

alzheimer's association

# living with alzheimer's

## for caregivers

Part 2

caring  
making decisions  
safety  
connection  
daily strategies

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## Resources for care

Stephanie cared for her mother at home.

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## Options for care

In-home care

- Family and friends
- Paid care aides
- Visiting nurses
- Respite

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### Options for care

- Continuing care retirement communities / companion care services



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### Options for care

- Continuing care retirement communities / companion care services
- Residential care homes



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### Options for care

- Continuing care retirement communities / companion care services
- Residential care homes
- Long-term care
  - Memory care units
  - Nursing home care



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### The promise

*"I'll never put you in a nursing home –  
I promise."*

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### The promise



Mary O'Hara, LCSW, is a social worker at the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University's Feinberg School of Medicine.

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### Considering a move

- Families often consider a move to a facility for 24/7 care.
- Try involving others close to the person to help make decisions.
- Begin by visiting more than one care residence.

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### Facilitating a move

- Keep it brief and simple.
- Acknowledge your own feelings.
- Reassure the person by responding to his or her feelings rather than the content of what is being said.
- Redirect any upsetting thoughts.
- Team up with family, friends, and/or professionals.
- Seek counseling if needed.

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### Facilitating a move



Elizabeth Gould, LCSW, is Director of State Programs for the Alzheimer's Association's national office.

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### Adjusting to a move



- Set up the bedroom so it looks familiar.
- Bring in favorite comforting items from home.
- Changes are common, so monitor functioning.
- You are still a caregiver, but with more help now.
- Take care of yourself as well.

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### Monitoring care



- Mood
- Behavior
- Mental status

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### Powers of attorney and capacity

- Plans made at an earlier stage for powers of attorney may be used now.
- In the late stage, a person may be determined to be incapacitated, or unable to act on his or her own behalf.
- Physicians and the court determine incapacitation.

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### Guardianship

- Needed when:
  - The person with dementia is single.
  - The family cannot agree.
- Need:
  - A physician's statement.
  - A court hearing.



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### Efforts at life extension

- Mixed feelings are normal.
- Suffering can be avoided.
- Nutrition issues should be considered carefully.

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### Feeding tube consideration

- Tube feeding is sometimes suggested by medical staff when eating problems arise.
- Long-term tube feeding has no apparent advantages and a number of disadvantages.
- Assisted oral feeding is the preferred method of intervention for eating issues.

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### Hospice



- Provides care and comfort
- Includes:
  - Medical care
  - Equipment
  - Pain management/palliative care
  - Support services for families
- Can be provided in the home or in senior living settings
- Covered by Medicare

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### Myths about hospice/palliative care

- *Myth: Bringing in hospice means giving up on the person.*
  - **Reality: Hospice provides care and comfort for the entire family to help with the end of life once it is inevitable.**
- *Myth: Hospice will leave the person I care for drugged and unable to function.*
  - **Reality: Hospice will include palliative care so the person will get what is needed to manage pain. Newer treatments allow the pain to be controlled while not overly sedating the person.**

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### Hospice



Stephanie cared for her mother at home.

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### End-of-life

- Expect a mix of feelings:
  - Sadness
  - Exhaustion
  - Relief and guilt
- Discover a way to honor the person's spirit
- Call on others

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### End-of-life decisions

- Respecting end-of-life wishes
- Ensuring advance directives are in place
- Maintaining comfort and connection

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### The end-of-life experience



Melanie Chavin, is Vice President, Program Services at the Alzheimer's Association's Greater Illinois Chapter.

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### Grief

- Feeling a familiar yet new kind of loss is normal.
- Anticipatory grief may be followed by more traditional grief.
- Symptoms of grief include:
  - Periods of helplessness
  - Changes in appetite and sleep patterns
  - Anger and frustration
  - Social withdrawal

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## Contact us - we can help

- alz.org®**
  - Alzheimer's Navigator
  - Community Resource Finder
  - ALZConnected
  - Alzheimer's and Dementia Caregiver Center
  - Safety Center
- 800.272.3900**
  - 24/7 Helpline – Available all day every day
- alz.org/findus**
  - Support groups, education programs and more available in communities nationwide
- training.alz.org**
  - Free online education programs available at training.alz.org

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## Get involved


volunteer

advocate



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## Summary

- Options for care
- Monitoring care
- Legal capacity
- Hospice/palliative care
- End-of-life issues



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