



Identify and Address Alzheimer's and Dementia in Adults with Intellectual
and developmental disabilities through Prevention and Training

LIST OF RESOURCES

I. LOCAL ORGANIZATIONS

Alzheimer's Association (Desert Southwest Chapter)

<https://www.alz.org/dsw>

Chapter Office & Central Arizona Region

340 E Palm Lane, Suite 230
Phoenix, AZ 85004

Northern Arizona Region

3111 Clearwater Drive, Suite A
Prescott, AZ 86305

Southern Arizona Region

1159 N Craycroft Road
Tucson, AZ 85712

https://www.alz.org/alzheimers-dementia/research_progress/clinical-trials/about-clinical-trials

Area Agencies on Aging:

Maricopa County - Area Agency on Aging, Region One

<https://www.aaaphx.org/>
1366 E. Thomas Rd. Ste.
108
Phoenix, AZ 85014
(888) 264-2258

Pima County - Pima Council on Aging, Region Two

<https://www.pcoa.org/>
8467 E. Broadway Blvd.
Tucson, AZ 85710
(520) 790-7262



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**Yavapai, Coconino, Navajo, Apache Counties - Northern Arizona Council of
Governments (NACOG)**

<https://www.nacog.org/>

119 East Aspen Avenue Flagstaff, AZ 86001

(928) 774-1895

Prescott Valley

3130 Robert Rd

Prescott Valley, AZ 86314

(928) 775-9993

Flagstaff

323 N San Francisco Ste. A

Flagstaff, AZ 86001

(877) 521-3500

**Mohave, La Paz, Yuma Counties - Western Arizona Council of Governments
(WACOG)**

<https://www.wacog.com/>

Yuma

1235 S. Redondo Center Dr.

Yuma, AZ 85365

(928) 782-1886

La Paz

1713 Kofa, Ste. D

Parker, AZ 85334

(928) 669-9496

Mohave

208 N. 4th St.

Kingman, AZ 86401

(928) 753-6247

Pinal and Gila Counties - Pinal-Gila Council for Senior Citizens

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

8969 W. McCartney Rd.

Casa Grande, AZ 85194

(520) 836-2758

**Cochise, Graham, Greenlee, Santa Cruz Counties - Southeastern Arizona
Governments Organization (SEAGO)**

<https://www.seago.org/>

Bisbee Senior Association

300 Collins Rd.

Bisbee, AZ 85603

(520) 432-2528



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Navajo Nation - Navajo Area Agency on Aging

https://newmexico.networkofcare.org/aging/services/agency.aspx?pid=NavajoAreaAgencyonAgingWindowRockAZ_1534_1_0

P.O. Box 1390
Window Rock, AZ 86515
(928) 871-6743

Inter Tribal Council of Arizona

<http://itcaonline.com/>

2214 N. Central Ave.
Phoenix, AZ 85004
(602) 258-4822

Arizona Caregiver Coalition

<https://azcaregiver.org/>

P.O. Box 21623
Phoenix, AZ 85036 (888)
737-7494
CRL@AZCaregiver.net

Arizona Center on Aging, University of Arizona

<https://aging.arizona.edu/> 1501

N. Campbell
P.O. Box 245027
Tucson, AZ 85724
(520) 626-5800

Arizona Department of Economic Security:

Division of Aging and Adult Services (DAAS)

<https://des.az.gov/services/aging-and-adult/division-aging-and-adult-services>

(844) 770-9500

Division of Developmental Disabilities (DDD)

<https://des.az.gov/services/disabilities/developmental-disabilities>

(844) 770-9500

Arizona Hospice and Palliative Care Organization (AHPCO)

<https://www.ahpco.org/>

(480) 491-0540

info@ahpco.org



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Arizona Geriatrics Society

<https://www.azgs.org/>

1510 E. Flower St.

Phoenix, AZ 85016

(602) 529-3529

info@azgs.org

AZ Links

<https://azdaars.getcare.com/consumer/>

II. WEB-BASED & NATIONAL

Disabilities & Dementia

1. **“Aging and End of Life Webinar Series - Dementia Among Adults with Down Syndrome: Individual Differences in Risk and Progression.”** Wayne Silverman, Ph.D.
<https://aaidd.org/docs/default-source/events/dementiaamongadultswithds.pdf?sfvrsn=0>
 - *An overview of information on progression of adults with DS.*
2. **“Care Partner Sheets.”** The University of Arizona Center on Aging.
<https://www.uofazcenteronaging.com/care-partners>
3. **“Down syndrome and Alzheimer’s disease.”** Alzheimer’s Association.
<https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome>
 - *Explains AD and prevalence, causes, symptoms, diagnosis, outcomes, treatment and research for individuals with DS.*
4. **“Down syndrome and Alzheimer’s disease.”** Down Syndrome Australia Network, Alzheimer’s Australia, The Center for Developmental Disability Health Victoria.
https://www.downsyndrome.org.au/documents/resources/health/Down_syndrome_and_Alzheimers_disease.pdf
 - *Booklet exploring the link between Alzheimer’s and Down Syndrome, diagnosis, and supporting someone with DS and AD.*
5. **“IDD and Dementia Report.”** Research Triangle Institute.
<https://nadrc.acl.gov/node/169>
 - *White paper presenting the current state of services and support for individuals with dementia and IDD and DS.*



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6. **“It’s Your Move - Down Syndrome and Dementia.”** Down’s Syndrome Scotland.
https://lx.iriss.org.uk/sites/default/files/resources/It%27s%20Your%20Move_Down%27s%20Syndrome%20and%20Dementia.pdf
 - *A guide for general practitioners to ensure accurate diagnosis and intervention for people with DS.*

7. **“My Thinker’s Not Working’ A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports.”** NTG.
<https://www.the-ntg.org/publications>
 - *Provides an in-depth summary of the challenges the nation faces regarding the increasing frequency of dementia found in older people with ID/DS.*
 - *Contains the National Intellectual Disabilities and Dementia Action Plan – 20 recommendations for building a system of quality “dementia capable” services nationally.*

8. **“The National Task Group on Intellectual Disabilities and Dementia Practices Guidelines for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities.”** NTG.
<https://www.the-ntg.org/publications>
 - *The intent of this document created and disseminated by the NTG is to provide a framework for physicians to clarify key principles of assessment and management of dementia in adults with I/DD.*

Caring for a Person with Alzheimer’s Disease

9. **“Brain Health As You Age: You Can Make a Difference.”** Administration for Community Living (ACL), National Institute of Health (NIH), Centers for Disease Control (CDC).
<https://www.nia.nih.gov/health/brain-health-resource>
 - *One-page flyer outlining diseases and conditions that affect brain health, and risk factors that can be controlled or prevented.*
 - *Resource booklet regarding key facts about brain health and aging.*
 - *PowerPoint presentation and Educator Guide.*

10. **“State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map.”** CDC, Alzheimer’s Association.
<https://www.cdc.gov/aging/pdf/2018-2023-Road-Map-508.pdf>

11. **“Caregiver Stress Check: What Caregivers Need to Know to Stay Healthy.”** Alzheimer’s Association.
https://www.alz.org/national/documents/brochure_caregiver_stress_checklist.pdf



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- 12. "Alzheimer's Caregiving."** National Institute on Aging.
<https://www.nia.nih.gov/health/alzheimers/caregiving>

 - *Areas addressed are stages of AD, understanding how AD changes people, challenges and coping strategies, helping others understand, planning for health, legal and financial issues, safety, everyday care, adapting activities, medical problems, medications, and taking care of self.*

<https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals>
(for medical professionals)
- 13. "Dementia-Capable States and Communities: the Basics."** Jane Tilly, DrPH; Joshua M. Wiener, PhD.; Elizabeth Gould, MSW, LCSW.
<https://acl.gov/sites/default/files/triage/BH-Brief-Dementia-Capable-Basics.pdf>.

 - *Article discusses the HHS National Plan to Address Alzheimer's Disease and the five goals.*
 - *Describes the key aspects of a model dementia-capable system, elaborates on each, and provides examples with links to resources.*
- 14. "Dementia Friendly America."**
<https://www.dfamerica.org/>
- 15. "Eating/Feeding Issues in Dementia: Improving the Dining Experience."** *End of Life Journal with St. Christopher's.*
https://www.stchristophers.org.uk/wp-content/uploads/2015/10/practice-development-1.EoLJ_Vol4_No1_Dementia.pdf

 - *Discussion of issues around eating/feeding that may put a person with dementia at risk for malnutrition.*
 - *Areas covered include physical factors, AD symptomatology, environmental factors, quality of caregiver/patient interactions, etc.*
 - *Numerous suggestions and talking points.*
- 16. "Habilitation Therapy for Alzheimer's and Dementia Care."** Deborah Bier, PhD.
<https://psychcentral.com/lib/habilitation-therapy-for-alzheimers-and-dementia-care/>

 - *An all-inclusive behavioral approach to caring for people with dementia that focuses on his or her remaining abilities, not abilities the person has lost due to the disease.*
- 17. "I Have Alzheimer's."** Alzheimer's Association.
<https://www.alz.org/help-support/i-have-alz>
- 18. "Alzheimer's Navigator."** Alzheimer's Association.
<https://www.alzheimersnavigator.org/>

 - *Online tool to create a customized action plan and link to local resources.*
- 19. "National Alzheimer's Project Act."** Assistant Secretary for Planning and Evaluation (U.S. Department of Health and Human Services).
<https://aspe.hhs.gov/national-alzheimers-project-act>

20. **“National Institute on Aging: Alzheimer’s Disease Education and Referral (ADEAR) Center”**.
<https://www.nia.nih.gov/health/about-adear-center>
21. **“Program to Encourage Active, Rewarding Lives (PEARLS).”** University of Washington, CDC.
<https://depts.washington.edu/hprc/evidence-based-programs/pearls-program/>
22. **“Providing Safe and Effective Nutrition for People with Dementia.”** Administration for Community Living (ACL).
<https://www.youtube.com/watch?v=EDkYF6JgiiY>.
 - *PowerPoint presentation about the importance of nutrition for people with dementia.*
 - *Discussion of challenges to ensuring nutritious intake of food as well as strategies to deal with those challenges.*
23. **“Staying Safe. Steps to Take for a Person with Dementia.”** Alzheimer’s Association.
https://www.alz.org/national/documents/brochure_stayingsafe.pdf
 - *Pamphlet discussing the need for a safety plan because of the changes in the brain from AD, and measures to take improve safety at home, in the community, and emergency situations.*
24. **“Assessing Pain in Older Adults with Dementia.”** Alzheimer’s Association.
<https://consultgeri.org/try-this/dementia/issue-d2.pdf>
 - *Article about tools for assessing pain in people with dementia.*
25. **“10 Early Signs and Symptoms of Alzheimer's.”** Alzheimer’s Association.
https://alz.org/alzheimers-dementia/10_signs

Caring for a Person with Intellectual and Developmental Disabilities and Alzheimer’s Disease

26. **“Disability Distress Assessment Tool.”** Edinburgh University (Matt Hayes), Northgate Palliative Care Team and St. Oswald’s Hospice.
<https://www.wihb.scot.nhs.uk/LD/toolkit/disdat%20Assess%20tool%2009.pdf>
27. **“Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia.”** NTG.
<https://www.the-ntg.org/publications>
 - *Guidelines developed by NTG to promote use of the staging model to develop services for individuals with DS and ID. The staging model follows the flow from pre-diagnosis, early recognition of symptoms, through to the early, mid and late-to-end stages of the progression of dementia. Examples are given for each stage for programmatic and therapeutic activities to offer that may help compensate as well as support the individual experiencing decline in function.*
 - *Ancillary issues are also discussed, and these include abuse and neglect; financial considerations; managing choice and liability; medication; and nutrition.*
28. **“Keep Talking About Dementia.”** Down’s Syndrome Scotland.
<https://www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Lets-Talk-About-Dementia-final-version-05.08.15.pdf>



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- *Information for siblings and professionals about DS and dementia.*
- *Provides basic information about the role of siblings as potential caregivers/decision makers, and the need for a greater understanding for them to perform the role of health care advocate.*

29. "Living with Dementia." Down's Syndrome Scotland.

<https://www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Living-with-Dementia-final-05.08.15.pdf>

- *Discusses adaptations to the home of a person who has DS and dementia.*
- *Identifies specific behavioral challenges and ways to change the environment to ameliorate confusion, and gives insight to how dementia is experienced by people with DS.*

30. "NTG Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia." NTG.

<https://www.the-ntg.org/publications>

- *Includes detailed information on challenges for health care advocacy and access with guidelines for addressing the challenges.*
- *Identifies essential information needed in order to effectively advocate for appropriate healthcare interventions.*
- *Outlines procedures for post-medical appointment follow-up.*
- *Encourages long-term planning.*
- *Recommendations for environmental modifications.*

31. "What is Dementia?" Down Syndrome Scotland.

https://lx.iriss.org.uk/sites/default/files/resources/What%20is%20dementia_0.pdf

- *An illustrated booklet explaining dementia for adults who have a learning disability.*

Behaviors

32. "Behaviors: How to Respond When Dementia Causes Unpredictable Behaviors."

Alzheimer's Association.

https://www.alz.org/national/documents/brochure_behaviors.pdf

- *Discusses different behaviors in people with AD, identifying causes, and strategies for dealing with them.*

33. "Challenging Behaviors - Common Questions." Alzheimer's Association.

https://www.alz.org/national/documents/statements_antipsychotics.pdf

- *Discussion about the use of antipsychotic medications as therapy of behavioral and/or psychotic symptoms.*



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Preparing for Disaster & Wandering Safety Tips

- 34. "Autism/ID/Alzheimer's Wandering Prevention Safety Tips."** Montgomery County Department of Police, Maryland.
<https://www.montgomerycountymd.gov/POL/Resources/Files/PDF/Lifesaver/AutismAlzheimerBrochure2016.pdf>
 - *Tip sheet of preventative measures to be taken to ensure safety in the event a person with Alzheimer's or Autism leaves home unexpectedly.*
- 35. "Responding to the Wandering and Exit-seeking Behaviors of People with Dementia."** Jane Tilly, DrPH.
<https://acl.gov/sites/default/files/triage/BH-Brief-WanderingExit-Seeking.pdf>
 - *Discusses person-centered care for people with dementia and the importance of developing interventions that are personalized for each person.*
 - *Gives examples of practices used in various states to address wandering.*
- 36. "Preparing for Disaster for People with Disabilities and other Special Needs."** FEMA, American Red Cross.
https://www.redcross.org/content/dam/redcross/atg/PDF_s/Preparedness_Disaster_Recovery/General_Preparedness_Recovery/Home/A4497.pdf
 - *Booklet to assist individuals, caregivers, and families to plan ahead for when disaster strikes.*

Palliative Care and End of Life

- 37. "Five Wishes".** Aging with Dignity.
<https://fivewishes.org/>
- 38. "Caring at the End of Life".** American Association on Intellectual and Developmental Disabilities (AAIDD).
<https://aaidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life#.WSYTV-%20vyvIU>
- 39. "Choosing Long-Term Care".** University of Arizona Center on Aging, Alzheimer's Association Desert Southwest Chapter.
https://www.uofazcenteronaging.com/sites/default/files/choosing_long_term_care.pdf
- 40. "Let's Talk About Death."** Down's Syndrome Scotland.
<https://lx.iriss.org.uk/sites/default/files/resources/Let%27s%20talk%20about%20death.pdf>
 - *A booklet about death and funerals for adults who have a learning or intellectual disability.*
- 41. "Meeting the End of Life Needs of Older Adults with Intellectual Disabilities."** Philip McCallion, Mary McCarron, Elizabeth Fahey-McCarthy and Kevin Connaire.
<https://cdn.intechopen.com/pdfs-wm/27625.pdf>
- 42. "My Life, My Wishes: Sharing My Journey."** Lynne Tomasa, Sonoran University Center for Excellence in Developmental Disabilities.
<http://sonoranucedd.fcm.arizona.edu/publications/1275>



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43. **“Providing palliative care to people with intellectual disabilities: services, staff knowledge, and challenges.”** Gary Stein.
<https://www.ncbi.nlm.nih.gov/pubmed/19021488>
44. **“Resources in Developmental Disabilities and Coping with Grief, Death and Dying.”** The Elizabeth M. Boggs Center on Developmental Disabilities and Coping with Grief, Death and Dying.
<http://rwjms.rutgers.edu/boggscenter/projects/documents/EndofLifeResources3pp.july09.pdf>
 - *A list of resources related to death and dying for people with developmental disabilities.*
45. **“Supporting People with Disabilities Coping with Grief and Loss.”** Scope, Disability Means Possibility.
<https://dsagsl.org/wp-content/uploads/2019/02/Grief-Packet.pdf>
 - *A picture book to help individuals with disabilities understand and cope with grief and loss.*
46. **“When it may be Time to Stop Treatment”** University of Arizona Center on Aging, Alzheimer’s Association Desert Southwest Chapter.
<https://www.uofazcenteronaging.com/care-sheet/care-partners/dementia-when-may-it-be-time-stop-treatment>
47. **“Talking End of Life ...with people with intellectual disability”.** TEL.
<https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>

Additional Working Resources and Lists

48. **“Aging and Down Syndrome – A Health & Well-Being Guidebook.”** National Down Syndrome Society (NDSS).
 - English
https://www.ndss.org/wp-content/uploads/2018/12/NDSS_Guidebook_FINAL.pdf
 - Spanish
https://www.ndss.org/wp-content/uploads/2018/10/NDSS_Guidebook_Final-Spanish-1.pdf
 - *Informational brochure about aging with Down Syndrome that covers the following topics: General overview of aging with DS, Common medical conditions, Emotional and psychiatric well-being, Introduction of Alzheimer’s disease, Caregiver’s guide to Alzheimer’s, Planning for old age.*
49. **“Supporting people with learning disabilities through the palliative care journey.”** Palliative Care Pathway, The Prince and Princess of Wales Hospice.
<https://www.princeandprincessofwaleshospice.org.uk/userfiles/Tab%201%20-%20the%20hospice/4%20-%20Our%20Services/Learning%20disability%20support/269615%20Support%20Pathway%20final.pdf>



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- 50. "Working Resources List on Dementia Care Management and Intellectual Disabilities."** PCAD Project.
<http://docplayer.net/19063220-Pcad-project-working-resources-list-on-dementia-care-%20management-and-intellectual-disabilities.html>