

# NAVIGATING THE DEMENTIA JOURNEY



Creating your own road map

[dementiafriendlynevada.org](http://dementiafriendlynevada.org)



# DEAR READER,

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Living with dementia is a journey. This notebook was created as part of Nevada's Dementia Friendly mission to recognize and support individuals living with dementia and their care partners. It is designed to help you navigate your journey with dementia with the understanding that no two journeys are the same.

To help you create your personal road map, we have filled the notebook with information about community resources, words of wisdom from those who have lived the journey and links to resources for more in-depth information. The heart of the notebook is the "Getting to Know Resources" section. These pages highlight the range of services and programs that can help individuals with dementia live as independently as they can, along with links to resources, especially for care partners.

We hope this notebook provides guidance, support and inspiration as you navigate your journey with dementia.

Sincerely,

The Dementia Friendly Southern Nevada Team

## WORDS OF WISDOM

The road on this journey is winding, bumpy and sometimes dark and scary. But I have learned I am not alone; others are on this journey too.

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# OVERVIEW OF DEMENTIA

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## WHAT IS DEMENTIA?

- Dementia is a general term for a decline in memory, judgment and thinking severe enough to interfere with daily life.
- Alzheimer's disease is the most common type (60-80%).
- Other common types are vascular, Lewy body and frontotemporal dementia.
- Dementia is not a normal part of aging.
- For more information:

See: "Dementia" at [Medlineplus.gov/dementia.html](https://medlineplus.gov/dementia.html)

Visit: Cleveland Clinic Lou Ruvo Center for Brain Health Lynne Ruffin Smith Library, 888 W. Bonneville Avenue, Las Vegas, NV 89106 or call 702.483.6033.

# DIAGNOSIS AND TREATMENT

## HOW IS DEMENTIA DIAGNOSED

- Diagnosis is based on an assessment of medical history, current health, cognitive function, behavior or personality changes, and ability to carry out daily tasks. In addition, lab tests, brain scan, and neurological evaluations may be ordered.
- Cognitive tests evaluate memory, problem-solving, and language skills.
- Commonly used cognitive tests include the Montreal Cognitive Assessment (MoCA) and the Mini-Mental State Examination (MMSE).

## TREATMENT

- Treatment depends on type of dementia and symptoms.
- Current treatments may improve some symptoms and help maintain ability to carry out daily tasks for some time.
- Treatments seek to manage symptoms that impact daily living.
- At this time, there is no cure or effective treatment to stop disease progression.

## RESEARCH

- To learn about opportunities to participate in research, ask your doctor or visit:
  - Alzheimer's Association Clinical Trials — [Bit.ly/AlzClinicalTrials](https://bit.ly/AlzClinicalTrials)
  - Alzheimer's Disease Education and Referral Center (ADEAR) — [nia.nih.gov/alzheimers/clinical-trials](https://nia.nih.gov/alzheimers/clinical-trials)

# GETTING TO KNOW RESOURCES: CREATING YOUR PLAN

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There are many types of resources that can offer support to an individual living with dementia and their care partners. As each person's experience is different, specific services/programs may be more helpful at various times or stages over the course of illness.

*Each type of resource is described on the following pages and color-coded for care partners and/or persons with dementia.*



- BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS
- CAREGIVER SERVICES
- LEGAL & FINANCIAL
- LIVING ARRANGEMENTS & SAFETY
- MEDICAL CARE
- RESPITE
- SUPPORT SERVICES & EDUCATION PROGRAMS
- TRANSPORTATION
- VETERANS SERVICES
- WELL-BEING





## WORDS OF WISDOM



- What worked today may not work tomorrow but may work the day after.
- I have learned to minimize anxiety through calmness and un-hurried bathing and dressing.
- Think about ways to substitute “yes and” for “no”. For example, a response to “I knew Elvis personally” may be “Yes and that must have been exciting. Tell me about it” instead of “No, I know you never met Elvis personally”.



# BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS

- Behaviors and psychological symptoms associated with dementia may be due to many factors such as loss of brain function, medication interactions, communication challenges, changes in daily routine, hunger, lack of sleep and pain.
- Common symptoms are depression, anxiety, delirium, agitation, aggression, hallucinations, paranoia, pacing, repetitive questions, *sundowning* and sleep issues.
- Behaviors are often a form of communication, especially as verbal skills are impacted.
- Behaviors can be addressed using a variety of non-drug approaches. Examples include participating in activities of interest to the person, physical exercise and modifying the home environment or routine to reduce potential causes of upset.

## Tips

- Look for underlying causes and patterns of behavior. Sudden or significant changes may indicate an underlying physical issue.
- Contact your local Nevada Care Connection Resource Center to learn about programs to understand these symptoms. See Page 34 for contact information)

## For More Information

- Managing Behaviors Associated with Dementia: Resource Guide for Caregivers — [Bit.ly/ResourceGuideBehaviors](https://bit.ly/ResourceGuideBehaviors)
- Caregiver's Guide to Understanding Dementia Behaviors — [Bit.ly/CaregiversGuidetoUnderstanding](https://bit.ly/CaregiversGuidetoUnderstanding)



## WORDS OF WISDOM ■

- “Put your oxygen mask on first”- that means take a break, plan a vacation, do things that help recharge your battery - as it may be a long haul.
- Think of caregiving as a job. To be successful, you have to learn new things, adapt to changes, plan for the short and long term and expect the unexpected.
- When I heard the statistic that a significant number of caregivers die before their loved one, I began to take better care of myself.

# CAREGIVER SERVICES

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- Providing care and support to a loved one with dementia can be rewarding and challenging.
- Caregivers assist with many tasks such as hands-on care, meals, medications, housekeeping, transportation, medical appointments, finances and coordinating care. As the disease progresses, different types of assistance may be needed.
- Caregivers can experience a range of feelings such as stress, burnout, guilt, loss, compassion and love.
- Caregivers may neglect their own needs increasing their risk for depression and health issues.
- Programs and services exist to help caregivers build knowledge, skills, and practice self-care.

## Tips

- Respite is essential. It allows the caregiver to take a break from responsibilities of caregiving.
- Group programs have the added benefit of meeting others who share similar experiences.

## For More Information

- Caregiving resources can be found at AARP, Alzheimer's Association, Alzheimer's Foundation of America, Cleveland Clinic Lou Ruvo Center for Brain Health, Family Caregiver Alliance and Caregiver Action Network (See pages 34-37 for contact information)
- See Glossary beginning on page 50 for listing of local programs for caregivers



## WORDS OF WISDOM ■

- It is imperative while in the early stages of dementia to see an attorney to ensure all legal paperwork is in order while the person with dementia still has the ability to make legal decisions.
- Financial planning is one of the most important things you can do. First we tackled everyday tasks such as paying bills and then looked at the legal documents needed for making financial decisions if she is no longer able to do so.

# LEGAL & FINANCIAL

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- Advance directives are legal documents that state a person's wishes and go into effect only if the person is incapacitated and unable to speak for themselves. Examples include a living will, durable power of attorney for health care and Professional Orders for Life Sustaining Treatment (POLST).
- Individuals with dementia may be at greater risk of abuse, neglect and financial exploitation.
- A guardian may be appointed by a court if an individual is legally determined to be unable to take care of himself and/or his finances.

## Tips

- Report abuse, neglect, exploitation, isolation or abandonment of a person with dementia to Nevada Adult Protective Services, 888-729-0571.
- Nevada has a free "Lockbox" where certain advance directives can be stored electronically and easily accessed by health care providers.
- Financial planning can help identify care-related expenses and options to cover costs.

## For More Information

- Nevada Adult Protective Services — [Bit.ly/NVAdultProtectiveServices](https://bit.ly/NVAdultProtectiveServices)
- Legal & Financial Planning for Alzheimer's Disease — [Bit.ly/LegalFinancialPlanning](https://bit.ly/LegalFinancialPlanning)
- Managing Money with Alzheimer's Disease — [Bit.ly/ManagingMoneyAlzheimers](https://bit.ly/ManagingMoneyAlzheimers)
- Long Term Care — [longtermcare.acl.gov](https://longtermcare.acl.gov)



## WORDS OF WISDOM



- Wandering tends to happen early so buying an ID bracelet or necklace is essential.
- Ensure your home has locks your loved one cannot open so they won't leave without your knowledge.

## Tips

- Complete a home safety checklist to look for potential hazards.
- Modifications to one's home can help a person remain there for as long as possible.
- Encourage an individual to always carry ID; consider using a medical alert or emergency response system.
- Prepare for an emergency by having copies of key documents, current photo of person and extra medications.

# LIVING ARRANGEMENTS & SAFETY

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- The housing needs of an individual living with dementia change over the course of their illness.
- Living options include living at home with support, living with family/friends, assisted living facilities, group-care homes and memory care.
- Changes in memory, coordination and perception impact a person's ability to keep themselves safe at home and in the community.
- Wandering and becoming lost is a common and potentially dangerous occurrence even early in the illness.

## For More Information

- Alzheimer's Disease: Housing Options and Long-Term Care Services — [\*Bit.ly/Housing-LongTermCare\*](https://bit.ly/Housing-LongTermCare)
- Residential Care including Care Facility Checklist — [\*Bit.ly/ResidentialCareChecklist\*](https://bit.ly/ResidentialCareChecklist)
- A Guide for Families: Keeping the Person with Memory Loss Safer at Home — [\*Bit.ly/VAHomeSafety\*](https://bit.ly/VAHomeSafety)
- Home Safety Checklist for Alzheimer's Disease — [\*Bit.ly/SafetyCheckList\*](https://bit.ly/SafetyCheckList)
- Finding Long-Term Care for a Person with Alzheimer's Disease — [\*Bit.ly/FindingLongTermCare\*](https://bit.ly/FindingLongTermCare)



## WORDS OF WISDOM ■

- We had a long process to get to a diagnosis.
- It has been helpful to talk with our neurologist and pharmacist to find solutions when there have been medication issues. One tip that worked for us was to take our medications together.



# MEDICAL CARE

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- Individuals experiencing dementia symptoms can benefit from a comprehensive medical exam. Sudden or significant changes may indicate an underlying physical issue.
- Ongoing medical care is an important component in managing the illness.
- Persons with dementia may experience medication issues including the inability to communicate side effects, take medications as prescribed and swallow pills.
- For dementia-related symptoms that start suddenly, get worse or cause concern, consult a health care professional.

## Tips

- Start a notebook to track medical appointments, medications, symptoms and questions.
- Regular routine medical and dental care is important for persons with dementia.
- Care Connection Resource Center staff can assist with Medicare and Medicaid insurance questions.

## For More Information

- Welcome to Alzheimers.gov — [alzheimers.gov](http://alzheimers.gov)
- Alzheimer's Disease — [Medlineplus.gov/alzheimersdisease.html](http://Medlineplus.gov/alzheimersdisease.html)



## WORDS OF WISDOM ■

- If I don't take care of me, who will take care of him?
- No one intends to be a caregiver; you wake up one morning and realize you are.
- Don't wait to call for help. Ask family, friends or contact an agency to spend a few hours with your loved one so you can step away to refresh and regenerate.

# RESPITE

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- Respite is defined as a break from the responsibilities of caregiving.
- Taking a break from caregiving tasks is essential.
- Respite services can take place inside or outside the home. It can be offered one-to-one or in a group setting such as art, music therapy and Memory Café-Respite.
- Respite vouchers may be available to defray respite care costs.

## Tips

- For each caregiver, the concept of respite is different. Some find it helpful to spend time without their loved one such as visiting with friends, going to a doctor's appointment or participating in an enjoyable activity; others seek joint programs where the person with dementia is welcome.
- To learn more about respite options and vouchers to help pay for care, contact Nevada 2-1-1, Nevada Care Connection Resource Center, Alzheimer's Association, or Helping Hands of Vegas Valley. Contact information can be found on pages 34-35.

## For More Information

- ARCH National Respite Network and Resource Center — [archrespite.org](http://archrespite.org)
- Respite Care — [bit.ly/AlzRespiteCare](http://bit.ly/AlzRespiteCare)



## Tips

- Create a plan to identify current needs and wishes, types of services that would be helpful, individuals/organizations who could provide assistance and unmet needs.
- Build your support team which can include family, friends and neighbors along with faith-based, health care and social service organizations.
- Review and update the plan often, especially when there are changes.



# SUPPORT SERVICES & EDUCATION PROGRAMS

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- There are many types of services and education programs to support an individual living with dementia over the course of their illness.
- Nevada 2-1-1 and Nevada Care Connection Resource Centers can assist you to identify and connect with helpful services and programs. Contact information can be found on page 34.

## Support Services

Care Consultation	Hospital2Home
Companion	Memory Cafe-Respite
Counseling	Personal Care
Helpline	Physical & Occupational Therapy
Home Health	Shopping/Meal Preparation



## WORDS OF WISDOM

- I was glad to know there were services but didn't think I needed any help, especially early in the disease, until it became clear just how much support I needed.
- Think creatively, if you can't "go in the front door, find an open window".
- Learn as much as you can to make your journey easier.

# SUPPORT SERVICES & EDUCATION PROGRAMS

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## **DISEASE-BASED EDUCATION**

Many organizations offer education programs on a wide range of topics to increase knowledge and understanding of dementia.

## **LIBRARIES**

Books, videos and pamphlets are available to provide comprehensive information on a broad range of topics. Organizations including the Alzheimer's Association and Cleveland Clinic Lou Ruvo Center for Brain Health have extensive library resources. Internet lending is available through the Cleveland Clinic's Lynne Ruffin-Smith Library at *lruffin-smith@overdrive.com*. Public libraries also offer many information resources.

## **HEALTHY BRAINS**

An online program featuring six pillars of brain health which can help reduce the risk for brain disease. Visit [healthybrains.org](https://healthybrains.org) to complete a lifestyle check-up self-assessment and receive personalized brain health tips.

## **HEALTHIER LIVING**

A six-week workshop that helps individuals living with a chronic condition set goals to enhance personal health and well-being. (Evidence-based)





# TRANSPORTATION

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- For persons with dementia driving skills are negatively impacted by changes in memory, perception, judgment, reasoning, attention and visual/spatial abilities.
- As dementia progresses an individual may no longer be able to safely drive or use public transportation alone.
- A transportation plan can help identify alternate options so an individual can remain active and engaged in their community.

## Tips

- Begin talking about driving-related issues early in the disease process; consider a professional driving evaluation to assess skills and a “driving contract” for reducing and stopping driving.
- Transportation options include support from family/friends, ride sharing, Nevada’s Taxi Assistance Program, Regional Transportation Services, and Veteran’s Medical Transportation Network.
- Contact Nevada 2-1-1 or Care Connection Resource Center to help with transportation questions. See Resource Listings on page 34 for contact information or visit [nevadaadrc.com](http://nevadaadrc.com).

## For More Information

- Dementia & Driving — [Bit.ly/DementiaandDriving](http://Bit.ly/DementiaandDriving)
- Dementia, Caregiving and Transportation — [Bit.ly/DementiaTransportation](http://Bit.ly/DementiaTransportation)



# VETERANS SERVICES

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- Veterans with dementia can receive a full range of health care and support services through the Department of Veterans Affairs. For information, call 844-698-2311.
- Caregiver support is also provided. For information, call 855-260-3274, or visit [www.caregiver.va.gov](http://www.caregiver.va.gov).

## SUPPORT FOR A VETERAN MAY INCLUDE:

- Adult Day Health Care
- Home-based primary care
- Homemaker and home health
- Hospice
- Nursing home
- Palliative care
- Respite care

## For More Information

- Dementia Care — [Bit.ly/VADementiaCare](http://Bit.ly/VADementiaCare)
- Veterans Health Library — [www.veteranshealthlibrary.org](http://www.veteranshealthlibrary.org)
- VHA Office of Rural Health Dementia Caregiver Video Series — [ruralhealth.va.gov/vets/resources.asp](http://ruralhealth.va.gov/vets/resources.asp) — *Scroll down to caregiver video series*



## WORDS OF WISDOM ■

- Counting my blessings with a big smile on and inside of me.
- The sense of well being runs deep when we feel valued.
- Seek out joy and laughter; it's there!
- For both the patient and caregiver, it's best to start early to take advantage of any opportunity to be as strong as you can for as long as you can.

# WELL-BEING

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Practice the principles of wellness at any age or stage:

- Eat more fruits, vegetables and whole grains.
- Drink water.
- Incorporate physical activity into your routine.
- Visit with family and friends.
- Minimize the risk of falls.
- Use a bedtime ritual to prepare for sleep.
- Think about ways to reduce daily stress.

## For More Information

- Global Council on Brain Health — [Bit.ly/AARPBraInHealth](https://www.bit.ly/AARPBraInHealth)
- Living Well with Dementia — [Nhs.uk/conditions/dementia/living-well-with-dementia](https://www.nhs.uk/conditions/dementia/living-well-with-dementia)
- Practical Tips for Living Well with Dementia — [Bit.ly/PracticalTipsDementia](https://www.bit.ly/PracticalTipsDementia) — Scroll down to “Living Well with Dementia”

# SPECIAL CHALLENGES

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## DRIVING

- As dementia progresses driving skills will be impacted.
- Look for drivers getting lost, dents, driving too slow/fast, bad judgment in changing lanes or turning, not obeying traffic signs/signals.
- Talk often about when to reduce or stop driving. Consider a "driving contract", physician letter or professional driving evaluation.

### For More Information:

- At the Crossroads: Family Conversations about Alzheimer's, Dementia and Driving — [Bit.ly/CrossroadsDriving](http://Bit.ly/CrossroadsDriving)
- Dementia and Driving — [Caregiver.org/dementia-driving](http://Caregiver.org/dementia-driving)

## LIVING ALONE

- Many people with dementia live alone.
- Risk factors for those living alone include challenges with carrying out activities of daily living, financial exploitation, unsafe home environment, falls/injuries, social isolation and taking medications as prescribed.
- Planning ahead to minimize risks, address safety concerns and strengthen support for daily activities can help an individual maintain their independence.

### For More Information:

- If You Live Alone — [Bit.ly/IfYouLiveAlone](http://Bit.ly/IfYouLiveAlone)
- Living Alone: Handbook for Helping People Living Alone with Dementia Who Have No Known Support — [nadrc.acl.gov/node/157](http://nadrc.acl.gov/node/157)

# SPECIAL CHALLENGES

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## WEAPONS

- Weapons and firearms may pose a significant risk to a person with dementia and others.
- Create a safety plan for weapons which may include removing them from the home.

### For More Information:

- Firearm Safety — [Bit.ly/FireArmSafety](https://bit.ly/FireArmSafety)

## PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD)

- Individuals with IDD have a similar risk of dementia as the general population; the prevalence is higher for individuals with Down syndrome.
- It can be challenging to diagnose dementia for persons with IDD; new guidelines are being developed for evaluation, diagnosis and treatment.
- Specialized dementia capable services are important for individuals with IDD to continue residing in community settings.

### For More Information:

- My Thinker's Not Working — [aadmd.org/ntg/thinker](https://aadmd.org/ntg/thinker)



## DEMENTIA FRIENDLY NEVADA

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Affiliated with Dementia Friendly America, Dementia Friendly Nevada brings together persons living with dementia, care partners, organizations, businesses and advocates to:

- Broaden awareness of dementia.
- Guide people to receive an accurate diagnosis.
- Encourage persons living with dementia to continue to participate in community life.
- Ensure access to information, resources and support services.

For more information, please visit [dementiafriendlynevada.org](http://dementiafriendlynevada.org).





# NEVADA “NO WRONG DOOR”

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“No Wrong Door” is a way of delivering services, with the goal to make it easier for people to learn about and receive the support they need.

## NEVADA 2-1-1

- FREE service to help find information, services and other community resources.
- Call 2-1-1 (or 1-866-535-5654) to speak a trained specialist, 24/7.
- Search for services online at [nevada211.org](http://nevada211.org).

## NEVADA CARE CONNECTION RESOURCE CENTERS

- FREE one-to-one assistance for older adults, people with disabilities and caregivers:
  - Access resources and services.
  - Connect with caregiver programs.
  - Learn about veterans services and benefits.
  - Answer questions about health insurance, Medicare and Medicaid.

Available by telephone throughout the state, and walk-in centers located in Clark, Churchill, Elko, Lyon and Washoe counties. See Resource Listings on page 34 for contact information or visit [nevadaadrc.com](http://nevadaadrc.com).

# RESOURCE LISTINGS

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## NEVADA RESOURCES

- Nevada 2-1-1 Call 2-1-1 (or 1-866-535-5654) [nevada211.org](http://nevada211.org)
- Nevada Care Connection Resource Centers [nevadaadrc.com](http://nevadaadrc.com)
  - ◆ Clark, Esmeralda, Lincoln and Nye counties — Nevada Senior Services 702-364-2273 or Toll-Free: 844-850-5113, 901 N. Jones Blvd, Las Vegas 89108
  - ◆ Carson, Douglas, Mineral, Storey and Washoe counties — Access to Healthcare Network 877-861-1893, 4001 S. Virginia Street, Suite F, Reno 89502
  - ◆ Elko, Eureka, Humboldt, Lander and White Pine counties — Access to Healthcare Network 877-861-1893, 405 Idaho Street, Suite 214, Elko 89801
  - ◆ Churchill and Pershing counties — William N. Pennington Life Center 775-423-7096, 952 S. Maine Street Fallon, 89406
  - ◆ Lyon county — Lyon County Human Services 775-577-5009, 620 Lake Avenue, Silver Springs 89429
- Alzheimer’s Association 800-272-3900
  - ◆ Northern Nevada [alz.org/norcal](http://alz.org/norcal)
  - ◆ Southern Nevada [alz.org/dsw](http://alz.org/dsw)

- Cleveland Clinic Lou Ruvo Center for Brain Health 702-483-6000  
*ccf.org/nevada, keepmemoryalive.org/socialservices*
  - ◆ Medical, Social Work, Caregiver Services and Education
  - ◆ Lynne Ruffin-Smith Library 702-483-6033  
*keepmemoryalive.org/caregivers-community/library*
- Helping Hands of Vegas Valley 702-633-7264 *hhovv.org*
- Nevada Senior Services 702-648-3425 *nevadaseniorservices.org*
- Nevada Aging and Disability Services Division 702-486-3545  
*adsd.nv.gov*
  - ◆ Long Term Care Ombudsman Program and Advocate for Elders  
702-486-6930
  - ◆ Adult Protective Services 1-888-729-0571
  - ◆ Home and Community Based Care Waiver Program 702-486-3545
- Sanford Center for Aging 775-784-4774 *med.unr.edu/aging*
- Southern Nevada Senior Law Program 702-229-6596 *snsplp.org*
- Nevada Bureau of Health Care Quality and Compliance 702-486-6515  
*dphh.nv.gov/Reg/HealthFacilities/HealthFacilities\_-\_Home/*

# RESOURCE LISTINGS

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## WEBSITES

- AARP Caregiving Resource Center [aarp.org/caregiving](http://aarp.org/caregiving)
- Alzheimer's Association [alz.org](http://alz.org)
- Alzheimer's Foundation of America [alzfdn.org](http://alzfdn.org)
- ARCH Respite Network [archrespite.org](http://archrespite.org)
- Association for Frontotemporal Degeneration [theaftd.org](http://theaftd.org)
- Caregiver Action Network [caregiveraction.org](http://caregiveraction.org)
- Lewy Body Dementia Association [lbda.org](http://lbda.org)
- Family Caregiver Alliance [caregiver.org](http://caregiver.org)
- National Academy of Elder Law Attorneys [naela.org](http://naela.org)
- National Center on Elder Abuse [ncea.acl.gov](http://ncea.acl.gov)
- National Institute on Aging, Alzheimer's and Related Dementias Education and Referral Center [nia.nih.gov/alzheimers](http://nia.nih.gov/alzheimers)
- National Parkinson's Foundation [parkinson.org](http://parkinson.org)
- U.S. Department of Veterans Affairs, Geriatrics and Extended Care [www.va.gov/GERIATRICS/Alzheimers\\_and\\_Dementia\\_Care.asp](http://www.va.gov/GERIATRICS/Alzheimers_and_Dementia_Care.asp)
- U.S. Department of Veterans Affairs, VA Caregiver Support [www.caregiver.va.gov](http://www.caregiver.va.gov)
- U.S. Health and Human Services Alzheimer's Website [alzheimers.gov](http://alzheimers.gov)
- U.S. National Library of Medicine, MedlinePlus [medlineplus.gov/dementia.html](http://medlineplus.gov/dementia.html)

# YOUR RESOURCES

Record information about resources helpful to you.

RESOURCE NAME	CONTACT INFORMATION	SERVICES/PROGRAMS/ SUPPORT

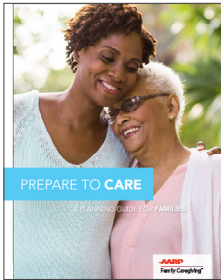
# RESOURCE PLANNING TOOLS

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Resource planning tools can help you navigate your journey with dementia. In this section, you will find sample tools, pages to record useful information and tracking sheets for doctor's appointments and medications.

Here are three sample tools highlighting strategies to create your personal road map to:

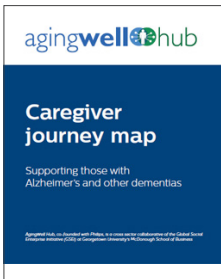
- Identify and connect with resources over the course of illness.
- Map your care team.
- Support care partners.



## **AARP PREPARE TO CARE: A CAREGIVER PLANNING GUIDE FOR FAMILIES**

“A practical tool to help you care for your family member or close friend. The guide follows five important steps that will help see you through your caregiving journey: Start the conversation, Form your team, Make a plan, Find support, Care for yourself.”

For more information and a copy of the booklet, visit: [bit.ly/AARPPpreparetoCare](http://bit.ly/AARPPpreparetoCare)



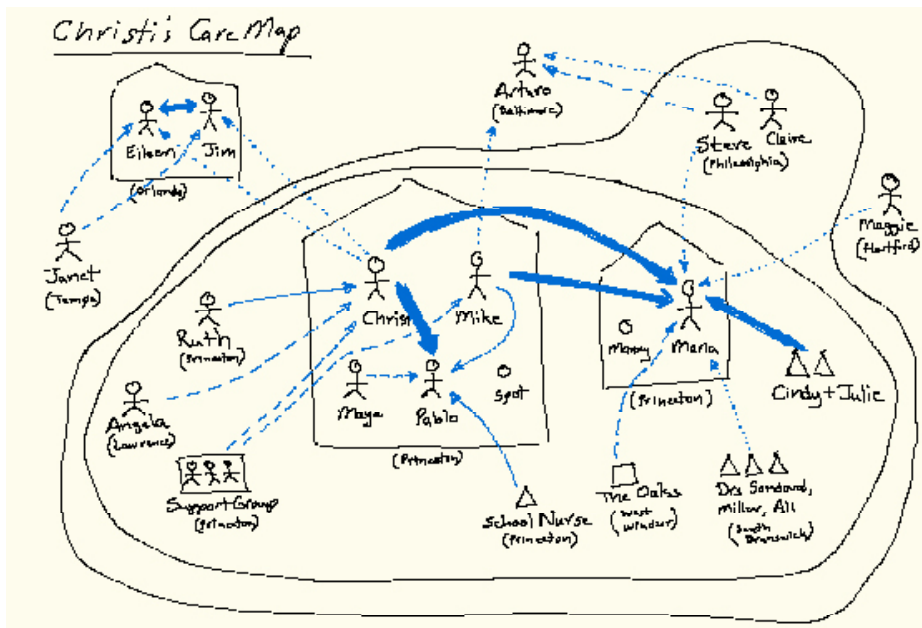
## **CAREGIVER JOURNEY MAP: SUPPORTING THOSE WITH ALZHEIMER'S AND OTHER DEMENTIAS**

“AgingWell Hub has created an integrated journey map for those caring for loved ones with Alzheimer's and other dementias. The map can be used to identify opportunities to provide support and intervention for caregivers, and in turn, to benefit their care recipients.”

For more information and a copy of the booklet, visit: [bit.ly/CaregiverJourneyMap](http://bit.ly/CaregiverJourneyMap)

# ATLAS OF CAREGIVING

“Caregiving happens within a web of relationships of relatives, friends, professionals, and organizations. People are often simultaneously caring for themselves, caring for others, and being cared for by others.”



“An Atlas CareMap is a drawing and a process for self-reflection and action, which also provides a catalyst for conversation. It is a diagram of a person’s care ecosystem, drawn by hand or computer, showing who cares for whom, and how.”

For more information and resources to draw your own CareMap, visit the Atlas of Caregiving website: <https://atlasofcaregiving.com/>

\*Reprinted with permission from Atlas of Caregiving

# NOTES

The Notes pages offer a place to record information helpful to you.  
Consider writing notes about:

- Tips and strategies – what worked for you, things to try.
- Successes – take time to recognize accomplishments and good days.
- Inspirations – experiences that encourage and nurture you over the course of your journey with dementia.

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# NOTES

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# DOCTOR'S APPOINTMENTS

<b>DATE</b>	<b>DOCTOR'S NAME</b>	<b>REASON FOR VISIT</b>

# DOCTOR'S APPOINTMENTS

QUESTIONS TO ASK	NOTES: INSTRUCTIONS, TEST RESULTS, FOLLOW-UP APPOINTMENTS, MEDICATIONS

# DOCTOR'S APPOINTMENTS

<b>DATE</b>	<b>DOCTOR'S NAME</b>	<b>REASON FOR VISIT</b>

# DOCTOR'S APPOINTMENTS

QUESTIONS TO ASK	NOTES: INSTRUCTIONS, TEST RESULTS, FOLLOW-UP APPOINTMENTS, MEDICATIONS

# MEDICATION LIST

<b>MEDICATION   MG</b> Name and strength	<b>DOSAGE   FREQUENCY</b> How much? / How often?	<b>PURPOSE</b> Prescribed to treat?	<b>NOTES/ QUESTIONS</b>

Pharmacy: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_



# MEDICATION LIST

<b>MEDICATION   MG</b> Name and strength	<b>DOSAGE   FREQUENCY</b> How much? / How often?	<b>PURPOSE</b> Prescribed to treat?	<b>NOTES/ QUESTIONS</b>

Pharmacy: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_

# GLOSSARY

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## **ACTIVITIES OF DAILY LIVING**

Everyday tasks such as eating, dressing, bathing, using the toilet and getting in and out of bed.

## **ADULT DAY CARE**

Community-based program offering health care and social services such as nursing care, therapeutic activities, meals and personal care to adults who would benefit from supervised care during the day.

## **ADVANCE DIRECTIVES**

Legal documents that state a person's wishes regarding medical care in the event the person is not able to make decisions or speak for themselves.

## **ALZHEIMER'S DISEASE**

An irreversible, progressive brain disorder that slowly destroys memory, thinking skills and eventually the ability to carry out everyday tasks.

## **\*BENJAMIN ROSE INSTITUTE (BRI) CARE CONSULTATION**

Telephone-based information and support service for caregivers across the lifespan. (Evidence-based)

## **CARE CONSULTATION**

Individualized guidance to help plan for care over the course of disease.

## **\*CARE PARTNERS REACHING OUT (CAREPRO)**

Skill building workshops for care partners supplemented by coach calls. (Evidence-based)

## **CARE PLAN**

Identifies programs and other resources to meet an individual's needs.

## **CARE TRANSITIONS**

Transfer of an individual from one care setting to another such as hospital to home.

*For information about any listings in glossary, contact Nevada 2-1-1.  
See Page 34 for contact information.*

**\*CARING FOR YOU, CARING FOR ME**

Workshops bringing together family and professional caregivers to discuss common issues.

**COMPANION**

Support and companionship provided by a paid or volunteer companion.

**CONGREGATE MEALS**

Nutritious meals served in community locations such as senior centers and senior housing.

**COUNSELING**

Professional guidance to help individuals, families or groups identify and seek solutions to problems or challenges.

**\*DEALING WITH DEMENTIA**

A four-hour workshop for family/professional caregivers on topics including best practices in caregiving and problem solving around dementia-related behaviors.

**DEMENTIA**

A general term for a decline in memory, judgment and thinking serious enough to interfere with daily life.

**DEMENTIA FRIENDLY**

A community, place or environment where people living with dementia and their care partners are respected and empowered.

**DEMENTIA WITH LEWY BODIES**

Type of dementia characterized by cognitive decline, visual hallucinations and parkinsonian motor symptoms.

**EARLY STAGE MEMORY LOSS PROGRAMS**

Programs especially designed for individuals experiencing early stages of dementia such as support groups and counseling.

**\*EARLY STAGE PARTNERS IN CARE (EPIC)**

Education and training for persons with early stage memory loss and their care partners. (Evidence-based)

**EVIDENCE-BASED PROGRAM**

A program that has been proven effective using an experimental design.

\* Caregiver Program

**FRONTOTEMPORAL DEMENTIA**

Type of dementia associated with shrinking of frontal and temporal anterior lobes of the brain, symptoms include behavior and language changes.

**GUARDIANSHIP**

Legal process to appoint a person authorized to make decisions on behalf of someone unable to do so.

**HEALTHY BRAINS**

An online program featuring six pillars of brain health which can help reduce the risk for brain disease. Offers a lifestyle check-up self-assessment tool and personalized brain health tips.

**HOME DELIVERED MEALS**

Nutritious meals delivered to the home of an individual who has difficulty shopping or preparing meals.

**HOME HEALTH**

Medical and related services such as skilled nursing or physical therapy provided in a home setting.

**HOMEMAKER/CHORE**

Assistance with daily household chores and house cleaning.

**HOSPICE**

Services to support an individual who is terminally ill and their family.

**HOSPITAL2HOME: DEMENTIA CAPABLE CARE TRANSITIONS**

Program supporting individuals with memory loss being discharged from the hospital to their homes.

**IN-HOME SERVICES**

Non-medical care such as personal care, homemaker/chore and meal preparation.

**MEDIC ALERT+SAFE RETURN**

24-hour emergency response service for individuals with dementia who may wander or have a medical emergency.

**MEMORY CAFE - RESPITE**

Respite program featuring engaging and evidence-based activities.

*For information about any listings in glossary, contact Nevada 2-1-1.  
See Page 34 for contact information.*

**MEMORY CARE FACILITY**

A residential care option designed to meet the specialized needs of individuals with dementia.

**NEVADA CARE CONNECTION RESOURCE CENTERS (CCRC)**

One-to-one assistance to help individuals of any age and caregivers explore options, plan for care and connect with services.

**NEVADA CARE CONNECTION TOOL BOX**

A range of programs and tools to support caregivers.

**NEVADA LOCKBOX**

Free, secure and confidential electronic registry to store advance directive documents.

**NEVADA NO WRONG DOOR**

Initiative to streamline access to services and offer individualized care.

**NEVADA 2-1-1**

Telephone or online service to connect individuals with information and services.

**PALLIATIVE CARE**

Designed to improve the quality of life of an individual with a serious illness by relieving discomfort, symptoms and stress.

**PARKINSON'S DISEASE**

Movement disorder with symptoms including trembling, stiffness, slow movement, and poor balance. As the disease progresses, memory and judgment can be impacted.

**PERSONAL CARE**

Assistance with daily tasks such as bathing, dressing and eating.

**PERSONAL EMERGENCY RESPONSE SYSTEM**

Enables individuals to summon assistance in an emergency.

**PHYSICAL & OCCUPATIONAL THERAPY**

Rehabilitative services to help individuals perform daily tasks as independently as possible.

**\*POWERFUL TOOLS FOR CAREGIVERS**

Six-week program to help family caregivers take better care of themselves while caring for a loved one. (Evidence-based)

\* Caregiver Program

**RESPIRE**

A break or relief for a family caregiver from caregiving responsibilities.

**\*ROSALYNN CARTER INSTITUTE - RESOURCES ENHANCING ALZHEIMER'S CAREGIVER HEALTH (RCI REACH)**

In-home intervention providing education and skill building to help caregivers address challenging symptoms and decrease stress.

(Evidence-based)

**SHOPPING/MEAL PREPARATION**

Assistance with meal planning, grocery shopping and meal preparation.

**SKILLED NURSING CARE**

Medically necessary care provided by skilled or licensed medical professional such as a nurse or physical therapist.

**SKILLS2CARE**

Occupational therapist visits home of person with dementia to understand challenges and develop strategies to support individual and caregiver.

(Evidence-based)

**SUNDOWNING**

Symptoms that appear or get worse in the afternoon or evening such as agitation, anxiety, pacing or confusion.

**SUPPORT GROUPS**

Opportunity to meet with others who have common experiences and concerns to share information, coping strategies and sense of community.

**24/7 HELPLINE**

Alzheimer Association's toll-free line for information and support, 800-272-3900.

**VASCULAR DEMENTIA**

Type of dementia caused by stroke or other conditions which reduce blood flow to the brain.

\* Caregiver Program

***For More Information about listings in glossary, contact Nevada 2-1-1 or Nevada Care Connection Resource Centers. See Page 34 for contact information.***



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