

CARING FOR THE CAREGIVER

Elder Friendly Futures

September 14, 2017

Lianne Hirano, MD

Assistant Professor

University of Washington, Dept of Medicine

Division of Gerontology & Geriatric Medicine

ELDER FRIENDLY FUTURES:

THE ESSENTIAL WORK OF CAREGIVING ACROSS COMMUNITIES

Nothing to disclose

Caring for the Caregiver

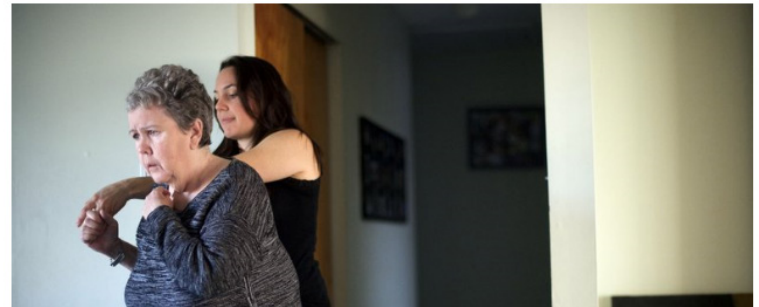
- Caregivers – who are they?
- What challenges do they face?
- Caring for the caregiver
- Tools/Communication
- Anticipatory Guidance

Caregivers

- Unpaid individual involved in assisting others w/ ADLs and/or medical tasks
- 43.5 million caregivers
- Majority of CG are women
- 85% are caring for a relative

Living With the Parents I'm Losing to Alzheimer's

As told to PAULA SPAN MARCH 4, 2016



Caregiver Challenges

Parent care continues to be the primary caregiving situation for mid-life caregivers w/ 70% of caregivers between ages 50-64



Caregiver Challenges: Financial/Economic

- Caregivers suffer loss of wages, health insurance and other job benefits, retirement savings or investing, and Social Security benefits.
- Single women caring for their elderly parents are **2.5 times** more likely than non-caregivers to live in poverty in old-age
- 10 million caregivers over 50 who care for their parents lose an estimated **\$3 trillion** in lost wages, pensions, retirement funds and benefits

In 2010, Elizabeth Wolf, then 30, was living in Vermont, working for a nonprofit and happily exploring new pursuits, from raising chickens to contra dancing.

But after several disturbing phone calls from and about her parents, Louis and Nancy Brood, she moved back into the split-level in Mt. Laurel, N.J., where she and her siblings had grown up, with her now husband, Casey Wolf. She expected to arrange caregiving help for her parents, then return to Vermont.

Five years later, she is still taking care of her 81-year-old father and 65-year-old mother, both with [dementia](#). Ms. Wolf, who volunteers with the Alzheimer's Association, writes about the experience at upsidedowndaughter.com.

Caregiver Challenges: Physical Health

- Physical care often provided by people who are themselves frail, ill, disabled
- Caregivers tend to minimize their own health problems and delay/forgo own health care
- 2X higher risk of adverse health outcomes
- Mortality risk 63% higher in older caregivers experiencing mental or emotional strain

Schulz R, Beach S. JAMA. 282:2215, 1999

Donelan K, et al. Health Aff 21:222, 2002

Schulz R, Sherwood PR, AJN 108(9 supp)23, 2008

Caregiver Challenges: Physical Health

- Compared to nonCGs, CGs who provide care to a spouse w/ dementia:
 - Report more infectious illness episodes
 - Poorer immune responses to flu and PNA vax
 - Slower wound healing
 - Increased risk of HTN
 - Increased risk for CAD
- Increased levels of IL-6 persisted even after spouse had died

Most of my “me time” is spent going to the gym; I see a therapist and get [acupuncture](#) a couple of times a month, too. These are the things I do to stay alive.

More than anything, the grief or loss I feel is in the form of loneliness. The isolation. I don't know how to relate to people my age.

Caregiver Challenges: Emotional/Psychological

- Caregivers twice as likely to be taking psychotropic meds
- Depression:
 - Up to half of all caregivers
 - In 61% of people giving care
>20 hrs/week



Caregiver Depression

- Associated with following CG factors:
 - Ineffective caregiver coping
 - Lack of social support
 - Greater duration, amount of care provided
 - Older age of caregiver
 - Spousal relationship
 - Female sex of caregiver

Schulz R, Sherwood PR, AJN 108(9 supp)23, 2008

Caregiver Depression

- Associated with following pt factors:
 - Dementia
 - Greater immobility
 - Greater ADL impairment
 - Behavior problems
 - More symptoms and symptom distress
 - Expressions of pain/discomfort
 - Psychological symptoms of distress (depression, apathy)

Schulz R, Sherwood PR, AJN 108(9 supp)23, 2008

Burdens of Dementia Caregiving

- Demands and negative impact generally higher than in non-dementia caregiving
 - More hours/week providing care
 - 20% give care for >5 years
 - More disruptive to family life
 - More negative mental health impact on caregiver
 - Reduced time for leisure, other social/family activity
 - Greater strain assoc w/behavioral problems, unpredictable disease course
- Caregiver depression/function often improves after death of care recipient (but not after NHP)

Neurol Clin 18:993, 2000

Schulz R et al. NEJM 349:1936, 2003

#1 NEW YORK TIMES BESTSELLER

Can't we talk about
something more
PLEASANT?



ROZ CHAST
A MEMOIR



Other Factors Determining Caregiver Distress: Not all bad news

- Caregiver personality (self-efficacy, optimism)
- Caregiver coping strategies
- Quality of relationship w/care recipient
- Economic and social support resources
- Caregiving intensity
 - Assisting w/BADLs >20 hrs/week \Rightarrow \uparrow depression, psychol distress; \downarrow self care, \downarrow self-reported health

Schulz R, Sherwood PR, AJN 108(9 supp)23, 2008

Once in a while I let myself think about what I've given up. Casey and I decided not to have children, but I feel like a mother to my parents.

I value the incredible intimacy I get to share with them. When I was a teenager, my mother was pretty critical; she ignored me for days at a time. I think she was overwhelmed by motherhood.

Now, this role that we share, it's changed the dynamic, the history of our relationship. However many years down the line, looking back, I'll think of the moments of tenderness I shared with her, every single day.

Caregiver Rewards/Satisfaction

- ~1/3 of caregivers report neither strain nor adverse health effects, especially early on
- Some report positive caregiving experience
- Increased self-esteem, sense of competence
- Satisfaction of knowing loved one is well cared for
- Pride
- Feeling appreciated, needed
- Finding meaning



Caregiver Tasks

- Monitoring/interpreting signs & symptoms, response to treatment
- Making decisions
- Assisting with or performing basic and instrumental ADLs
- Managing household
- Using medical equipment
- Providing emotional support and comfort
- Giving medications
- Adjusting to changing needs
- Accessing resources
- Negotiating health care system

Potential Needs

- Information about services
- Stress management & coping strategies
- Help with financial issues
- Help communicating with HC professionals
- Disease-specific info
- Help recruiting competent help
- Help learning care tasks



HEALTH & WELLNESS

You're taking care of someone with Alzheimer's, but who is taking care of you?



Patti Davis founded the Beyond Alzheimer's support group for caregivers. (Rick Loomis / Los Angeles Times)



By **Rene Lynch** · Contact Reporter

APRIL 16, 2016, 5:00 AM

After Ronald Reagan became America's most recognizable Alzheimer's patient, well-meaning friends, relatives and even strangers would routinely stop his daughter, Patti Davis, to ask: "How is he doing?"

Only occasionally would someone ask, "And how are you doing?"

NovoLog FlexPen
Insulin aspart (rDNA origin) injection

NOW I KNOW

Learn more

Click here for Full Prescribing Information

Indications and Usage
What is NovoLog® (insulin aspart [rDNA origin] injection)?
• NovoLog® is a man-made insulin used to control high blood sugar in adults and children with diabetes mellitus.

ADVERTISEMENT

In Case You Missed It



Finalists for 2016 Hugo Awards are named

11:19 AM



Tokyo Strike ramen bar and diner to open in Los Angeles

9:00 AM



Cunard celebrates Queen Elizabeth II and four ships she launched, in photos

8:30 AM

[See More](#)

What we can do throughout the course of dementia (and in general)

- **ASK** “How are YOU doing?”
- Listen and reflect, be present
- Acknowledge emotions (**NURSE**)
- **Normalize**



What We Can Do

- **Be sensitive to cultural, religious, age differences**
- Empathize with caregiver
- **Understand own biases**, keep them in check
- Know own knowledge limits & when to refer
- Link caregivers with appropriate services & support

Caregiver Assessment: Principles, Guidelines and Strategies for Change
Available at www.caregiver.org

Assess Readiness to Accept Support

- May initially reject or resist proffered care, but later seek and accept support
- Observed in a variety of progressive neurological diseases (MS, MND, AD)
- 3 phases in caregiver acceptance of support
 - Recognizing need for help
 - Giving self permission to obtain help
 - Realizing availability and adequacy of social supports

Mult Scler 10:219, 2004

West J Nurs Res 21:450, 1999

Identify Caregivers At Risk: Caregiver Self-Assessment Questionnaire

During the past week or so, I have...

- | | |
|--|--|
| 1 Had trouble keeping my mind on what I was doing. <input type="checkbox"/> Yes <input type="checkbox"/> No | 13 Had back pain. <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2 Felt that I couldn't leave my relative alone. <input type="checkbox"/> Yes <input type="checkbox"/> No | 14 Felt ill (headaches, stomach problems or common cold). . . <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3 Had difficulty making decisions. <input type="checkbox"/> Yes <input type="checkbox"/> No | 15 Been satisfied with the support my family has given me. <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4 Felt completely overwhelmed. <input type="checkbox"/> Yes <input type="checkbox"/> No | 16 Found my relative's living situation to be inconvenient or a barrier to care. <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5 Felt useful and needed. <input type="checkbox"/> Yes <input type="checkbox"/> No | 17 On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____ |
| 6 Felt lonely. <input type="checkbox"/> Yes <input type="checkbox"/> No | 18 On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ |
| 7 Been upset that my relative has changed so much from his/her former self. <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 8 Felt a loss of privacy and/or personal time. <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 9 Been edgy or irritable. <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 10 Had sleep disturbed because of caring for my relative. <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 11 Had a crying spell(s). <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 12 Felt strained between work and family responsibilities. . . <input type="checkbox"/> Yes <input type="checkbox"/> No | |

To interpret the score

Chances are that you are experiencing a high degree of distress:

- If you answered "Yes" to either or both questions 4 and 11; or
- If your total "Yes" score = 10 or more; or
- If your score on question 17 is 6 or higher; or
- If your score on question 18 is 6 or higher

Self-evaluation

To determine the score:

- 1 Reverse score questions 5 and 15. (For example, a "No" response should be counted as "Yes" and a "Yes" response should be counted as "No.")
- 2 Total the number of "yes" responses.

<http://www.ama-assn.org//ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/geriatric-health/caregiver-health/caregiver-self-assessment.page>

Caring for Caregivers: Part of the team

- **Evaluate/treat caregiver and recipient as a unit**
- Treating pt at same time as caregiver may be synergistic
- Value caregivers as members of the care team
- Encourage self-care and health-promoting behaviors
- Facilitate communication, joint problem solving

Communication is Key

- Misunderstanding, lack of communication are extremely common between pts, families, providers
- Problem areas may include
 - Diagnosis
 - Prognosis
 - Decision making
 - Care preferences



Communicating with Family

- Consider obtaining some training in Palliative Care (UW Graduate Certificate in Palliative Care, www.uwpctc.org)
- Families want providers to be comfortable discussing death and dying
- Families need timely, clear communication
- Families will have diverse perspectives on various treatments (end-of-life care, life-sustaining treatment, for example)
- **Talk less, listen more**

Listen and Express Empathy

- Careful listening reduces risk of caregiver depression
- Use empathic listening
 - “How have things been going for you and your family?”
 - “What worries you the most about caring for your mother?”
 - “This must be a difficult time for you.”
 - “How can I help?”
 - “Tell me what’s upsetting you the most.”
 - “This must be hard for you to accept.”
- Bear witness to suffering

Emanuel EJ et al. Ann Intern Med 132:451, 2000
Rabow MW et al. JAMA 291:483, 2004

NURSE

- Naming: “It sounds like you are frustrated.”
- Understanding: “This helps me understand what you are thinking.”
- Respecting: “I think you have done an amazing job trying to care for him at home.”
- Supporting: “I will do my best to make sure you have what you need.”
- Exploring: “Could you tell me a little more about what you mean when you say that...”

<http://vitaltalk.org/guides/responding-to-emotion-respecting/>

Empathy, Reflection, Validation

- Assess family dynamics and caregiver emotions
- Recognize, validate common feelings (**normalize**)
- Reassure family caregivers they are providing good care



Transitions and Guidance

- Initial diagnosis of dementia
- Advanced planning for healthcare and finances
- Safety (eg driving, guns, meds, cooking)
- Managing behavioral symptoms
- Changes in care setting
- End-of-life care

Anticipatory Guidance

- “proactive developmentally based counseling technique that focuses on the needs of a child at each stage of life”
- Can this model be used to provide our CGs with Anticipatory Guidance for pts with dementia?

Seven Stages of Alzheimer's: The Global Deterioration Scale (GDS)

Stage	Memory Loss	Functional Loss
1	None	Normal function
2	Very mild decline	Pt may feel as though they are having memory lapses but not noticed by family and friends.
3	Mild decline	Trouble remembering names and performing some complex activities. May lose or misplace valuable possessions.
4	Moderate decline	Greater difficulty with performing complex tasks, such as instrumental activities of daily living (managing finances, shopping). May be becoming moody or withdrawn.
5	Moderately severe decline	May still be independent with eating and toileting. May forget own address. May require assistance with choosing weather-appropriate clothing.
6	Severe decline	Personality changes may take place. May need assistance with activities of daily living. Experiences disturbed sleep. May wander and become lost.
7	Very severe decline	Likely need assistance with all aspects of care. May or may not retain verbal abilities. Muscles may become rigid; swallowing impaired.

Anticipatory Guidance: Initial Diagnosis

- Entry into CG role
- Coping w/ losses and changes
- Feelings of isolation (social stigma)
- ❖ Provide information on dementia and its trajectory/prognosis
- ❖ Potential resources (including support groups, online)

Principles of Caregiver Assessment

- Communicate to caregiver that purpose of assessment is to help the caregiver
- Consider family caregivers a core part of healthcare team
- Develop a plan of care in collaboration with the caregiver
- Include in plan of care the services to be provided
- No single assessment approach or protocol is optimal for all care settings and situations

Caregiver Assessment: Principles, Guidelines and Strategies for Change

Available at www.caregiver.org

Caregiver Assessment: Where are you starting from?

- Care demands
 - Number of hours, nature of tasks
 - Expected duration of care
- Competing demands on caregiver time (paid work, child care, travel, etc.)
- Caregiver knowledge and skills
- Caregiver capabilities
- Additional support (other family?)
- Available resources



Anticipatory Guidance: Planning (Financial and Medical)

- Financial costs to CG (time off of work, out of pocket medical and CG expenses)
- Loss of financial capacity of pt
- ❖ Proactive planning on how future financial matters will be handled*
- ❖ Advanced Care Planning*, surrogate decision-maker*

*Important to address early so that the person w/ dementia can still participate in these discussions.

Anticipatory Guidance: Safety

- Driving
 - Guns
 - Cooking
 - Medication management
- ❖ Creative, individualized solutions
 - ❖ Taking the knobs off stove
 - ❖ Medisets, teaching CG how to administer injections, catheter care, etc

Anticipatory Guidance: Behavioral Symptoms

- Agitation, aggression, delusions
 - Wandering
 - Insomnia
- ❖ No easy answers
 - ❖ Creative, individualized approaches
 - ❖ Community resources
 - ❖ Pharmacologic interventions

Anticipatory Guidance: Changes in Care Setting

- Home → Facility
- Facility → Hospital → Facility
 - ❖ Adjustment period to new environment
 - ❖ Time trials (respite)
 - ❖ Delirium and sundowning

There was a point in May of 2013 — we'd been here two and a half years — when we had plans to move my parents into a facility. We were going to do a respite stay, and if they fit in, if it went well, we'd sell the house.

We did everything we could — we brought couches and furniture from their bedroom — to make the place feel homelike. But it wasn't home. For my dad, it lasted three days. He started having [panic attacks](#), to the point where he was throwing up.

He was still with it enough to call us. I remember getting a message from him, weeping. "It's Daddy. Please, me and Mom want to come home."

Everybody, including his doctor, said, "You have to leave him, you have to let him adjust." I couldn't do it. I would never judge the people who do, but I couldn't.

They've been here 40 years. All my dad ever wanted was this home. Who am I, if I take my dad from his home?

Anticipatory Guidance: End of Life Care and Beyond

- Recognizing that dementia is a terminal illness
 - 6 month mortality for pts who develop eating problems, PNA, or febrile illness is 40-45%
- ❖ Hospice, end-of-life care
 - ❖ Grief and bereavement

Caring for Caregivers

- Value caregivers as members of the care team
- Encourage self-care and health-promoting behaviors (ASK)
- Facilitate communication, joint problem solving
- Advance care planning and clear decision-making
- Empathy for family emotions (NURSE) and relationships
- Normalize

Thank you!