

alzheimer's association

living with alzheimer's

for caregivers

Part 2

caring
making decisions
connection
daily strategies
safety

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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

WALK TO END ALZHEIMER'S

volunteer

THE LONGEST DAY

advocate

alzheimers association

trialnettv

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Summary

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



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