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."

Adelman RD, et al. Caregiver burden: A clinical review. JAMA. 2014;311(10): 1052-1059.

Perspectives

Mrs. D: "I could not stand another 24 hours
husband mo
wouldn't
those p
help hi
things li

Daughter: "She thought she was responsible to…do just about all
of the caretaking…She did the
f don't worry the
l off maybe
feeling…"

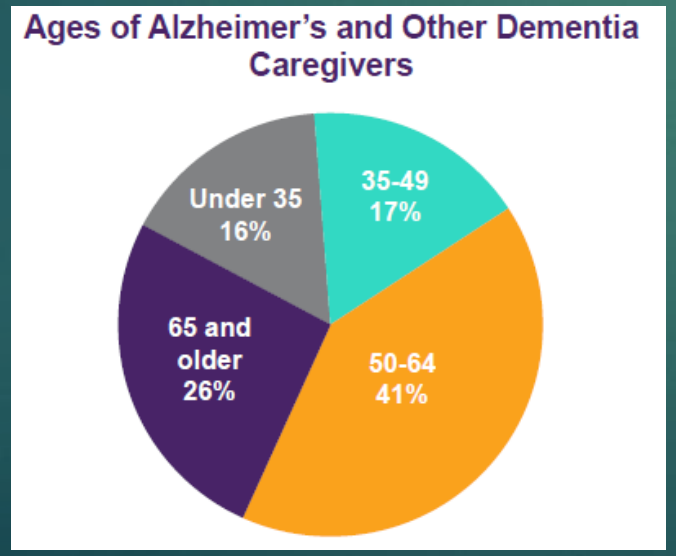
Dr: "The suicide attempt was originally precipitated by years of caregiver burden…Mrs. D stated that she was planning this for 2years. Every day when she thought about committing suicide…that made her feel better that she had an option."

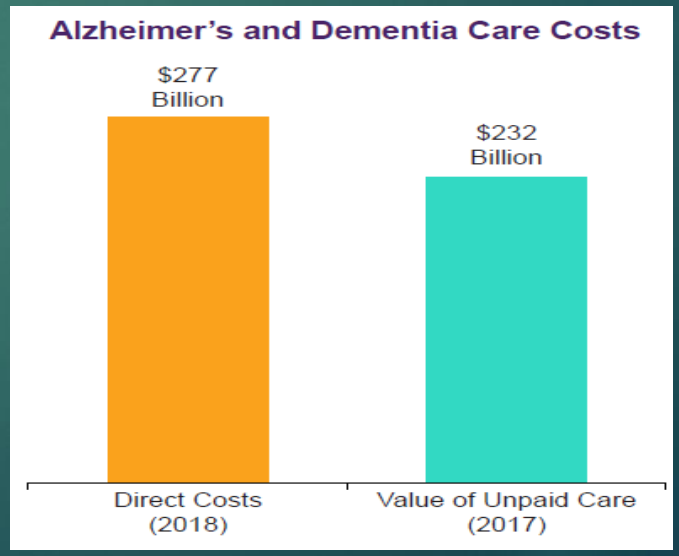
The Invisible Patient

- 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



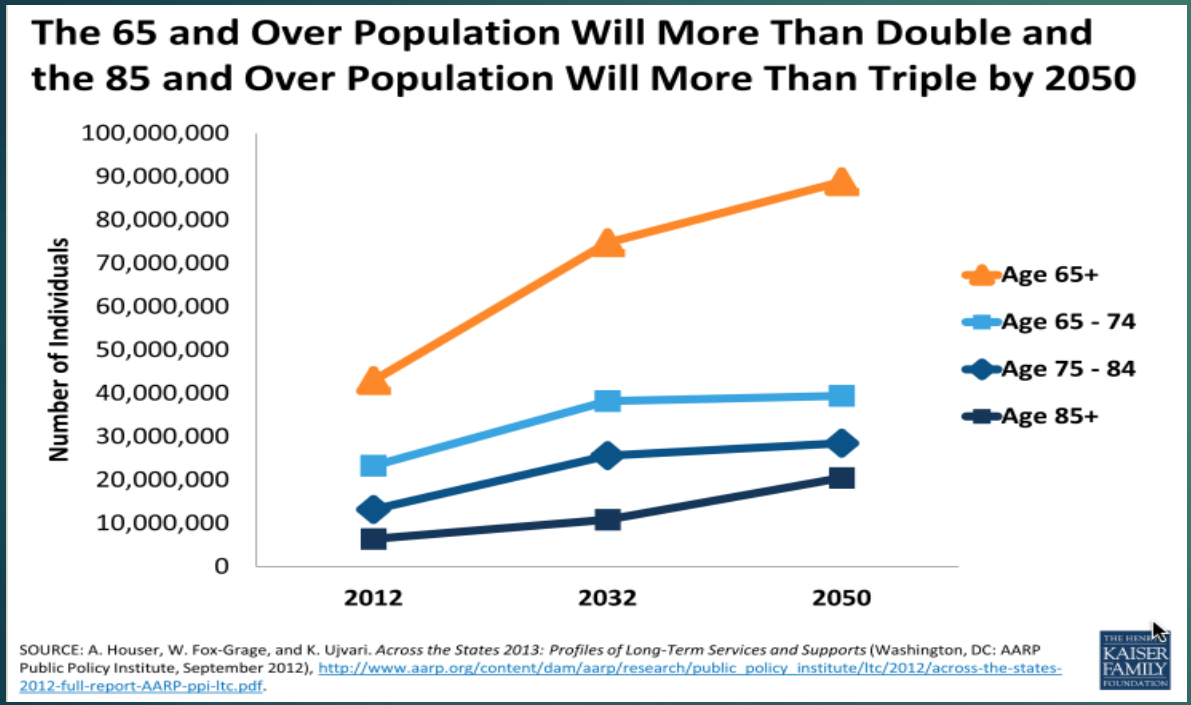


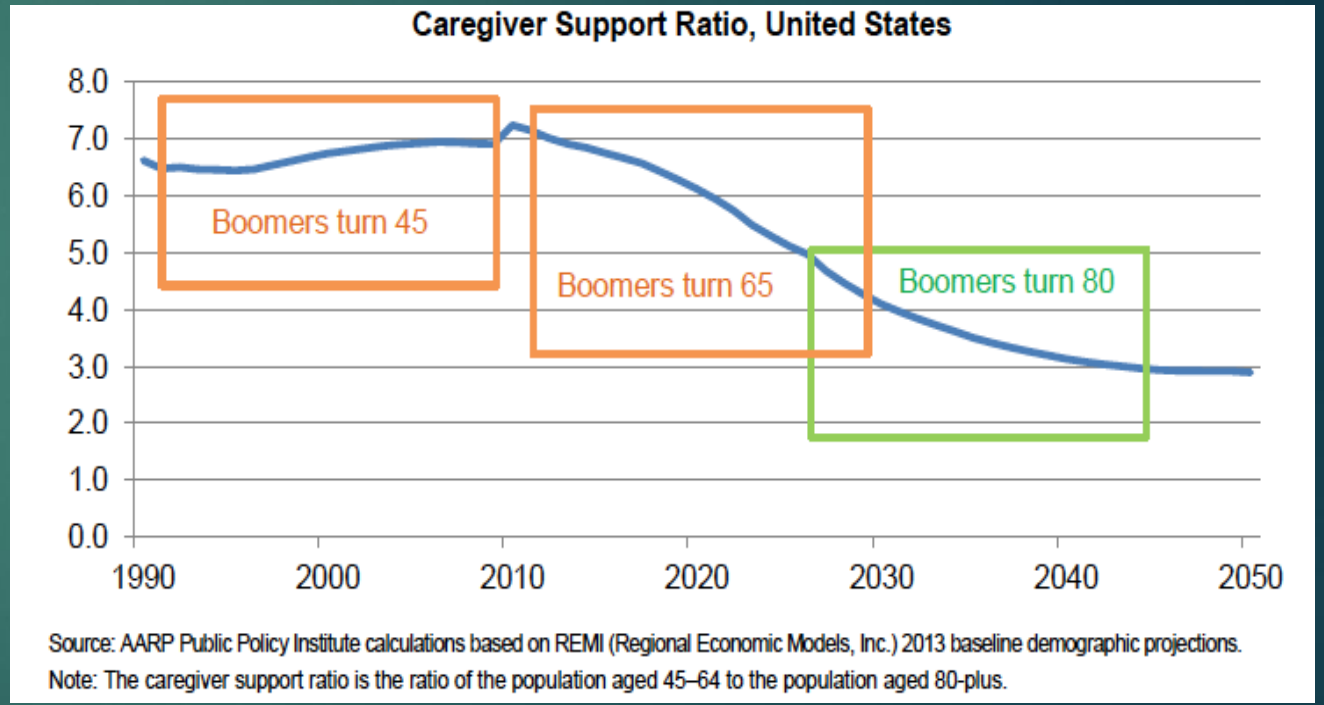
Alzheimer's Impact Movement Fact Sheet March 2018. alzimpact.org

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





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

https://pro.genworth.com/riiproweb/productinfo/pdf/157453C.pdf

2017 Annual Cost of Care in San Jose

		In Texas…
Home Health Aide:	$68,526	$45,760
Adult Day Health Care:	$25,480	$9,100
Assisted Living Facility:	$57,900	$42,000
Nursing Home (NH):	$107,675	$54,750
NH – Private Room:	$148,738	$72,635

Genworth.com/aging-and-you/finances/cost-of-care.html

Caregiver Burden Risk Factors

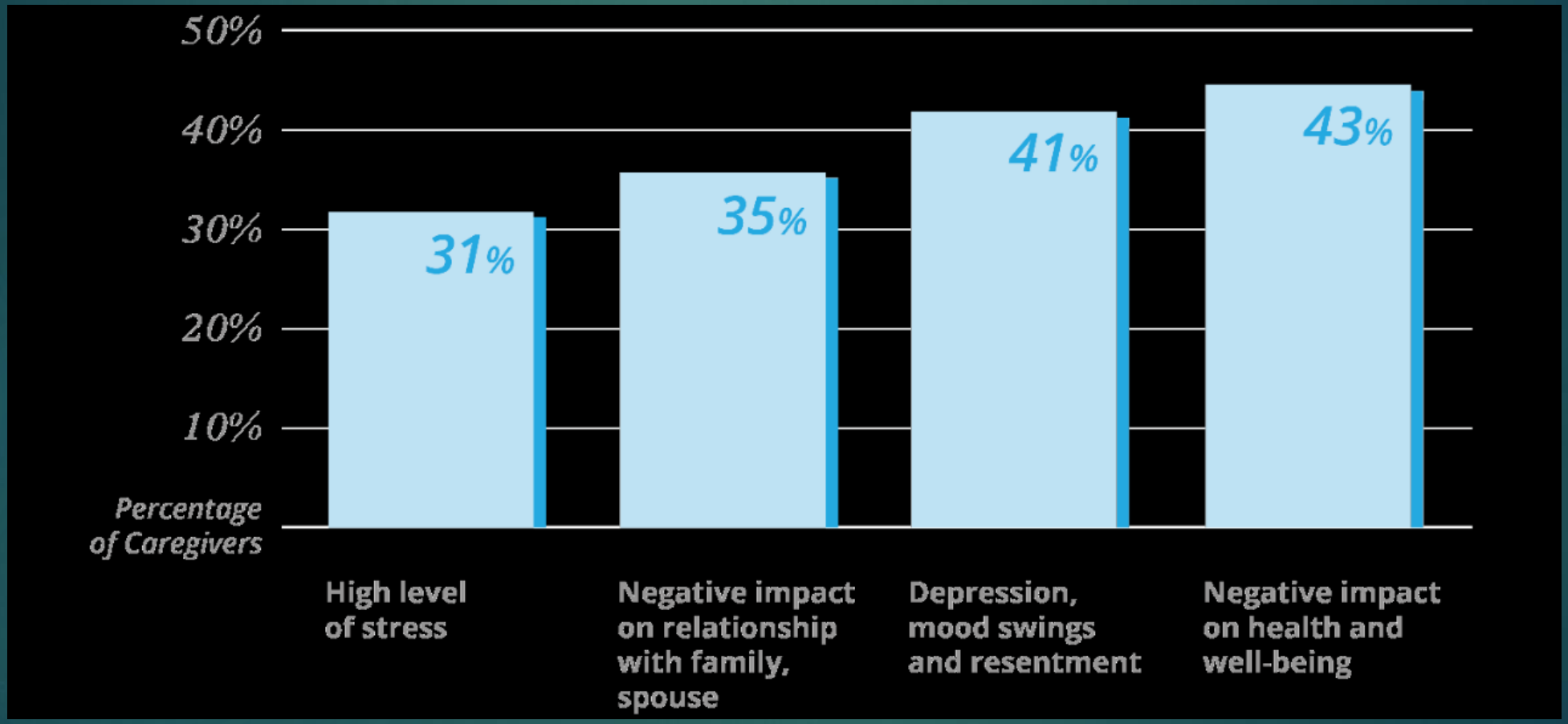
- Female gender
- Low educational attainment
- Residing with care recipient
- Depression
- Social isolation
- Higher number of hours spent caregiving
- Lack of choice in being a caregiver

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*

*Lee S, Colditz G, et al. Caregiving and risk of coronary heart disease in US women: a prospective study. Am J Prev Med. 2003;24(2):113-119.

Emotional Impacts of Caregiving



https://www.genworth.com/aging-and-you/family/caregiving.html

Self-Assessment

- Zarit Burden Assessment

CAREGIVER STRESS SELF-ASSESSMENT

(Dr. Steven Zarit, modified version)

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

QUESTIONS: "Do you feel...	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. ...that your loved one asks for more help than he/she needs?					
2. ...that because of the time you spend with your loved on that you don't have enough time for yourself?					
3. ...stressed between caring for your loved one and meeting other family or work responsibilities?					
4. ...embarrassed over your loved one's behavior?					
5. ...angry when you are around your loved one?					
6. ...that caring for your loved one currently affects your relationship with other family members or friends in a negative way?					
7. ...afraid of what the future holds for your loved one?					
8. ...your loved one is dependent on you?					
9. ... your health has suffered because of your involvement with your loved one?					
10. ... that you don't have as much privacy as you would like because of your loved one?					
11. .... that your social life has suffered because of you are caring for your loved one?					
12. ... uncomfortable about having friends over because you are caring for your loved one?					
13. .... that your loved one seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
14. ... that you don't have enough money to care for your loved one in addition to the rest of your expenses?					
15. ... that you will be unable to take care of your loved one much longer?					
16. ... you have lost control of your life?					
17. .... you want to leave the care of your loved one to someone else?					
18. ... you should be doing more for your loved one?					
19. .... you could do a better job in caring for your loved one?					
20. .... burdened caring for your loved one?					
Total responses per column					
Multiply total by scale (Never = 0, Rarely = 1, Sometimes = 2, Quite Frequently = 3 Nearly always = 4					
Grand total:					

SCORING: 0-20 = Little/No Stress 21-40 = Mild/Moderate Stress
41-60 = Moderate/Severe Stress 61-80 = Severe Stress

Be Proactive!

- Be informed
- Keep your love ones involved
- Stay connected

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

https://www.grepmed.com/images/631/functionalassessmentstagingtest-assessment-functional-alzheimers-palliative-geriatrics-diagnosis

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Physician Orders for Life-Sustaining Treatment (POLST)

Follow these orders until orders change. These medical orders are based on the patient's **current** medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.
Guidance for Health Care Professionals.
http://www.ohsu.edu/polst/programs/documents/Guidebook.pdf

Patient Last Name:	Patient First Name	Middle Int
Date of Birth: (mm/dd/yyyy)	Gender: ☐ M ☐ F	Last 4 SSN: ☐☐☐☐
Address: (street / city / state / zip)		

A — Cardiopulmonary Resuscitation (CPR): *Patient has no pulse and is not breathing.*

Check One

- ☐ **Attempt Resuscitation/CPR**
- ☐ **Do Not Attempt Resuscitation/DNR**

When not in cardiopulmonary arrest, follow orders in **B** and **C**.

B — Medical Interventions: *If patient has pulse and/or is breathing.*

Check One

- ☐ **Comfort Measures Only** (**A**llow **N**atural **D**eath). Relieve 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.*** **Treatment Plan: Maximize comfort through symptom management.**
- ☐ **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.*** **Treatment Plan: Provide basic medical treatments.**
- ☐ **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 and/or intensive care unit if indicated.*** **Treatment Plan: Full treatment including life support measures in the intensive care unit.**

Additional Orders: _____

C — Artificially Administered Nutrition: *Offer food by mouth if feasible.*

Check One

- ☐ No artificial nutrition by tube.
- ☐ Defined trial period of artificial nutrition by tube.
- ☐ Long-term artificial nutrition by tube.

Additional Orders: _____

D — Documentation of Discussion:

- ☐ Patient (Patient has capacity)
- ☐ Parent of minor
- ☐ Court-Appointed Guardian
- ☐ Health Care Representative or legally recognized surrogate
- ☐ Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)
- ☐ Other _____

Signature of Patient or Surrogate

Signature: ***recommended***	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 ☐

E — Signature of Physician / NP/ PA

My signature below indicates to the best of my knowledge that these orders are consistent with the patient's **current** medical condition and preferences.

Print Signing Physician / NP / PA Name: ***required***	Signer Phone Number:	Signer License Number: *(optional)*
Physician / NP / PA Signature: ***required***	Date: ***required***	Office Use Only

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED. SUBMIT COPY TO REGISTRY

Advance Directives **AND** Physician Order for Life-Sustaining Treatment (POLST)

Advance Directive	POLST
Legal document	Medical order
Outline of treatment preferences	Executes the treatment preferences
Multi-page document	One page document
Appoints a surrogate	Lists the surrogate
Not used by EMS	Used by EMS

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 w/ accompanying manuals often achieve higher effects
- Consistent attendance with at least 8 weeks had more positive effects
- Interdisciplinary group leaders were associated w/ a significantly higher effect

Chien LY, et al. Caregiver support groups in patients with dementia: a meta-analysis. Int J Geriatr Psychiatry. 2011; 26(10):1089-1098

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
- Family Caregiving Alliance: www.caregiver.org
- National Institute on Aging Alzheimer's Disease Education Center: www.nia.nih.gov/alzheimers