

The Caregivers Project

A collaboration between the UCSF
Osher Center for Integrative Medicine and the
Department of Neurosurgery

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Today's Agenda

- Why caregiving matters
- Insights into lives of caregivers
- Coping with the stress of caregiving



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What is Caregiving?

- **Informal caregiving:** support and lay medical care provided by family, partners, and friends.
- **Supportive care:** Transportation, shopping, homemaking, emotional support, nutritional care, personal care, & financial mgmt.
- **Medical care:** dressing changes, administer medications, clinical observation



Some Facts about Caregiving

- 1 out of 4 Americans will be a caregiver for a family member
- Caregiving is associated with morbidity, mortality, and economic strain



Costs of Caregiving: Physical Health

- Decline in immune function^{1,2}
- Increased cell aging, cancer risk¹
- Increased mortality³

Caregiver Health Effects Study (Schulz et al³)

-4 year study, 392 caregivers and 427 non-caregivers., >66 yrs old

-Caregivers with strain had mortality risk 63% higher

1 Epel, Proc Nat Acad Sci, 2004: 101: 17323

2 Kiecolt-Glaser

3 Schulz, JAMA, 1999, 282: 2215



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Costs of Caregiving: Mental Health

- **Depression & anxiety**

- “Burden” - Exhaustion, financial strain, disrupted usual activities, and continuous caregiving
- 1/2 with clinical depression
- 61% of “intense” family caregivers depressed
- Wives > husbands

Hebert & Schulz, 2006, J Palliative Med, 9:1174-1187

Cochrane. Am J Pub Health. 1997;87:2002

Barry, Kasl, Prigerson, 2002, Am J Ger Psych, 10:447-457

Pirraglia, 2005, Gem. Int Med, 20:510-514



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Costs of Caregiving: Financial Disruption

- 20% of caregivers quit work or make major life changes
- 31% lose most or all of their family savings

Covinsky. JAMA. 1994;272:1839
Hayman. J Clin Onc. 2001;19:3219



The Caregivers

An Open Eye Pictures Production

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A Moment for Reflection

What struck you about these stories?



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Stresses of Caregiving

- Relationship tensions
 - Goals
 - Preferences regarding information
 - Treatment issues
- Caregiving activities
 - Medications
 - Trips to MD or hospital
- Personal issues
 - Uncertainty
 - Loss of normal life



Coping with the Stress of Caregiving: Maintaining Positive Well-Being

- Feeling depressed is a normal response
- People experience positive moments even when stress is severe
- How? (Suggestions for *anyone* coping with chronic stress)



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Strategy 1

Relinquish untenable goals and substitute new goals that are both realistic and meaningful

- *Helps sustain sense of control*
- *Creates renewed sense of purpose*
- *Allows hope and optimism with respect to new goals*



“Doing things for him helps me because there is so little I can do to change the situation. Just by doing the little day-to-day things that need to be done for him and doing them willingly. I’m doing something for him. It’s all I can do. It makes me feel better to be able to do these things for him.”

Caregiver of terminally ill patient



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Strategy 2

Infuse ordinary events with positive meaning

- *Provides a “breather” from distress*
- *Helps restore resources*



“It’s a hoot. Doing actually nothing. We’re like an old married couple. He’s on the sofa. I’m on the chair. The old TV along the wall. Just being there with him. Being together. We do nothing except talk. We make something to eat. Play with the cats. It’s calming. Telling him he’s cute no matter what his hair looks like! It’s just like..being with an old shoe. There’s no outside world – just us.”

Partner of man with AIDS



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Strategy 3

**Reflect on
growth in
personal
strengths and
resources
(benefit finding)**

*Reinforces positive
beliefs about self
and the world*



I have learned that I am a stronger person than I probably ever imagined and that I have more resources within me than I could have ever imagined. ...I would have never chosen to go through the loss of him. But it has been a very positive thing for my life because I am a much stronger, much better person going through this side of it all.

Bereaved caregiver



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Strategy 4

Focus on what really matters, and reorder priorities accordingly

- *Motivates coping*
- *Helps sustain commitment*



Things that used to bother me ... I don't even think about them now. When my daughter has a good day, I have a good day. That's all that matters.

Mother of child with chronic illness



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Resources for Caregivers

Center for Caregiver Training

www.caregiving101.org

Family Caregiver Alliance

www.caregiver.org

National Alliance for Caregiving

www.caregiving.org

United States Administration on Aging, National Family Caregiver Support Program

<http://www.aoa.gov/prof/aoaprogram/caregiver/carefam/carefam.asp>



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A photograph of a sunset or sunrise sky. The sun is partially visible at the bottom center, glowing with bright yellow and orange light. The sky is filled with wispy, white and light-colored clouds that catch the low light of the sun, creating a soft, ethereal glow. The upper portion of the sky transitions into a deep, dark blue. The overall mood is peaceful and awe-inspiring.

Thank you!