

Caregiving for Persons Living with Dementia (PLwD)

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Overview

- Caregiving 101: definition, importance, and basic rules
- Roles and Duties
- Caregiver Self-Care

CAREGIVING 101

What is Caregiving?

- It is a broad range of mostly unpaid help with multiple kinds of health-related activities provided by a friend, family member, partner, or neighbor to a care recipient.

Importance of Caregiving

- Caregiving gives you:
 - A chance to give back
 - A sense of purpose/meaning
- Your efforts keep persons living with dementia in their homes longer.
- You are the link between the medical care system and the person living with dementia.

Basic Rules of Caregiving

Caregiving can last a long time.

- “Self-care is not selfish. You cannot serve from an empty vessel.” — [Eleanor Brown](#)
- Pace yourself.
- Plan on getting help.

CREATE A CARE PLAN

Prepare & Gather Important Information

- Health, personal, financial and legal
- Health care wishes of the person living with dementia
- Lists of diagnoses, doctors, allergies, and medications

Financial, Health, & Personal Details

Financial information	Health information	Personal information
Bank accounts (numbers, locations), location of checkbooks	Diagnoses	Advance directives
Retirement account #s (pension, 401K, IRA); passwords; life insurance	Medications	Power of attorney
Investments (stocks, bonds, real estate), broker/financial planner; passwords, associated checkbooks	Contact info for doctors and dentists	Location of original will and copies
Social Security number; Location of original social security card	Medicare info (HIC – Health Insurance Claim number)	Lawyer (address)
Mortgage status/info (Who holds it? When are payments due? How much?)	Supplemental health insurance policy numbers	Life insurance
Other major debts (payment info); credit card location and permissions	Long-term care insurance	Burial arrangements (including insurance)
Recurring bills (rent, utilities, etc.)	Medicare Part D	

I. Disease Stages & Your Role

Disease Stage	Caregiver Role
No impairment (normal function)	Routine exchange of help and support
Very mild cognitive decline (may be normal age-related changes or earliest signs of dementia)	More frequent reminders, help with more complex, day-to-day tasks (e.g., preparing meals); discuss advance directives
Mild cognitive decline	Manage frustration and/or depression; arrange appointments; help the person with memory loss deal with job exit
Moderate cognitive decline	Cope with behavior; assist with shopping, housework, transportation/driving

II. Disease Stages & Your Role

Disease Stage	Caregiver Role
Moderately severe cognitive decline	Provide limited assistance with more daily activities (dressing and bathing); nighttime sleep management; address more severe behavioral challenges; arrange for paid services and support; begin or review end-of-life care planning
Severe cognitive decline	Assist with more activities; approaching the need for significant care support
Very severe cognitive decline	Provide substantial help with most, if not all, daily activities; update end-of-life care planning

ROLES & DUTIES

Multiple Roles

- Care provider
- Care coordinator/case manager
- Medical and financial information resource
- Advocate
- Emotional supporter

Duties as a Care Provider

- Manage the household.
- Assist with daily tasks.
- Oversee taking of medications.
- Supervise activities/provide reminders.
- Identify help from home and community-based service providers.
- Deal with challenging behaviors such as wandering.
- Oversee others who provide paid and unpaid care.

Duties as a Care Coordinator/Case Manager

- Maintain accurate records.
- Keep track of appointments.
- Ask for help when needed.
- Work with paid case managers.

Duties as an Information Resource

- Keep track of prescriptions and diagnoses.
- Understand how care for one problem might affect others.
- Navigate insurance coverage and fill out forms.
- Manage finances.

Duties as an Advocate

- Determine goals of care.
- Talk with health care providers.
- Make the wishes of the person living with dementia known to everyone.
- Advocate within care facilities.
 - You can improve safety in hospitals and nursing homes by saying something if you see something dangerous.

Duties as an Emotional Supporter

- Encourage person living with dementia to keep active.
- Provide comfort and support.

USE AVAILABLE RESOURCES

Tools & Resources

- The Caregiver Readiness Tool* can help you decide on the best caregiving role for you.
- Other resources:

[Caregiver Assessment Tool](#)

[Caregiver Briefcase](#)

*Kane, R.L. and Ouellette, J. (2011). The Good Caregiver. New York, New York, Penguin Press.

The Caregiver Readiness Tool

Each potential caregiver should ask himself/herself the following questions:

Caregiver Readiness Questions	Yes	No
1. Am I physically able to provide the needed assistance? (Could I continue doing this work for weeks? Months? Years? Do I have physical limitations for the work involved?)		
2. Do my skills fit the profile of the tasks that need to be done?		
3. Am I prepared to perform intimate caregiving chores like bathing and helping with toileting?		
4. Think about the kinds of help your person living with dementia needs. Do I have the temperament to be a caregiver for a sustained period? (Will I become easily upset and angry? Am I able to stay calm and treat family members with patience and kindness even when I feel tired and overworked with the responsibilities of being a caregiver?)		
5. Can I free my schedule to be available when needed? (Can I free my schedule to be available at a moment's notice or for extended periods of time? Is my schedule flexible enough to provide help whenever needed?)		

The Caregiver Readiness Tool

Each potential caregiver should ask himself/herself the following questions:

Caregiver Readiness Questions	Yes	No
6. Can I afford to reduce or stop working? (Do I need to continue to work to meet my family's and my current or future financial needs?)		
7. Am I willing to reduce or neglect other obligations in order to give the care needed? (Do I have any roles or responsibilities that cannot be neglected?)		
8. Am I free of other people who already depend on my help (e.g., children, relatives)?		
9. Giving care will not unduly stress other family relationships, i.e., with my spouse or other family members?		
Caregiver Readiness Total (# of yeses in items 1-9)		

- These first 9 items that should be answered affirmatively if you are taking on caregiving.

The Caregiver Readiness Tool: Supports

Each potential caregiver should ask himself/herself the following questions:

Caregiver Protection Questions	Yes	No
10. How will I protect myself from getting so involved that I never take a break or get help? (Am I willing to ask for help if I need it? Is there help readily available for respite care? Do I have a list of contacts to ask for help when I need a break?)		
11. Would I be willing to purchase care to supplement the care I can give? (Do I have the financial resources to purchase supplemental care? Would I be willing to pay someone to help me provide the care that is needed?)		
12. Do the people around me support me in my decision? (Are they willing to share in some of the responsibilities? Do the important people in my life know about the caregiving responsibilities I am taking on? Do they agree with my taking that role?)		
Caregiver Protection Total (# of yeses in items 10-12)		

- Items 10 to 12 address ways of getting support to maintain caregiving.

The Caregiver Readiness Tool*: Other Issues

Each potential caregiver should ask himself/herself the following questions:

Questions that address the long-term effect of caregiving	Yes	No
13. Will giving care change my relationship with the older person?		
14. If I am unable to provide direct care, do the care recipient and I have the adequate financial resources to provide for the type of care that is needed?		

*Kane, R.L. and Ouellette, J. (2011). The Good Caregiver. New York, New York, Penguin Press.

CAREGIVER HEALTH

Take Care of Yourself

- Dementia care takes a heavy toll on your health.
- An ill caregiver cannot give good care.
- You may experience
 - Depression
 - Anxiety
 - Anger/frustration/guilt

Summary

- Dementia caregivers play many roles.
- Caregiving does not stop when a person living with dementia enters a new home.
- Staying healthy allows you to take better care of others.