Don’t Go It Alone:
HEALTHY CAREGIVING, COMMUNITY AND CONNECTION

Philip Choe, D.O.
A Patient’s Story

“It didn’t seem like there was anything that anybody could do for him…I was doing all the house and yard work and taking care of him…this was very hard for me.”

Mrs. D: “I could not stand another 24 hours… I asked my husband more than once, wouldn’t he like some of those people to come in and help him? She thought she was responsible to do just about all of the caretaking… She did the parent thing of don’t worry the kids about how bad off maybe Dad is, or how she was feeling…”

Dr: “The suicide attempt was originally precipitated by years of caregiver burden… Mrs. D stated that she was planning this for 2 years. Every day when she thought about committing suicide… that made her feel better that she had an option.”

Daughter: “She thought she was responsible to do just about all of the caretaking… She did the parent thing of don’t worry the kids about how bad off maybe Dad is, or how she was feeling…”
The Invisible Patient

- Suffering in silence
- “Yes…but” syndrome
- No medical code
Caregiving

- Process of caring for another person's health needs
- 65% are women
- 26% are 65 years old and older
- In 2017: 16.1 million family members and friends provided 18.4 billion hours of unpaid care to people with dementia
  - 86% providing care for 1 year
  - 50% providing care for 4+ years

Alzheimer’s Impact Movement Fact Sheet March 2018. alzimpact.org
Caregivers

- **Informal**: unpaid family members or friends
- **Formal**: privately hired workers who are paid for out of pocket or by agency employed workers funded by private insurance, public payers, or long term care insurance
  - NO enteral feeds
  - NO medication administration
  - Must have some supervision by visiting nurses
Aging in the United States

The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050

- Age 65+
- Age 65 - 74
- Age 75 - 84
- Age 85+

Number of Individuals

2012 2032 2050

Caregiver Support Ratio, United States

- Boomers turn 45
- Boomers turn 85
- Boomers turn 80

Source: AARP Public Policy Institute calculations based on RSMI (Regional Economic Models, Inc.) 2013 baseline demographic projections.
Note: The caregiver support ratio is the ratio of the population aged 45-64 to the population aged 80 plus.
Role of Caregivers

- Assist with Instrumental Activities of Daily Living (IADL)
  - Grocery shopping/Meal preparation
  - Transportation
  - Finances
  - Household chores
- Assist with Activities of Daily Living (ADL)
  - Bathing
  - Dressing
  - Eating
  - Transferring
  - Toileting
Caregiver Outcomes

- **Positive Outcomes**
  - Sense of personal accomplishment
  - Fostering family togetherness
  - Satisfaction of helping others

- **Negative Outcomes**
  - Stress/burden
  - Anxiety (new or increased)
  - Sleep deprivation/disruption of good sleep hygiene
  - Depression
  - Social isolation
  - Declining health
  - Financial hardship
Caregiver Stress/Burden

- Unequal exchange of assistance among people who stand in close relationship to one another resulting in emotional and physical stress on the caregiver.
- The burden is inversely related to cognitive function.
- Burnout lead to dire outcomes.
The Cost of Caregiving

- 77% of caregivers missed time from work
- 52% of caregivers had to work fewer hours
- 11% of caregivers lost their jobs due to providing care
2017 Annual Cost of Care in San Jose

- Home Health Aide: $68,526
- Adult Day Health Care: $25,480
- Assisted Living Facility: $57,900
- Nursing Home (NH): $107,675
- NH – Private Room: $148,738

In Texas...
- Home Health Aide: $45,760
- Adult Day Health Care: $9,100
- Assisted Living Facility: $42,000
- Nursing Home (NH): $54,750
- NH – Private Room: $72,635

Genworth.com/aging-and-you/finances/cost-of-care.html
Caregiver Burden Risk Factors

- Female gender
- Low educational attainment
- Residing with care recipient
- Depression
- Social isolation
- Higher number of hours spent caregiving
- Lack of choice in being a caregiver
Clinical Outcomes of Caregiver Burden

- Depression/Anxiety
- Social isolation
- Elevated blood pressure (hypertension)
- Reduced immune function
- Increased risk of Coronary Heart Disease (CHD) for women
  - Caregiving to a disabled/ill spouse ≥ 9hrs/wk*

Emotional Impacts of Caregiving

- High level of stress: 31%
- Negative impact on relationship with family, spouse: 35%
- Depression, mood swings and resentment: 41%
- Negative impact on health and well-being: 43%

Self-Assessment

- Zarit Burden Assessment
Be Proactive!

- Be informed
- Keep your love ones involved
- Stay connected
<table>
<thead>
<tr>
<th>Stage</th>
<th>Stage Name</th>
<th>Characteristic</th>
<th>Expected Untreated AD Duration (months)</th>
<th>Mental Age (years)</th>
<th>MMSE (score)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Normal Aging</td>
<td>No deficits whatsoever</td>
<td>--</td>
<td>Adult</td>
<td>29-30</td>
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<tr>
<td>2</td>
<td>Possible Mild Cognitive Impairment</td>
<td>Subjective functional deficit</td>
<td>--</td>
<td></td>
<td>28-29</td>
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<tr>
<td>3</td>
<td>Mild Cognitive Impairment</td>
<td>Objective functional deficit interferes with a person’s most complex tasks</td>
<td>84</td>
<td>12+</td>
<td>24-28</td>
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<tr>
<td>4</td>
<td>Mild Dementia</td>
<td>IADLs become affected, such as bill paying, cooking, cleaning, traveling</td>
<td>24</td>
<td>8-12</td>
<td>19-20</td>
</tr>
<tr>
<td>5</td>
<td>Moderate Dementia</td>
<td>Needs help selecting proper attire</td>
<td>18</td>
<td>5-7</td>
<td>15</td>
</tr>
<tr>
<td>6a</td>
<td>Moderately Severe Dementia</td>
<td>Needs help putting on clothes</td>
<td>4.8</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>6b</td>
<td>Moderately Severe Dementia</td>
<td>Needs help bathing</td>
<td>4.8</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>6c</td>
<td>Moderately Severe Dementia</td>
<td>Needs help toileting</td>
<td>4.8</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6d</td>
<td>Moderately Severe Dementia</td>
<td>Urinary incontinence</td>
<td>3.6</td>
<td>3-4</td>
<td>3</td>
</tr>
<tr>
<td>6e</td>
<td>Moderately Severe Dementia</td>
<td>Fecal incontinence</td>
<td>9.6</td>
<td>2-3</td>
<td>1</td>
</tr>
<tr>
<td>7a</td>
<td>Severe Dementia</td>
<td>Speaks 5-6 words during day</td>
<td>12</td>
<td>1.25</td>
<td>0</td>
</tr>
<tr>
<td>7b</td>
<td>Severe Dementia</td>
<td>Speaks only 1 word clearly</td>
<td>18</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>7c</td>
<td>Severe Dementia</td>
<td>Can no longer walk</td>
<td>12</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>7d</td>
<td>Severe Dementia</td>
<td>Can no longer sit up</td>
<td>12</td>
<td>0.5-0.8</td>
<td>0</td>
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<tr>
<td>7e</td>
<td>Severe Dementia</td>
<td>Can no longer smile</td>
<td>18</td>
<td>0.2-0.4</td>
<td>0</td>
</tr>
<tr>
<td>7f</td>
<td>Severe Dementia</td>
<td>Can no longer hold up head</td>
<td>12+</td>
<td>0-0.2</td>
<td>0</td>
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</table>
## Physician Orders for Life-Sustaining Treatment (POLST)

A. **Cardiopulmonary Resuscitation (CPR):** Patient has no pulse and is not breathing.
- [ ] Attempt Resuscitation (CPR)
- [ ] Do Not Attempt Resuscitation (DNR)

B. **Medical Interventions:** If patient has pulse and/or is breathing.
- [ ] Comfort Measures Only (Allow Natural Death). Provide pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction, and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.
- [ ] Limited Additional Interventions in addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit.
- [ ] Full Treatment: In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital or other invasive care unit if indicated. Treatment Plan: Full treatment including life support measures in the intensive care unit.

C. **Artificially Administered Nutrition:** Offer food by mouth if feasible.
- [ ] No artificial nutrition by tube
- [ ] Defined trial period of artificial nutrition by tube
- [ ] Long-term artificial nutrition by tube

D. **Documentation of Discussion:**
- [ ] Patient (Patient has capacity)
- [ ] Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)
- [ ] Parent of minor
- [ ] Court-Appointed Guardian

E. **Signature of Patient or Surrogate:**
- Signature:
- Name (print):
- Relationship (write “self” if patient)

This form will be sent to the POLST Registry unless the patient wishes to opt out. If so, check opt out box.

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**Signature of Physician / NP / PA:**
- My signature below indicates that I have reviewed these orders with the patient and that the patient was capable of making an informed decision.
- **Physician / NP / PA Name:** required
- **Signer Phone Number:**
- **Signer License Number (professional):**
- **Date:** required
- **Office Use Only:**
Advance Directives **AND** Physician Order for Life-Sustaining Treatment (POLST)

<table>
<thead>
<tr>
<th>Advance Directive</th>
<th>POLST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legal document</td>
<td>Medical order</td>
</tr>
<tr>
<td>Outline of treatment preferences</td>
<td>Executes the treatment preferences</td>
</tr>
<tr>
<td>Multi-page document</td>
<td>One page document</td>
</tr>
<tr>
<td>Appoints a surrogate</td>
<td>Lists the surrogate</td>
</tr>
<tr>
<td>Not used by EMS</td>
<td>Used by EMS</td>
</tr>
</tbody>
</table>
Stay Connected!

- Caregiving burden has been found to be reduced with the following:
  - Strong communication with medical providers
  - Support of an interdisciplinary team
  - Involvement of educational programs and caregiver support groups
Geriatric Team Model

- Geriatrician
- Clinical Nurse Specialist/Nurse Practitioners
- Social Worker
- Pharmacist
- Physical Therapist
- Optometrist
- And more!
Geriatric Team Goals

- Incorporate the needs and preferences of both care recipient and the caregiver in all planning
- Improve caregivers’ understanding of their role
- Create an individualized and coherent plan together with other medical providers
Support Groups

- Modest size groups involving education and training have greater effects on caregiver burden.
- Psychoeducational groups are more effective at improving caregiver’s psychological well-being and depression.
- Structured groups with accompanying manuals often achieve higher effects.
- Consistent attendance with at least 8 weeks had more positive effects.
- Interdisciplinary group leaders were associated with a significantly higher effect.

DICE

D  escribe
I  nvestigate
C  reate
E  valuate
Caring For Yourself...So You Can Care For Others

You may feel:

- You should be able to do everything yourself
- That it’s not all right to leave the person with someone else
- No one will help even if you ask
- You don’t have the money to pay someone to watch the person for an hour or two

EVERYONE needs help

- It’s okay to ask help from family, friends
- Ask people to help out in specific ways (like making a meal, visiting, etc)
- Call for help from home health care or adult day care services
Resources: Start Here

- Alzheimer’s Association: [www.alz.org](http://www.alz.org)
- Family Caregiving Alliance: [www.caregiver.org](http://www.caregiver.org)
- National Institute on Aging Alzheimer’s Disease Education Center: [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)