

Lessons Learned

**20+ Years
Behind The Scenes of
Dementia Care Decisions**

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Background

Weekly Meetings at Memory Care Communities in San Diego over 20 years

- Dementia knows no barriers
- Caregivers come in all shapes and sizes
- Human nature prevails
- Isolation and acceptance
- If you've met one, you've met one
- Every problem has a solution

*Thousands of stories from families just like yours
The struggles, the guilt, the realizations, and the relief*

Lessons Learned

Caregivers

Drafted By Circumstances

- Caregiving is not a universal trait
- Timing/Location not always the best
- You are NOT alone
- Seek out support
- You come first—you are the most important member of the team

Lessons Learned

Dementia Knows No Barriers

- Education
- Ethnicity
- Gender
- Age Range is Expanding
- Economic Status

Human Nature is a Strong Force

- Independence–Autonomy
- Honoring parents'/elders' wishes
- I promised my husband, mother, father...
- They are OK for now (denial)
 - ✓ Is it safe?
 - ✓ Could it be better?
 - ✓ What could go wrong?
 - ✓ Risk vs. confrontation

Guilt & Denial

- Suppresses important information
- Paralyzes progress
- Pushes away solutions
- Builds up—Blows up

Guilt and Denial

The Danger Zones

- Isolation—“Use it or lose it”
- Safety risks at home
 - ✓ Stoves/mechanical equipment
 - ✓ Steps & stairs
 - ✓ Furniture
 - ✓ Medications
 - ✓ Wandering
 - ✓ Scams/financial abuse

Breaking Through

- Ask a trusted friend for an honest assessment
 - “Give it to me straight”
- Get a second opinion—take it to heart
- Ask for help—make a few small decisions
- Create a plan and move forward

Warning Signs: Caregiver Burnout

Physical Health

- Caregiver's health begins to decline
- Risks of injury arises: lifting, transferring, combativeness, violence

Emotional Toll

- Resentment and anger are present all of the time
- Feelings of hopelessness, chronic fatigue and depression become routine

Warning Signs: Environment

The current living environment and the surroundings are no longer safe for the person with dementia:

- Stairs
- Exit seeking/gates/elopement
- Gas stoves/open flames
- Trip hazards

Warning Signs: Delusions

Profound memory loss and hallucinations

- No longer recognize spouse/family members
- Frightened by living in a home
- Increased paranoia or combativeness

When Placement is the Next Step: What to Look For

- Designed for residents with dementia and memory loss
- An engaging activity program with participatory programs throughout the entire day
- Staff receives a higher level of training and support
- Nurses on staff 24 hours a day to evaluate/assess when there is a change of condition
- Physical plant is designed to be safe and secure to prevent wandering and resident injuries

Words of Wisdom

- Relief comes in seeking/accepting help
- Be kind to yourself
- Don't test or quiz
- Name the negative—"It's the disease"
- Little white lies—save the soul
- You are worthy & deserving of a break/time
- Don't question the past
- Look ahead & plan for change

Resources

ActivCare Communities

ActivCareLiving.com

(888) MEM-LOSS

(888) 636-5677

Family Caregiver

Resource Center

CaregiverOC.org

(800) 543-8312

Alzheimer's Orange County

alzoc.org

(844) HELP-ALZ

(844-435-7259)

Alzheimer's Association

alz.org

(800) 272-3900