

Supporting People with Dementia: A Resource Guide for Social Workers

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Introduction

The number of people with dementia is rapidly growing. In Los Angeles County, the number of adults with Alzheimer’s disease alone is expected to increase by 150% and impact more than 405,000 people by 2040.¹ As a result, there is an increasing need for a dementia-capable workforce skilled in effectively supporting people living with dementia, their families, and caregivers.

Social workers are essential to any care team involved in improving the quality of life of people with dementia and supporting their families and caregivers. Approximately 73% of social workers report providing care to older adults at the highest risk of developing dementia, yet few have specialized geriatric training (4%).²

This resource guide aims to provide social workers with resources that can enhance their knowledge and skills in working with people living with dementia, their families, and caregivers.








Alzheimer's Disease and Related Dementias

Dementia is a general term used to describe symptoms related to a decline in cognitive abilities, such as changes in memory, thinking, and behavior.³ Dementia is caused by a range of conditions that affect the brain including Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, and mixed dementia.

Dementia has been linked to a number of modifiable and non-modifiable risk factors. The most prominent risk factor for developing dementia is increasing age. However, dementia is NOT a normal part of aging. Other biological risk factors include family history, genetics, race/ethnicity, and gender. Modifiable risk factors that may increase the chances of developing dementia include uncontrolled hypertension or diabetes, traumatic brain injury, and lifestyle behaviors such as smoking, physical inactivity, and diet.

Learn more about the different types of dementia:

	Alzheimer's Disease (AD) ⁴ 	Vascular Dementia (VD) ⁵ 	Lewy Body Dementia (LBD) ⁶ 	Frontotemporal Dementia ⁷ 	Mixed Dementia ⁸ 
Description	<ul style="list-style-type: none"> • Most common type of dementia • Symptoms appear gradually and progress over time • Typical age of diagnosis is ≥ 60 years; some cases in the mid-30s-60s 	<ul style="list-style-type: none"> • Symptoms often overlap with AD and may appear gradually or suddenly after a stroke • Typical age of diagnosis is ≥ 65 years 	<ul style="list-style-type: none"> • Affects parts of the brain related to thinking, movement, and behavior • Symptoms appear gradually and worsen with time • Typical age of diagnosis is ≥ 50 years; some cases in the early 30s 	<ul style="list-style-type: none"> • Caused by damage to the frontal lobes or temporal lobes of the brain • Symptoms appear gradually and worsen over time • Typical age of diagnosis is 40s to 60s 	<ul style="list-style-type: none"> • A condition in which more than one dementia occurs in the brain • Most common mixed dementia combinations include AD/VD and AD/LBD • Usually identified after death in an autopsy
Signs and Symptoms	<ul style="list-style-type: none"> • Difficulty remembering new information • Repeating questions • Difficulty with daily tasks such as reading a watch 	<ul style="list-style-type: none"> • Confusion • Difficulty with language, such as speaking or understanding speech • Problems with balance 	<ul style="list-style-type: none"> • Visual hallucinations • Muscle stiffness • Sleep disorders such as Rapid Eye Movement (REM) or excessive sleep 	<ul style="list-style-type: none"> • Excessive or withdrawn emotions • Easily distracted • Difficulty with language, such as speaking, writing, and reading 	<ul style="list-style-type: none"> • Symptoms differ depending on the affected brain regions

Resources

Expand your own awareness and knowledge about dementia:

- [Alzheimer's Association Education Center](#) - *Alzheimer's Association*. Offers 13 free, on-demand programs to learn more about Alzheimer's disease and dementia. Each program is approximately 1 hour in duration and are also available in Spanish. **(Web)**
- [AFA Partners in Care: Supporting Individuals Living with Dementia](#) - *Alzheimer's Foundation of America*. Offers on-demand training for interacting and caring for people with dementia. The training is five and a half hours, costs \$74, and social workers can receive 5.5 General Social Work Practice continuing education credits. **(Web)**
- [Alzheimer's & Related Dementias](#) - *Alzheimers.gov*. Read more about the different types of dementia and find information and resources you can share with clients. **(Web)**
- [Dementia Care Training Course](#) - *Bureau of Health Workforce, Health Resources and Services Administration*. Offers free, on-demand training with sixteen modules focused on dementia outpatient care. All modules include a presentation, faculty guide, and continuing education information. **(Web, PowerPoint, PDF)**
- [Social Work and Dementia Training Presentation](#) - *USC/Rancho California Alzheimer's Disease Center*. Find a PowerPoint presentation designed on strengthening social worker's knowledge about dementia and highlighting their role in supporting people and families living with dementia. **(PDF)**

Supporting People living with Dementia

Getting a diagnosis of dementia is a life-altering event for people and their families. Dementia is a progressive condition, and you may interact with people at different stages of the condition. It is important to remember to treat people with dementia with compassion, respect, and dignity. As a social worker, you are a valuable resource for someone with dementia, their caregivers, and families. You may play a role in assessing cognitive impairment, providing counseling or case management services, facilitating access to dementia-related information and local resources, and/or helping people navigate the healthcare system.⁹



**DEMENTIA IS
NOT
A NORMAL PART OF AGING.**

Key Considerations: Comorbidities and Dementia

People with dementia are more likely to have multiple co-morbid chronic diseases such as hypertension and diabetes that can lead to poorer health outcomes, including preventable hospitalization visits.¹⁰ Having multiple chronic diseases can introduce many challenges as the severity of dementia increases. For instance, the person may have:

- Difficulty communicating or remembering symptoms
- Difficulty self-managing their chronic diseases
- Difficulty communicating sources of pain

Understanding the impact of co-occurring chronic conditions among people with dementia is essential for assessing their needs and can help improve their health outcomes. Consider¹¹:

- Providing regular clinical appointment reminders
- Clarifying symptoms using closed questions
- Tailoring disease management activities to the lifestyle requirements of the person

Resources

Find tools and best practices for supporting people with dementia:

- 🔗 [Communicating with People Living with Dementia](#) - *Alzheimer Society*. Find materials on how dementia affects communication and learn tips and strategies for communicating with people living with dementia. **(Web, PDF)**
- 🔗 [Dementia Care Training, Module 13: Clinical Social Workers and Clinical Psychologists Course](#) - *Bureau of Health Workforce, Health Resources and Services Administration*. This module offers best practices and strategies in supporting people with dementia and their caregivers, includes a presentation, faculty guide, and continuing education information. **(Web, PowerPoint, PDF)**
- 🔗 [Dementia from the Inside](#) - *Social Care Institute for Excellence*. Watch this video to learn about the experience of someone living with dementia from their perspective. **(Web)**
- 🔗 [Elder Abuse and Dementia Tip Sheet](#) - *Los Angeles County Aging and Disabilities Department*. Download an informational sheet discussing the impact of elder abuse on people with dementia and warning signs. To report elder abuse, call 877-477-3646. **(PDF)**
- 🔗 [Handbook for Helping People Living with Alone with Dementia Who Have No Known Support](#) - *National Alzheimer's and Dementia Resource Center*. Offers guidance and tools for working with people with dementia living alone in the community. **(Word)**

- 🔗 [Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals](#) - *National Alzheimer's and Dementia Resource Center*. This guide provides background information, tools, and strategies for working with people living with intellectual and developmental disabilities and dementia. **(PDF)**
- 🔗 [Provider Practice Tools](#) – *Dementia Friendly America*. Find care coordination practice tools and additional resources to support clients with memory concerns. **(Web, PDF)**

Supporting Families and Caregivers

Providing care to someone with dementia can impact the health and well-being of caregivers and families. Caregivers and families can benefit from services including legal counseling, emotional support, disease education, respite, and more. Social workers play an important role in helping caregivers and families connect to the resources they need the most. It is important to also understand that the caregiving experience is varied across different cultures and races. Family dynamics, language, cultural norms, and many additional factors can influence dementia care.



Resources

Find tools and additional resources on supporting families and caregivers of people living with dementia:

- 🔗 [Caring for Those Who Care, Resources for Providers: Meeting the Needs of Diverse Family Caregivers](#) - *Diverse Elders Coalition*. Offers information and resources on what you need to know to support diverse family caregivers. **(PDF)**
- 🔗 [Dementia Care Specialist Toolkit for Dementia Care Management](#) - *Alzheimer's Los Angeles*. Offers tools to support dementia care management. **(PDF)**
- 🔗 [Hit Pause: Helping Dementia Families Deal with Anger](#) - *Duke Family Support Program*. Offers typical scenarios and suggested responses when providing help and emotional support to caregivers and families. **(PDF)**
- 🔗 [NASW Standards for Social Work Practice with Family Caregivers of Older Adults](#) - *National Association of Social Workers*. Provides standards to enhance your knowledge and skills in supporting family caregivers of older adults. **(PDF)**

Client Resources

Here are some resources you can give to people living with dementia, their families, and caregivers.



Advance Care Planning

- [Advance Planning Guides for Persons with Dementia and Caregivers](#) - *National Alzheimer's and Dementia Resource Center*. Three guides for people living with dementia on health care planning, planning for care, and financial planning, and one guide for caregivers on making decisions for someone with dementia. **(PDF)**
- [Conversation Starter Guides](#) - *The Conversation Project*. Offers conversation starter kits for those wishing to communicate their end-of-life care wishes and the people that care for them. There are guides designed for people supporting someone living with dementia, they are available in English, Spanish, and Chinese. **(Web, PDF)**
- [Five Wishes](#). Offers a user-friendly advance directive tool that people can buy for themselves and their family. Five Wishes Paper is available in 30 languages for \$5.00. **(Web, PDF)**
- [Prepare for Your Care](#). Offers a free 5-step online program to help people make medical decisions for themselves and others. Handouts for clients and additional materials are available in English and Spanish. **(Web, PDF)**







Caregiver and Family Support

- [Caring for Yourself as a Dementia Caregivers](#) - *Los Angeles County Department of Public Health*. This handout provides information to caregivers on how to look after themselves and shares resources available to them. **(PDF)**
- [Caregiver Training Videos and Webinars](#) - *UCLA Alzheimer's and Dementia Care Program*. This series of webinars and videos help caregivers understand how to better care for people with dementia. Videos are offered in English, Spanish, Korean, and Vietnamese. **(Web)**
- [Caregiver Tip Sheets](#) - *Alzheimer's Los Angeles*. Download tip sheets for caregivers with suggestions on managing common challenges and situations, including bathing, communication, keeping the home safe, and more. Tips sheets are available in English, Spanish, Chinese, and Japanese. **(Web, PDF)**
- [Still Standing: A Guide for Loving Through Alzheimer's and Related Dementias](#) - *A Ministry of Due West United Methodist Church*. A guide for caregivers on topics related to commonly asked questions, responsibilities as a new caregiver, communicating with doctors, and more. **(PDF)**







Resources in Los Angeles

-  [Alzheimer's Association California Southland Chapter](#). Offers free educational programs and support groups for people with dementia, families, and caregivers in Los Angeles, Riverside, San Bernardino, Kern, Tulare, Kings and Inyo counties. Services are offered in English, Spanish, and Korean. **(Web)**
-  [Alzheimer's Los Angeles](#). Offers free programs and services such as caregiver workshops and support groups for people impacted by dementia. Services are offered in Spanish, Japanese, Chinese, and Korean. **(Web)**
-  [LA Found](#) - *Los Angeles County Aging and Disabilities Department*. A program designed to help caregivers locate their loved one with Alzheimer's dementia, autism, or any cognitive impairment in the event they go wandering by using a system of trackable bracelets. **(Web)**
-  [USC Family Caregiver Resource Center](#). Offers low to no-cost services to family caregivers and friends who care for people over 60 with chronic medical conditions, such as dementia. **(Web)**



Other Related Resources

-  [Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers](#) - *National Down Syndrome Society*. A guidebook with information and resources for caregivers of people living with Alzheimer's disease and Down syndrome. **(Web, PDF)**
-  [Brain Health Begins with Your Heart](#) - *Los Angeles County Department of Public Health*. A fact sheet highlighting the connection between heart health and brain health with tips and resources on how to keep both healthy. **(PDF)**
-  [Forgotten Memories/Recuerdos Olvidados Fotonovela](#) - *USC Family Caregiver Support Center*. A fotonovela on dementia in English and Spanish that families can watch or download that discusses early signs of dementia and encourages families to discuss their concerns with a doctor. **(Web/PDF)**
-  [Next Steps After an Alzheimer's Diagnosis Checklist](#) - *National Institute on Aging*. A two-page handout that outlines next steps for people wanting more information following an Alzheimer's disease diagnosis. Also available in English and Spanish. **(Web, PDF)**

For more information and resources, visit us at www.bit.ly/healthybrainla

REFERENCES

1. Ross, L, Beld, M, and Yeh, J. (2021). Alzheimer's Disease and Related Dementias Facts and Figures in California: Current Status and Future Projections. Report prepared for the California Department of Public Health, Sacramento, CA at the Institute for Health and Aging, University of California, San Francisco, CA.
2. Institute of Medicine (US) Committee on the Future Health Care Workforce for Older Americans. (2008). *The Professional Health Care Workforce. Retooling for an Aging America: Building the Health Care Workforce.* National Academies Press, Washington (DC).
<https://www.ncbi.nlm.nih.gov/books/NBK215402/>
3. Alzheimer's Association. (2022). *2022 Alzheimer's Disease Facts and Figures. Special Report. More Than Normal Aging: Understanding Mild Cognitive Impairment.*
<https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
4. Alzheimer's Association. (n.d.). *What is Alzheimer's Disease?* <https://www.alz.org/alzheimers-dementia/what-is-alzheimers>
5. Mayo Clinic. (2021). *Vascular Dementia.* <https://www.mayoclinic.org/diseases-conditions/vascular-dementia/symptoms-causes/syc-20378793>
6. National Institute on Aging. (2021). *What is Lewy Body Dementia? Causes, Symptoms, and Treatments.*
7. Alzheimer's Association. *Frontotemporal Dementia.* <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/frontotemporal-dementia>
8. Alzheimer's Association. (n.d.). *Mixed Dementia.* <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/mixed-dementia>
9. Grand JH, Caspar S, Macdonald SW. (2021). Clinical features and multidisciplinary approaches to dementia care. *J Multidiscip Healthc*, 4, 125–147. <https://doi.org/10.2147/JMDH.S17773>
10. Centers for Disease Control and Prevention. (2020). *Chronic Diseases and Cognitive Decline – A Public Health Issue.* <https://www.cdc.gov/aging/publications/chronic-diseases-brief.html>
11. Ibrahim, J. E., Anderson, L. J., MacPhail, A., Lovell, J. J., Davis, M. C., & Winbolt, M. (2017). Chronic disease self-management support for persons with dementia, in a clinical setting. *Journal of multidisciplinary healthcare*, 10, 49–58. <https://doi.org/10.2147/JMDH.S121626>