

# Assisting Caregivers Plan through the Stages

Communicating with patients and family caregivers through the stages of dementia is probably the most important role you will play over the course of the disease. Alzheimer's disease and related dementias are chronic, progressive diseases lasting on average six to 10 years, but can vary from three to 20 years. Between diagnosis disclosure and end of life, there may be many years in which to educate patients and caregivers on the progress of the disease.

The most common causes of death directly related to ADRD are aspiration pneumonia and hypovolemic shock, but older patients often have a number of other chronic diseases contributing to death, including hypertension, chronic heart failure, COPD, diabetes, etc., as well as may suffer strokes, myocardial infarction, arrhythmias, or pulmonary emboli.

Individuals with ADRD often develop UTIs, pneumonia, or infected pressure ulcers, which require ongoing observation and care. Individuals with dementia and their caregivers need education on disease specific information, as well as patient care information, health-care services, community resources, and importantly, caregiver self-care.

It is important that the provider display empathy for the experience the individual and family member are going through, and take the necessary time to listen. This will involve:

- Allow for longer patient visits and schedule regular check-ins either in person or telephone.
- Opportunity to assess caregiver stress and depression, and recommend separate appointments for caregivers as appropriate.
- Express understanding of the gravity of the road they are traveling.

## 5 Critical Issues to Discuss at Time of Diagnosis

1. Primary diagnosis – assess amount of detail requested by patient and family
2. Contributing factors to the diagnosis
3. Work, driving, managing finances
4. Personal and home safety, including presence of firearms or other weapons
5. Need to have caregiver with individual while they absorb the diagnosis

## To Discuss as Soon as Possible while Individual can make own Decisions

- Medication options
- Driving – legal obligation to report to DMV but DMV makes assessment and decision
- Finances
- Legal Issues
- Advanced Directives and POLST

## 5 Action Steps for the Family

1. Establish legal responsibility and create legal documents
2. Understand diagnostic process, symptoms and course of memory loss/dementia
3. Self-care for the caregiver
4. Join a support group
5. Plan for the future

## To Discuss with Family in the First Six Months Post-Diagnosis

- With whom clinician may discuss patient care
- Update HIPAA form
- Identifying primary decision maker(s)
- Create/modify Advance Care Directive & POLST
- Power of Attorney or fiduciary, bank accounts
- Checklist of where important documents kept
- Discussing post-mortem preferences
- Planning in case of illness of caregiver

## To Discuss During the First Year Post-Diagnosis

- Education for both individual and caregivers
- Community resources
- Social resources
- Housing options
- Treatment of cognitive and behavioral symptoms
- Communication strategies
- Diet, exercise, sleep, alcohol, social interaction
- Clinical Trials

## Making Referral for Palliative and Hospice Care

Palliative care consultation – consider when patient and family may benefit from team-based approach

- Social workers, nurses, other care professionals can provide assistance

Hospice – can add extra support, counseling

- When anticipate 6 months or less to live
- Payment through Medicare, VA, MediCal or other insurance – no charge to patient
- Poor prognostic indicators