GRIEVE WELL.