

# The Caregiver Role in Shared Decision-Making with Persons Living with Dementia

We developed this module under a contract from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The Department of Health and Human Services, Office of Women's Health, funded this work.

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# Overview

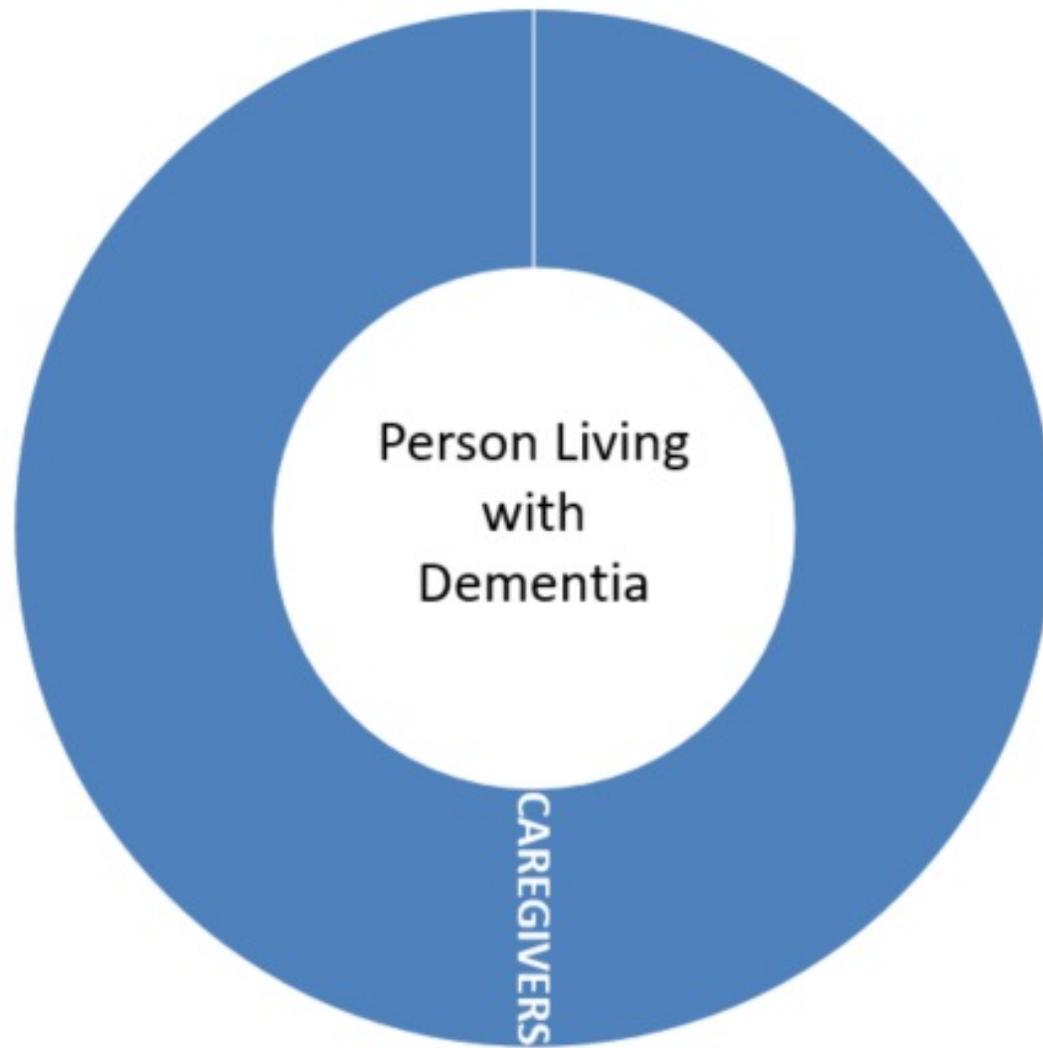
- The importance of shared decision-making
- Decisions to make upon leaving the hospital
- Long-term care options

# DECISION-MAKING

# What is Shared Decision-Making?

- [Shared Decision-Making](#): Persons living with dementia, partners, involved neighbors, caregivers, family members, and their health care team make health care decisions together, taking into account the evidence available, as well as the desires of the persons living with dementia.

# Shared Decisions



# Guidelines

- Focus on values, goals, and preferences.
- Have persons living with dementia participate.
- Respect differences in opinions.
- Seek an advocate or mediator.

# Treatment Decisions

- Revisit treatment decisions often.
  - Watch for behavioral changes.
  - Address *your* needs and priorities.
- Be aware of possible interference between dementia and treatments for other medical conditions.
- Ask questions and seek additional opinions, and information.

# Advanced Planning

- Listen to wishes of the person living with dementia.
- Make decisions about future care.
- Discuss medical care and treatment.
- Write decisions down.
- Let others know the results.

# Information Sources

- Health care team
- [Alzheimer's Association](#)
- [Alzheimer's Disease Education & Referral Center \(ADEAR\)](#)
- [Administration for Community Living](#)
- [Centers for Medicare & Medicaid](#)
- [Eldercare locator](#)

# HOSPITAL DISCHARGES

# Hospital Discharge Process

- **Doctor:** writes a discharge order
- **Discharge planner:** arranges hospital release; contacts family
- **Patient or Caregiver:** receives discharge instructions
  - The discharge plan will include information on care needed after leaving the hospital, medications, warning signs, follow-up care, etc.
- **Care manager:** consider hiring to help talk to the discharge planner

# Planning: Hospital Discharges

- Prepare to make decisions quickly.
- The health of the person living with dementia may change following a hospital stay.
- Work with the hospital discharge planner and medical team.
- Make decisions about required, available, and affordable care.
- Determine which provider you will use.

# Before Discharge: Considerations

- Should you provide more, or different, care following the hospital stay?
- What are the different care options? Are they affordable?
- Which care facilities have openings?
- Will insurance cover some options?
- Should you choose another facility while you are on the waiting list for your first choice?

# LONG TERM CARE (LTC)

# Overview: Long Term Care

- LTC includes:
  - Home health care
  - Home and community-based services
  - Rehabilitation unit
  - Assisted living
  - Nursing homes
  - Hospice care
- Use [this 2-Step Framework tool](#) to help you determine your best options for long-term care (LTC).

# Option 1: Home Health Care

- **Definition:** a Medicare service supervised by registered nurses, which provides active nursing care
- Staff may also include physical, occupational, and speech therapists, and social workers.
- Home health aides provide the bulk of the care.
- Focus is on regaining strength, and learning tasks which allow patients to live safely at home.

# Option 2: Personal Care

- **Definition:** Minimally trained workers provide assistance with basic care needs at home
- Nurses may supervise personal care providers.
- Medicare does not cover this care, however Medicaid may cover it for certain people.

# Option 3: Rehabilitation Units

- **Definition:** licensed facilities that provide rehabilitation
- Nurses, and physical and occupational therapists, provide most of the care to patients.
- To be covered by Medicare, patients must receive at least 3 hours of therapy each day.

# Option 4: Adult Day Health Center

- **Definition:** Care provided outside the home in special centers
  - Care may be mostly social, or may include services like physical therapy.
  - Care typically includes a meal.
  - Care may provide transportation to, and from, a patient's home.
- This care provides socialization for the patients, and relief to their caregivers.

# Option 5: Assisted Living

- **Definition:** provides personal care support services to patients living in self-contained units
  - Services may include meals, medication management, bathing, dressing and transportation.
  - Facility likely includes living quarters, a private bathroom, and some cooking and food storage facilities.
- Independent living
- Patients typically pay costs outright, but Medicaid may be used for some, depending on the state.

# Option 6: Nursing Home

- **Definition:** residential care for those recently discharged from the hospital, as well as longer term care
- Nursing homes are required to provide nursing staff capable of caring for frail residents.
- Some include special care units for persons living with dementia.
- Patients pay out-of-pocket or via Medicaid.
  - Medicare does not pay for nursing home stays

# Option 7: Hospice Care

- **Definition:** care that lessens pain and symptoms of people close to death and gives emotional and spiritual support
- Most often provided at home
- For people expected to live less than 6 months
- Is a Medicare and Medicaid benefit that may be appropriate for many persons living with dementia

# CHOOSING A CARE PROVIDER

# Questions for Home Care Providers

- What kind of therapists are available?
- Is there weekend care?
- Can the special needs of the person living with dementia be met?
- What does it cost?

# Questions for Residential Providers

- To evaluate a nursing home, ask the questions provided in our presentation: **What to Consider When Choosing a Nursing Home**
- To evaluate an assisted living facility, ask the questions in our presentation: **What to Consider When Choosing an Assisted Living Facility**

# Summary

- Decision-making is crucial for everyone's well-being.
- You will need to revisit decisions on a continual basis, especially as the person living with dementia's health changes.
- Making shared decisions can reduce stress.
- Ask questions, seek out second opinions, and use the internet wisely.
- Good decision-making takes considerable time and effort.