

The Role of A Patient Advocate

A glimpse of a caregiver's life

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Today's Goals:

- Introduce the Geriatric team approach
- Review the concepts surrounding Long Term Care
- Discuss how one can be a Patient Advocate
- Discuss the caregiver's role during hospital discharge

Geriatric Team Model

- Geriatrician
- Clinical Nurse Specialist/Nurse Practitioners
- Social Worker
- Pharmacist



By The Numbers...

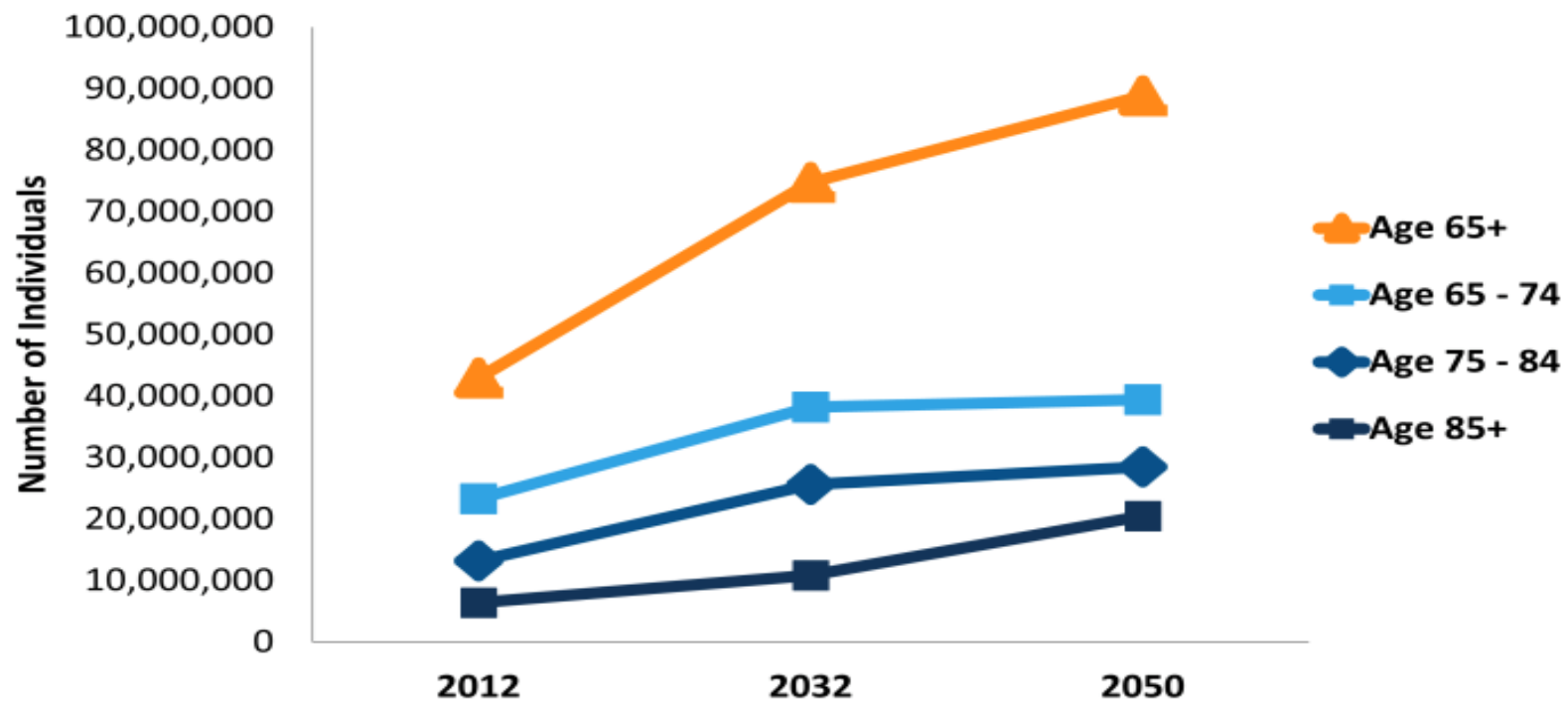
- 7,428 board certified geriatricians
- ▶ <2% of primary care physicians
- ▶ 1:2,526 (Geriatrician:Patient Ratio)

American Board of Medical Specialties. 2013-2014 ABMS Board Certification Report. AOA Specialty Board Certification. Certification statistics as of December 2014. The Journal of the American Osteopathic Association. 2015;114 (4), 275-278.

Projections of the Population by Age and Sex for the United States: 2010 to 2050 (NP2008-T12), Population Division, U.S. Census Bureau; Release Date: August 14, 2008.

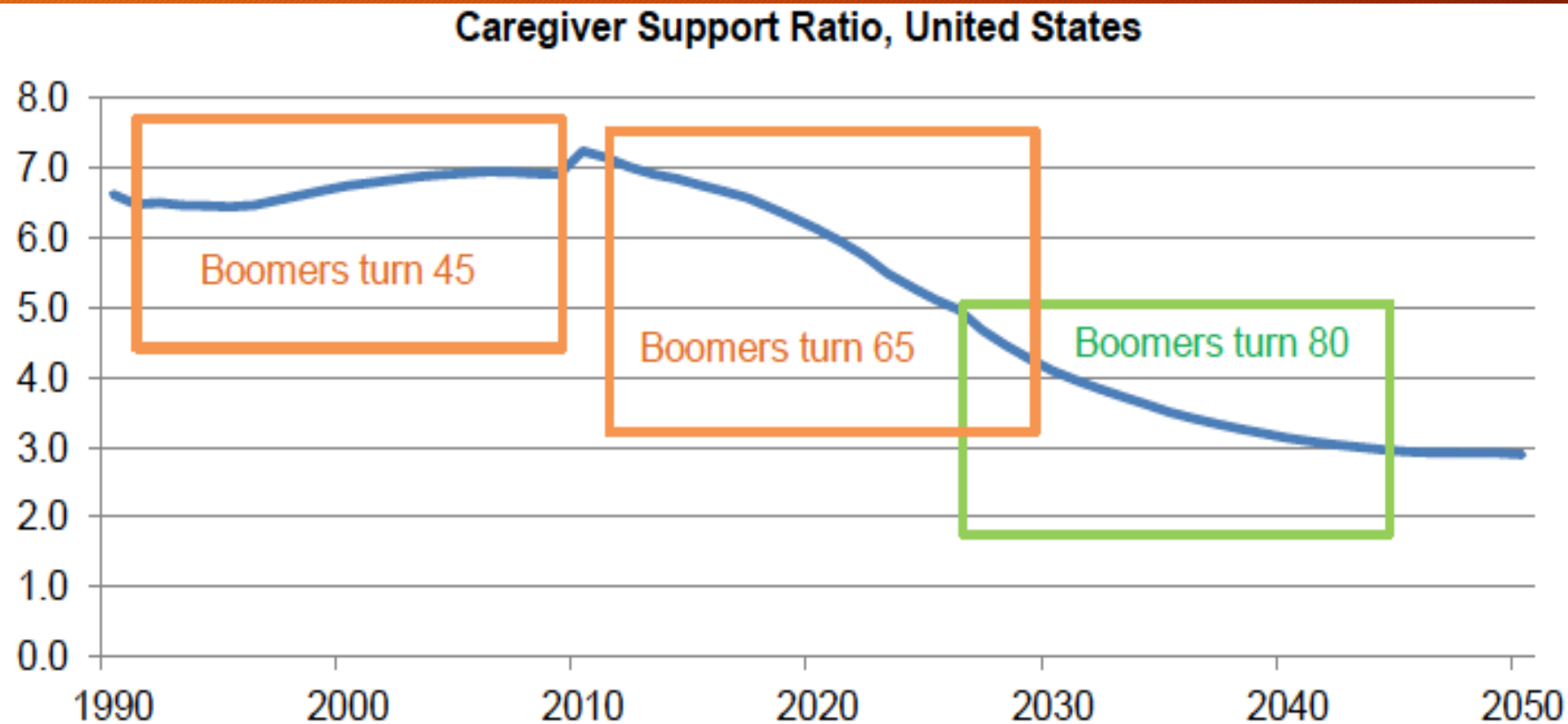
Aging in the United States

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



SOURCE: A. Houser, W. Fox-Grage, and K. Ujvari. *Across the States 2013: Profiles of Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, September 2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf.

Caregiver Support Ratio



Source: AARP Public Policy Institute calculations based on REMI (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.

Long Term Care

- Provision of non-medical services (“custodial care”) intended to compensate for functional deficits by a direct care provider
- ~52% of Americans turning 65 today will require Long-Term Care for at least 2 years*
- 1 in 7 will require Long-Term Care for more than 5 years
- 1 in 6 will spend at least \$100,000 out-of-pocket for Long-Term Care

* US Department of Health & Human Services - Office of the Assistant Secretary for Planning and Evaluation. “Long-term services and supports for older Americans: risks and financing research brief. Melissa Favreault and Judith Dey. 7/1/15

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

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

True or False

Long term care is fully covered by Medicare



FALSE

Role of Caregivers

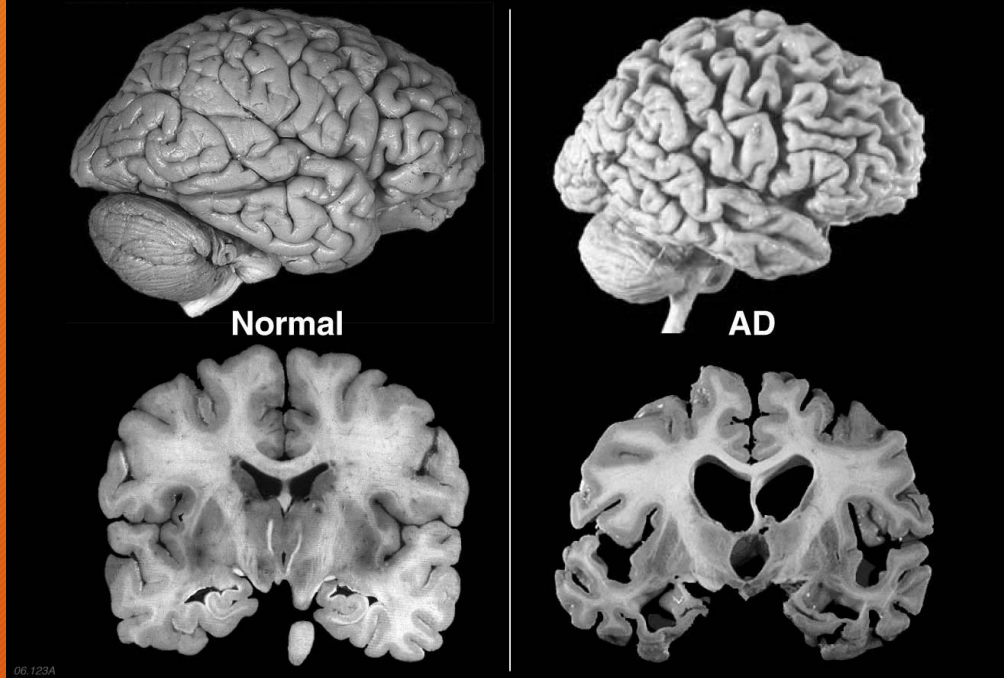
- Assist with Instrumental Activities of Daily Living (IADL)
 - Grocery shopping/Meal preparation
 - Transportation
 - Finances
 - Household chores
- Assist with Activities of Daily Living (ADL)
 - Bathing
 - Dressing
 - Eating
 - Transferring
 - Toileting

The Patient Advocate

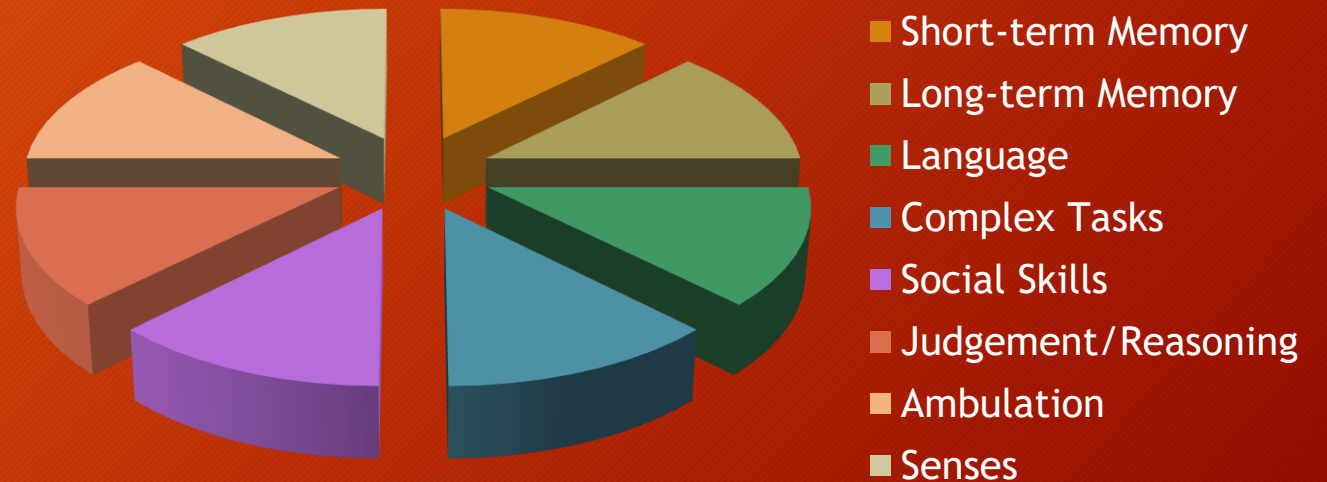
- Be informed
- Keep them involved
- Stay connected
- Be their voice
- Be proactive

1. Be informed: A little bit about the aging brain

Brain Atrophy in Advanced Alzheimer's Disease



Caring Concepts, Inc. and Roger Brumback, M.D.



Dementia has many forms

- ⌘ Alzheimer's Dementia
- ⌘ Vascular Dementia
- ⌘ Lewy Body Dementia
- ⌘ Frontotemporal Dementia
- ⌘ Mixed Dementia
- ⌘ Parkinson's Dementia
- ⌘ Normal pressure hydrocephalus
- ⌘ Cerebral vasculitis
- ⌘ Corticobasal degeneration
- ⌘ Chronic traumatic encephalopathy

Progression of Alzheimer Dementia

	Mild Cognitive Impairment	Early/Mild Impairment	Middle/Moderate Impairment	Late/Severe Impairment
Functional Deficits	None	<ul style="list-style-type: none"> - Managing finances - Driving - Managing medications 	<ul style="list-style-type: none"> - IADLs - Some ADLs - Gait/Balance 	<ul style="list-style-type: none"> - ADLs - Continence - Mobility - Swallowing
Cognitive Changes	<ul style="list-style-type: none"> - Some memory loss - Executive dysfunction - Mild language 	<ul style="list-style-type: none"> - Decreased insight - Short-term memory - Poor judgement 	<ul style="list-style-type: none"> - Disoriented to time/place - Worse memory - Getting lost - Repeating questions 	<ul style="list-style-type: none"> - Little or unintelligible verbal output - Loss of remote memory - Inability to recognize family
Behavioral Issues	None	<ul style="list-style-type: none"> - Social withdrawal - Mood changes - Apathy - Depression 	<ul style="list-style-type: none"> - Delusions - Agitation - Aggression - Restlessness - Wandering 	<ul style="list-style-type: none"> - Motor/verbal agitation - Sundowning
Complications	None	<ul style="list-style-type: none"> - Poor financial decisions - Medication errors 	<ul style="list-style-type: none"> - Inability to live at home - Falls 	<ul style="list-style-type: none"> - Pressure sores - Aspiration pneumonia

2. Keep them involved by...

- Start planning early
- Eliminate guesswork and prevent delay in care
- Review the legal and financial options
 1. Long-term care placement
 2. Financial and property
 3. Legal capacity

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 Init.
Date of Birth: (mm/dd/yyyy)	Gender:	Last 4 SSN:		
	<input type="checkbox"/> M <input type="checkbox"/> F	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Address: (street / city / state / zip)				

A Check One	CARDIOPULMONARY RESUSCITATION (CPR): <i>Patient has no pulse <u>and</u> is not breathing.</i>
	<input type="checkbox"/> Attempt Resuscitation/CPR
	<input type="checkbox"/> Do Not Attempt Resuscitation/DNR
When not in cardiopulmonary arrest, follow orders in B and C.	

B Check One	MEDICAL INTERVENTIONS: <i>If patient has pulse <u>and/or</u> is breathing.</i>
	<input type="checkbox"/> Comfort Measures Only (<u>Allow</u> Natural Death). 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. <i>Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.</i> Treatment Plan: Maximize comfort through symptom management.
	<input type="checkbox"/> 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). <i>Transfer to hospital if indicated. Generally avoid the intensive care unit.</i> Treatment Plan: Provide basic medical treatments.
	<input type="checkbox"/> 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. <i>Transfer to hospital and/or intensive care unit if indicated.</i> Treatment Plan: Full treatment including life support measures in the intensive care unit. Additional Orders: _____

C Check One	ARTIFICIALLY ADMINISTERED NUTRITION: <i>Offer food by mouth if feasible.</i>
	<input type="checkbox"/> No artificial nutrition by tube.
	<input type="checkbox"/> Defined trial period of artificial nutrition by tube.
	<input type="checkbox"/> Long-term artificial nutrition by tube.
Additional Orders: _____	

D	DOCUMENTATION OF DISCUSSION:
	<input type="checkbox"/> Patient (Patient has capacity)
	<input type="checkbox"/> Parent of minor
	<input type="checkbox"/> Court-Appointed Guardian
	<input type="checkbox"/> Health Care Representative or legally recognized surrogate
<input type="checkbox"/> Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)	
<input type="checkbox"/> Other _____	
Signature of Patient or Surrogate	
Signature: <u>recommended</u>	
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 <input type="checkbox"/>	

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: <u>required</u>
	Signer Phone Number: _____
Signer License Number: (optional) _____	
Physician / NP / PA Signature: <u>required</u>	
Date: <u>required</u>	
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

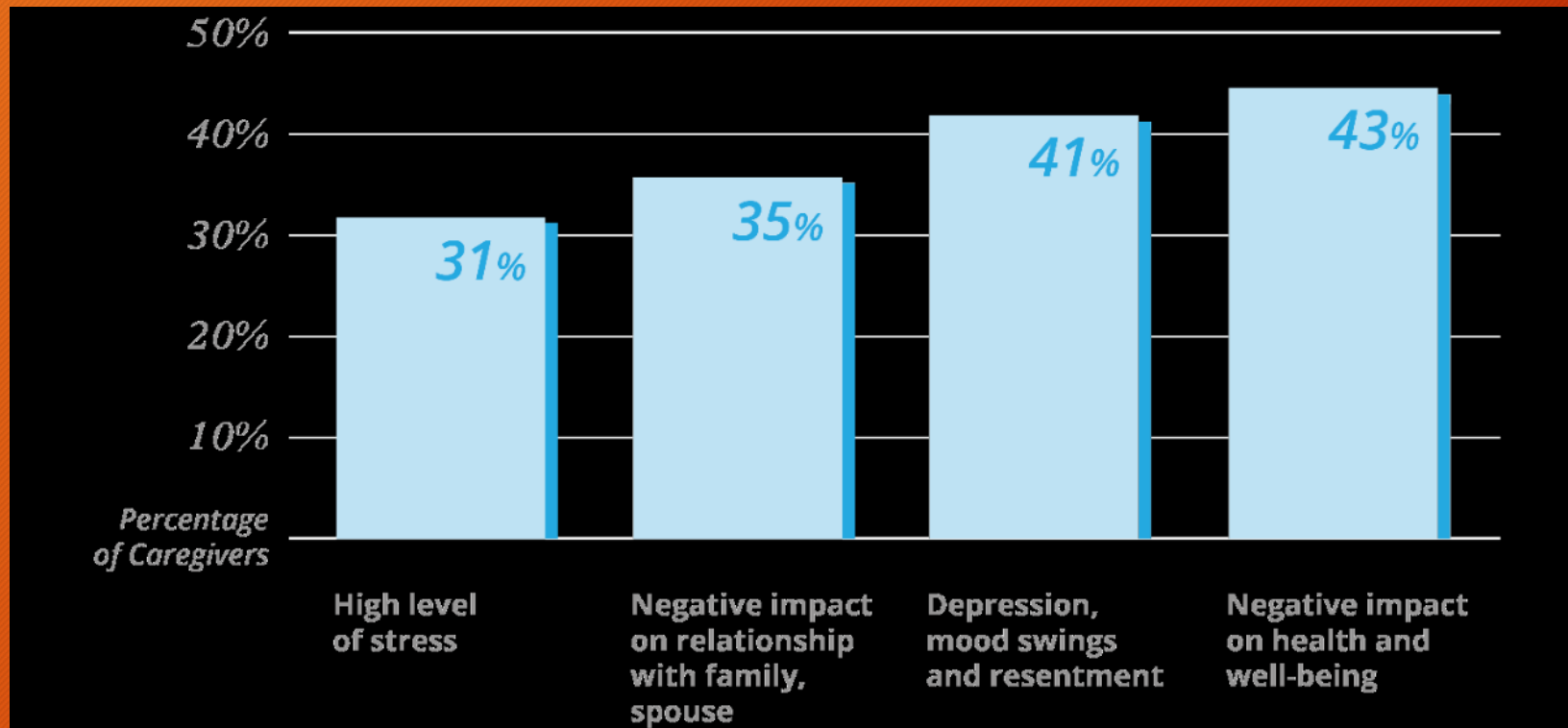
With great responsibility...

- Schedule burden
- Financial burden
- Family burden

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

Emotional Impacts of Caregiving



Caregiver Burden - Health Risks

- 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 \geq 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.

Self-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

41-60 = Moderate/Severe Stress

21-40 = Mild/Moderate Stress

61-80 = Severe Stress

3. But there is a solution: 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

4. Be their voice (especially during hospitalization)

- 1) VOICE your loved one's preferences early and communicate frequently with your medical provider.
- 2) **ALWAYS** have an updated list of medications (including over-the-counters!)
- 3) Do NOT assume they have access to your medical records. Do NOT assume all doctors have talked to each other yet.

4. Be their voice (especially during hospitalization)

- 4) **ALWAYS** request a copy of discharge summary, hospital records and instructions AND bring them to your doctor!
- 5) Follow up with your primary care provider after discharge.
- 6) It's okay to ask questions and to ask for help!

5. Be Proactive! Let's review...

- Be proactive by repeating the above steps:
 1. Be informed
 2. Keep them involved
 3. Stay connected
 4. Be their voice

Patient Resources: Start here

- Alzheimer's Association - <https://www.alz.org/care/overview.asp>
- AARP - www.aarp.org
- Genworth - <https://pro.genworth.com/riiproweb/productinfo/pdf/157453C.pdf>
- IRS Publications for Older Americans - www.irs.gov/individuals/seniors-retirees/publications-for-older-americans
- Medicare - www.medicare.gov