After the Diagnosis: Care and Support

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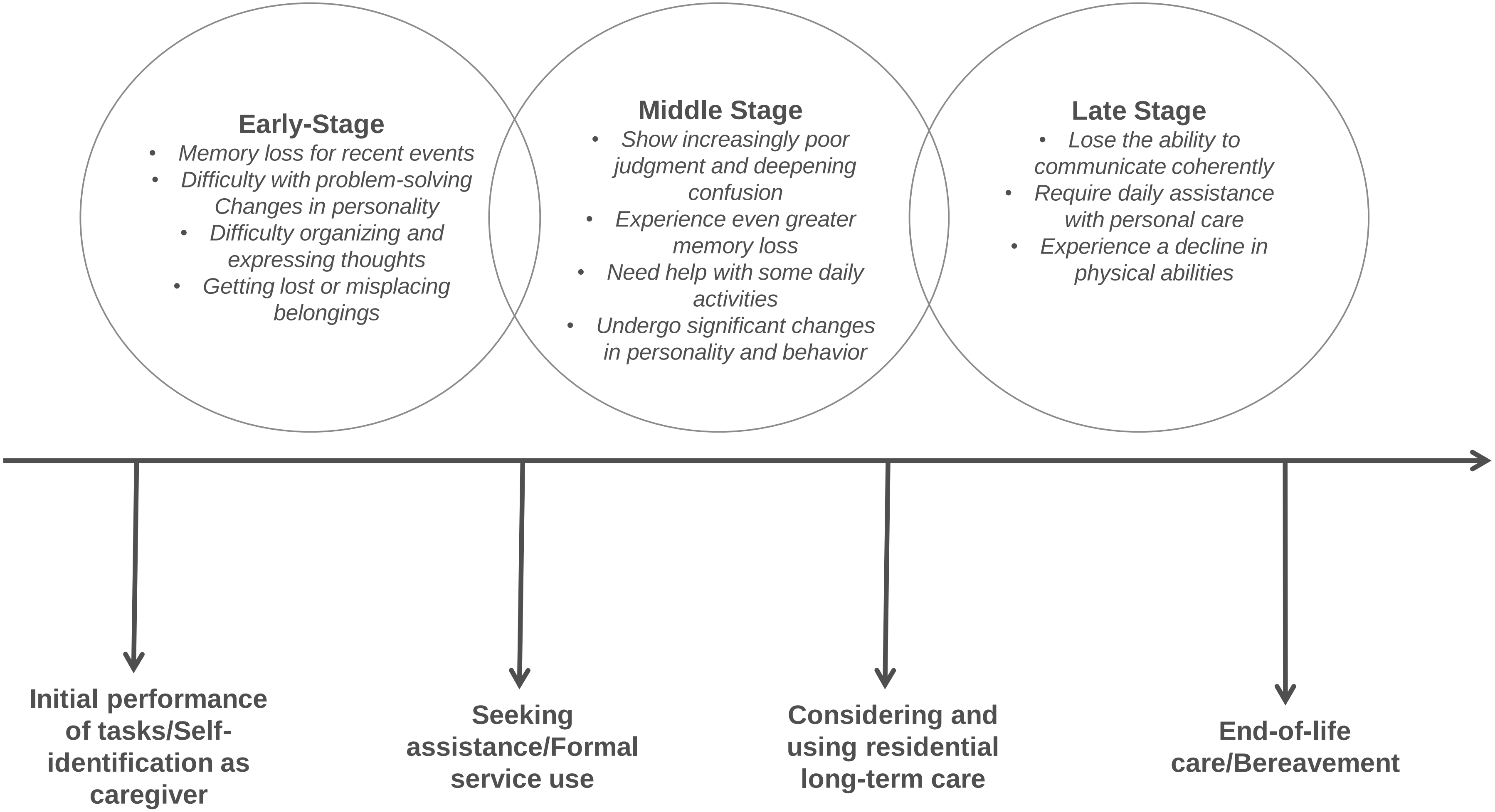
Background

- Provide an overview of resources and support that could help following the diagnosis transition
- Answer your questions (the best I can)



Early-Stage

- *Memory loss for recent events*
- *Difficulty with problem-solving Changes in personality*
- *Difficulty organizing and expressing thoughts*
- *Getting lost or misplacing belongings*

Middle Stage

- *Show increasingly poor judgment and deepening confusion*
- *Experience even greater memory loss*
- *Need help with some daily activities*
- *Undergo significant changes in personality and behavior*

Late Stage

- *Lose the ability to communicate coherently*
- *Require daily assistance with personal care*
- *Experience a decline in physical abilities*

Initial performance of tasks/Self-identification as caregiver

Seeking assistance/Formal service use

Considering and using residential long-term care

End-of-life care/Bereavement

Create a Care Plan

- Caregiving for Persons Living with Dementia
  - https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum

What Should Happen at a Diagnosis?

- What Should a Care Provider Do?
  - https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum

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 & Care Needs

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 & Care Needs

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

Working with the Healthcare Team

- https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum

Important Skills

Several skills will help you work well within the healthcare team.

- Be organized; make lists; take notes.
- Keep a watchful eye on any changes in behavior, or health of the person living with dementia.
- Persistently ask questions of the healthcare providers.
- Advocate for change if something is wrong, or you see room for improvement.

Skill 1: Organization

- Use a folder and/or computer for:
  - Continuously updating records
  - Tracking diagnoses, medications, and drug allergies
- To prepare for office visits:
  - Take notes/write down questions in advance.
  - Practice intended questions.
  - Send an e-mail to the healthcare provider.
  - Ask if you can record the visit on your cell phone.

Resources: Healthcare Provider Visits

- Discussing Your Concerns with Your Doctor: A Worksheet (National Institute of Health’s National Institute on Aging)

- Tips for Communicating with a Veteran’s Health Care Team (U.S. Department of Veterans Affairs)

Skill 2: Watchfulness

As the caregiver, you know the person living with dementia best.

- Identify any changes in health and report them immediately.
- Your input is especially important when care is provided in a new setting.

Skill 3: Persistence

Ensuring the best care possible means:

- Actively joining decision-making
- Receiving health updates
- Getting information on risks and benefits
- Getting answers to questions
- Dementia: What to Ask Your Doctor (National Institute of Health’s National Library of Medicine – Medline Plus)

Skill 4: Advocacy

In the best interest of the person living with dementia, you may need to choose a new healthcare provider.

- This is not easy.
- The clinic or other provider may enable a transfer.
- The right healthcare provider makes the caregiver’s job easier.

EARLY STAGE RESOURCES/SELF-IDENTIFICATION AS CAREGIVER

- The Wilder Foundation: What is a caregiver?
  - http://www.whatisacaregiver.org/

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.

Early-Stage Behaviors

Common behaviors in early stages of dementia include:

- Boredom and depression
- Personality and behavioral changes
- Complaints about memory
- Repeating questions

Managing Early-Stage Symptoms

To manage behaviors, you might try:

- Prevention
    - Maintain structure
    - Simplify the environment
    - Provide written reminders
    - Give positive reinforcement throughout the day
- Responding
    - Watch for frustration and provide reassurance
    - Avoid “testing” memory
    - Get depression treated, if present

EARLY STAGE RESOURCES/SELF-IDENTIFICATION AS CAREGIVER

- Community dementia programs
  - https://www.alz.org/mnnd/helping_you/programs_for_people_with_dementia

EARLY STAGE RESOURCES/SELF-IDENTIFICATION AS CAREGIVER

- The Alzheimer’s Disease Education and Referral Center
    - *Understanding Memory Loss* (https://order.nia.nih.gov/publication/understanding-memory-loss)
    - *Forgetfulness Age Page: Knowing When to Ask for Help* (https://order.nia.nih.gov/publication/forgetfulness-knowing-when-to-ask-for-help)
    - *What Happens Next? (Early-Stage Dementia Resource)* (https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis)
- Email lists/Newseltter
    - *National Institute on Aging* (https://www.nia.nih.gov/about/stay-connected)
    - *Perspectives* (http://adrc.ucsd.edu/news.html)
- Decision-Making Aid
    - *Alzheimer’s Disease: Should I Take Medications?* (https://www.healthwise.net/cochranedecisionaid/Content/StdDocument.aspx?DOCHWID=ty7566)
    - *Gene Test or Not?* (https://genetestornot.org/)

SEEKING ASSISTANCE/FORMAL SERVICE USE

- List of Dementia Clinics in Minnesota: Contact the Minnesota-North Dakota Chapter of the Alzheimer's Association: 952.830.0512
- ACT on Alzheimer's (http://www.actonalz.org/supporting-family-and-friend-caregivers)
  - *Understanding Stages and Symptoms of Alzheimer's Disease* (http://www.nia.nih.gov/alzheimers/topics/symptoms)
  - *The Basics: Memory Loss, Dementia, and Alzheimer's Disease* (http://training.alz.org/products/1016/the-basics-memory-loss-dementia-and-alzheimers-disease)
  - Alzheimer's disease at the Centers for Disease Control and Prevention (http://www.cdc.gov/aging/aginginfo/alzheimers.htm)
  - *The Alzheimer's Project* (HBO; http://www.hbo.com/alzheimers/)
  - *Caring for Mom & Dad* (PBS; http://www.pbs.org/wgbh/caringformomanddad/)
  - *Caring for a Person with Alzheimer's Disease* (https://order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide)
  - *Inside the Brain* visual tour of Alzheimer's disease, in multiple languages (http://www.alz.org/alzheimers_disease_4719.asp)

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