



Provider Guide to Post-Diagnostic Communication, Support, and Management of Dementia



Communicate the diagnosis

Use open ended statements and have a conversation with both the patient and caregiver
 Ex: Ask the caregiver, "If you had to give the diagnosis, what would it be?"

Explain the **biology and progression** of the disease and what the patient and caregiver should expect through different stages of dementia.

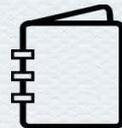
Keep Focus on the patient and caregiver

Anticipate questions

Establish Transparency by giving honest answers and facts

Develop a realistic plan

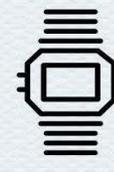
Prepare them for fragmented care and exposure to multiple providers



Support caregiver coping skills and advocacy for the patient through warm handoffs.

Allow **caregiver control** to make decisions and meet the patient's needs.

Recommend a **notebook** to keep track of appointments, which provider was seen, discussions, outcomes, dates, contact information, etc.

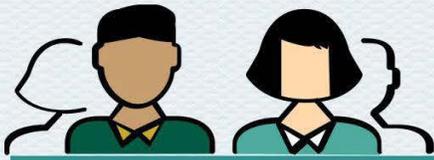


Talk to the patient about the diagnosis and ensure his/her understanding. Obtain his/her self-perceived abilities. Confirm with the caregiver.

Example: If the patient insists that they can **drive safely**, despite concerns by family members, ask the caregiver, "Would you let your children ride with them?"

Ask "What would be of real help?" Make personalized recommendations for independence and in-home safety.
 Examples: Medical Bracelet, Pill Box, Digital Sensors, Grab Bars, Baby Monitors

Provider Role in Caregiver Support

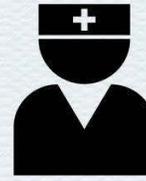


Caregivers

are the spouses, daughters, grandchildren, daughters-in-law, sons, and siblings of the patient. Others are friends, neighbors, and community members.

Many caregivers are **older** and have their own **health problems**. The caregiver's role can lead to high emotional strain, poor physical health, and increased mortality.

Many caregivers are referred to as the "**sandwich generation**", who are married and also raising children of their own.



Ethnic Diversity

may inhibit caregiver comfort to ask for clarification. Sensitivity to cultural expectations is important for care transitions.

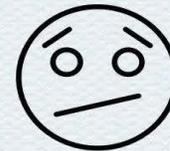
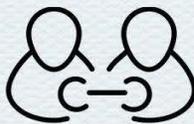
Consider

ethnic diversity, health literacy, and the relationship between the caregiver and patient prior to the diagnosis.

Reassure

the caregiver that you are the contact person for further questions.

As the **care manager**, you will advocate for the patient and coordinate care and services from many providers.



Health Literacy

issues may cause the patient and/or caregiver to refrain from asking questions to hide their lack of understanding.

Provide explanations and help them navigate the system.

Avoid using jargon. Educational materials should be at a 4th grade reading level.

Explore **lifelong** relationships and past family history with the caregiver and patient.

How have they previously coped with trauma? That will be indicative of how they will deal with the dementia diagnosis.

Assist with the caregiver's response to the diagnosis.

Recognize fear. The caregiver may ask, "How long is this going to last?" "How bad is this going to be?"

Help the caregiver understand the diagnosis. This can assist with coping and response.

Management Considerations



Consider Referring

the patient and caregiver to **psychotherapy or counseling services.** Counseling and help for coping with the diagnosis can be provided through referral to a care manager, care consultant, or a dementia-trained counselor.

Start With Non-pharmacological Interventions

aimed to prevent agitation and aggression and respond to episodes of agitated and aggressive behaviors to reduce their severity and duration, and/or reduce caregiver distress before resorting to pharmaceutical drugs.

Understand and Explain the limitations of available **drugs** for Alzheimer's disease. There is no evidence that the current FDA-approved drugs slow the underlying process or prevent progression. 1/3 of patients see some benefit in functional improvement and behavior changes.



Caregiver Assessment

Identify and document the caregivers' strengths, problems, and needs in their health record. Track health status and potential risks from caregiving, including physical strain, emotional stress, and depression.

Monitor and Assess the Health of the Caregiver

Primary care providers are encouraged to routinely identify Medicare beneficiaries who are caregivers as part of the Health Risk Assessment in the Medicare Annual Wellness Visit.

Manage Co-morbidities and Encourage Healthy Behaviors

- Control chronic disease
- Physical activity
- Nutrition
- Mental stimulation
- Mood
- Sense of purpose
- Socialization
- Sleep hygiene



Assessment Tools

- Modified Caregiver Strain Index (MCSI)
- Caregiver Stress/Strain Instrument
- Caregiver Depression/Stress

Ongoing Management

- Regular visits/Access to Urgent Care
- Social support
- Adequate Sleep
- Caregiver check in
- Identification of goals of care
- Prevention of adverse drug reactions
- Hospital and emergency room avoidance
- Mandated reporting (i.e. DMV, Elder Abuse)
- Capacity evaluation
- Palliative/End of Life Care

Clinical Trials trialmatch.alz.org 800-272-3900

The Alzheimer's Association TrialMatch is a free, easy-to-use clinical studies matching service that connects individuals with Alzheimer's, caregivers, healthy volunteers and physicians with current studies.

Caregiver Support and Resources

alzheimer's  association



Alzheimer's Association

www.alz.org

800-272-3900 (24/7 Helpline)

The world's leading voluntary health organization in Alzheimer's care, support, and research.

Family Caregiver Alliance/ Caregiver Resource Centers

www.caregiver.org

California CRCs serve more than 14,000 families and caregivers of adults affected by chronic and debilitating health conditions including, but not limited to, dementia.

Alzheimer's Day Care Resource Centers

(800) 510-2020

Provide services and support to both individuals with Alzheimer's and their caregivers.



Alzheimer's Foundation of America

www.alzfdn.org

1-866-232-8484

Services include a toll-free helpline, education, social services, care connection teleconference, support groups, and professional development.

eldercare locator

— Celebrating 20 Years —
Connecting You to Community Services



Eldercare Locator

www.eldercare.gov

1-800-677-1116

A public service of the U.S. Administration on Aging that connects consumers to services for older adults and their families.

California Alzheimer's Disease Centers

www.cdph.ca.gov/alzheimers

Provide diagnostic assessment to those with memory concerns; family and caregiver support and training; and education and training to community members and health care and social services professionals.



BrightFocus Foundation

www.brightfocus.org

1-800-437-2423

Provides a disease toolkit, tips & how-tos, facts & data, experts & advice on Alzheimer's disease.



California Department of Aging

www.aging.ca.gov

1-800-510-2020

Provides a variety of programs and services for seniors, caregivers, & adults with disabilities through local Area Agencies on Aging.

Programs include Community Based Adult Services, Family Caregiver Support, Legal Assistance and more.

Department of
SOCIAL SERVICES 

California Department of Social Services

www.cdss.ca.gov

Provides programs and services for vulnerable adults.

Services include In-Home Supportive Services, oversight of residential care facilities for the elderly, and Adult Protective Services which investigate reports of abuse of elders and dependent adults and arranges for services including money management and counseling.

Caregiver Support and Resources



California Department of Health Care Services www.dhcs.ca.gov

Provide services and support to seniors including Community-Based Adult Services, Multi-Purpose Senior Services Program, Assisted Living Waiver, In-Home Operations, and the Senior Care Action Network Health Plan.

Program of All-Inclusive Care for the Elderly www.calpace.org

1-888-633-PACE (7223)
Provides a comprehensive medical/social service delivery system in a PACE Center that provides and coordinates all needed preventive, primary, acute and long-term care services.

CalMediConnect www.calduals.org

Promotes integrated delivery of medical, behavioral, and long-term care services for people on Medicare and Medi-Cal called "Medi-Medi" or "dual eligible beneficiaries."



ARCH National Respite Network archrespite.org **1-919-490-5577**

Helps families locate respite and crisis care services in their communities.



Well Spouse Association www.wellspouse.org **(800) 838-0879**

Providing peer support and education about the special challenges and unique issues facing spousal caregivers.



Alzheimer's Disease Education and Referral Center (ADEAR) www.nia.nih.gov/alzheimers **1-800-438-4380**

A service of the National Institute on Aging which provides answers to questions, publications, referrals to local services, Spanish language resources, clinical trials information, training materials, guidelines, and updates.



California Department of Consumer Affairs www.dca.ca.gov **(800) 952-5210**

Provides consumer-protection services and information for seniors.

Services include a "Scambuster Kit" for seniors, Scam Stopper seminars, and a consumer resource center.



California Department of Justice/Office of the Attorney General www.oag.ca.gov **(800) 952-5225**

Provide protective services for seniors including a Missing Persons Unit, the Bureau of Medi-Cal Fraud and Elder Abuse, Elder Care Employer, and End of Life Care Planning.



Coalition for Compassionate Care of California coalitionccc.org **(916) 489-2222**

Provides programs and services for health care providers, patients, and caregivers, including Advanced Care Planning, Physician Orders for Life Sustaining Treatment, and Palliative Care resources.

References and Resources

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