

# Family Dynamics and Coping with Alzheimer's Disease

Marty Richards, MSW, LICSW  
NW GWEC's ADRD series  
May 17, 2022

Identify family dynamics:  
roles, rules and secrets  
affecting “families” in  
living with dementia

Explore feelings  
experienced by “families”  
and PLWD in coping with  
dementia

Look at ways “families”  
and PLWD find meaning  
and purpose in coping  
with dementia

Explore strategies to assist families, and PLWD's build on strengths and to best work with care team

## Basic Assumptions

- ▶ Dementia is a "family disease."
- ▶ Stigma is felt by the PLWD and the family.
- ▶ Unique families define concerns in their own individual ways.

## More Assumptions

- ▶ The PLWD and their family deserve to be treated with respect and dignity.
- ▶ The “frail” have much to teach the “well”.
- ▶ Change is constant.

## More Assumptions

- ▶ Persons may be at different places along the family developmental cycle.
- ▶ An effective tool for one situation may not work for another.

## More Assumptions

- ▶ Families have strengths and concerns.
- ▶ Carers build on resiliency and reciprocity.
- ▶ Each family has a cultural/diverse perspective.

Family and professional carers need to be aware of their own experiences in dealing with “family” and dementia.

Awareness of diverse groups is important:

- Health disparities
- Cultural commitment to care
- Their group's experience with health care

## Concerns of Families

These vary depending on

- The person with dementia
- The family system
- The progression of the dementia process
- The resources available

## Concerns of Families

- ▶ Often steeped in family dynamics
- ▶ Can be culturally determined
- ▶ Affect mentation, medication, meaning and mobility.

## A CareSharing Approach

- ▶ Person receiving care +
- ▶ Person receiving care=
- ▶ CARE PARTNERS

# Family Dynamics

- ▶ Roles
- ▶ Rules
- ▶ Secrets
- ▶ Responsibilities

## Roles

- ▶ May be culturally specified
- ▶ Are functional or relational
- ▶ Develop early in life and remain even when not helpful



## Roles

- ▶ May predict how a PLWD with dementia “fits in.”
- ▶ Naming roles may assist families.
- ▶ Sharing roles lifts some of the stresses experienced.

**Maintaining the role of “family member” for the person with dementia is KEY.**

## Rules

- ▶ Govern how families operate
- ▶ Are deeply rooted in religion, culture, and societal values
- ▶ “Reframing” can be useful.

## Secrets

- ▶ All families have them.
- ▶ Some are hidden for years.
- ▶ Old secrets may not be today’s secrets.
- ▶ Shame may exist around secrets.

## Secrets

- ▶ Understanding that secrets exist may keep them from “boiling up.”
- ▶ Acknowledging secrets can offer opportunities for forgiveness and working on “unfinished business.”

## Responsibilities

- ▶ Families constantly balance responsibilities.
- ▶ Each family works out its own equilibrium.
- ▶ Conflicts can exist between work and home.

## Responsibilities

- ▶ Issues come up between generations.
- ▶ Competing responsibilities can overwhelm persons.
- ▶ Benefits exist in aiding families to evaluate and make choices.

## Family Feelings

- ▶ Exist for the PLWD and family.
- ▶ Need to be acknowledged and named.
- ▶ May underlie some “unreasonable” demands

## Family Feelings

- ▶ Sadness
- ▶ Fear
- ▶ Anger
- ▶ Guilt

## Family Feelings

- ▶ Helplessness
- ▶ Hopelessness
- ▶ Powerlessness
- ▶ Ambivalence

## Family Feelings

- ▶ Are not “bad” or “good;” they are.
- ▶ Naming them may lessen negative impact.
- ▶ Sharing assists persons feel less alone.

## It is Also Possible to Share

- ▶ Laughter
- ▶ Love
- ▶ Joy
- ▶ The “spiritual”

## Assess Family Relationships

- ▶ Do long term positive family interactions exist?
- ▶ Is there history of conflicted relationships?
- ▶ What are the family strengths? Who are supports?

## Assess Family Relationships

- ▶ With whom does the PLWD and the family feel comfortable sharing about the illness and repercussions?

## Assess Family Relationships

- ▶ What has worked in the past that could be used now?
- ▶ What new skills could they learn?
- ▶ What is the best way to offer assistance?

## Ethical Dilemmas For the Family

- ▶ Revolve around “quality of life”
- ▶ What to tell...who to tell of the diagnosis/functional concerns



“Quality of life” has many meanings. Each person has a unique definition. It is important to know how a PLWD and their family perceive this.

## More Ethical Dilemmas

- ▶ Safety vs. autonomy
- ▶ Driving
- ▶ Decision making challenges
- ▶ Bounded choices

## Goals for Helping Families Cope:

- ▶ Change from a “crisis mentality” to a “comforting presence.”
- ▶ Small steps can move from “stigma and stagnation” to “well-being.”

## More Goals

- ▶ Entire family is the “unit of service”
- ▶ The PLWD has an important family role.

## Strategies for Assisting Families

- ▶ Utilize the gifts of all ages to keep the family functioning.
- ▶ Assist in negotiating barriers to service provision.

## Strategies

- ▶ Build on the internal resources of a family.
  - Sense of humor
  - Faith
  - Good communication
  - "True Grit"

## Strategies

- ▶ Teach limit setting.
- ▶ Model effective communication.
- ▶ Stress contingency planning.

## Strategies

- ▶ Build on “community” to support families
- ▶ Use realistic hope with the family, and keep hope alive in yourself.

## Strategies

- ▶ Make intentional use of spiritual support.
- ▶ Assist persons to have success in small increments.

## Strategies

- ▶ Offer realistic support.
- ▶ Build on coping skills that work for a family.
- ▶ Help develop new skills.
- ▶ Utilize education.

## Tools for Assisting

*Partnering with Your Healthcare Provider: A Resource for People Living with Memory Problems and their Care Partners (2022)*

Dementia Action Collaborative, Dementia and Palliative Education Network in partnership with Alzheimer's Association & UW School of Nursing

## Tools

*Dementia Legal Planning Project*  
*[www.dementialegalplanning.org](http://www.dementialegalplanning.org)*

Dementia Action Collaborative funded by the Aging & Long Term Support Administration/DSHS

## Creative Ways to Share

- ▶ Music
- ▶ Art
- ▶ Stories
- ▶ Poetry
- ▶ Connection to Faith Community

## Resources

- ▶ Bell, Virginia & Troxel, David. (2012). *A Dignified Life, Revised and Expanded: The Best Friends Approach to Alzheimer's Care: A Guide for Care Partners*. Baltimore: Health Professions Press.
- ▶ Boss, Pauline. (2011). *Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief*. San Francisco: Jossey-Bass.

- ▶ Dementia Action Collaborative. (2018). *Dementia Road Map: A Guide for Family and Care Partners*. [www.dshs.wa.gov/altsa/dementia-action-collaborative](http://www.dshs.wa.gov/altsa/dementia-action-collaborative).
- ▶ Diverse Elders Coalition. (March 2021). *Caring for Those Who Care: Resources for Providers: Meeting Needs of Diverse Family Caregivers*. [www.diverseelders.org/caregiving](http://www.diverseelders.org/caregiving).

## Creative Resources

- ▶ Alzheimer's Poetry Project  
[alzpoety.blogspot.com](http://alzpoety.blogspot.com)
- ▶ Freye Museum: "here-now"  
[http://freyemuseum.org/here\\_now](http://freyemuseum.org/here_now) programs
- ▶ Jewish Federation & Community Services of Boston (2017). *Starting Your Memory Café: A Tour Through the Toolkit*.  
<https://www.action.org/sites/files/documents>



- ▶ Modern Museum of Art: [www.moma.org/meet](http://www.moma.org/meet)  
me
- ▶ Time Slips [www.timeslips.org](http://www.timeslips.org)