



## A Partial Annotated Bibliography

Alhola, P. [Sleep deprivation: Impact on cognitive performance](http://www.ncbi.nlm.nih.gov/) [www.ncbi.nlm.nih.gov/..](http://www.ncbi.nlm.nih.gov/)

American Psychological Association [www.apa.org](http://www.apa.org) *Family Caregiving*

This fact sheet identifies the impacts of caregiving, including 40%-70% of caregivers have "significant symptoms of depression" with up to half of that group evidencing major depression. This fact sheet then identifies supports to help – education and counseling, respite, individual and group therapy, financial support, and support services such as day care and home health aides.

Arno, Peter S., "Economic Value of Informal Caregiving," presented at the Care Coordination and the Caregiving Forum, Dept. of Veterans Affairs, NIH, Bethesda, MD, January 25-27, 2006.

Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as 10 years off a family caregiver's life.

Arvedlund, Erin *Alzheimer's Edge: Those whose loved ones have dementia can learn strategies* *The Philadelphia Inquirer* July 17, 2016 p.E3 or [philly.com](http://philly.com) This article identifies a 6-week program at Penn Memory Center to teach caregivers strategies for self-care and managing dementia. It identifies feelings of "anger, exhaustion, burnout and isolation" as common among caregivers in the group. This article supports the value of learning skills in community, the connection being as important as the skill.

Cannuscio, C.C., C. Jones, I. Kawachi, G.A. Colditz, L. Berkman and E. Rimm, *Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study.* *American Journal of Public Health* 92:305-1311, 2002.

Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate is six times higher; for those caring for a parent the rate is twice as high.

Carter, Rosalynn. *Helping Yourself Help Others: a book for caregivers.* Random House 1994

Former First Lady Rosalynn Carter is a foremost advocate for family caregivers. In addition to being an author, she heads up the Rosalynn Carter Foundation for Family Caregiving. In her book, she has chapters on avoiding burnout and isolation, the impacts of each and what to do to ameliorate them. Support groups are high on her list.

Christakis, Nicholas D., Professor, Health-care Policy, Harvard Medical School, Boston and Suzanne Salamon, M.D., Associate Chief, Geriatric Psychiatry, Beth Israel Deaconess Hospital, Boston, *New England Journal of Medicine*, Feb. 16, 2006.

A wife's hospitalization increased her husband's chances of dying within a month by 35%. A husband's hospitalization boosted his wife's mortality risk by 44%.

Epel, Elissa S., Elizabeth H. Blackburn, Jue Lin, Firdaus S. Dhabhar, Nancy E. Adler, Jason D. Morrow, and Richard M. Cawthon. *Accelerated telomere shortening in response to life stress* December, 2004 *PNAS* vol. 101, no. 49, pp17312-17215

Dr. Epel et al state that numerous studies identify the links between stress and poor health outcomes. However, theirs is one of the first to identify biologically what happens as a result of stress. Comparing the telomeres (the "caps" at the ends of chromosome bundles that serve as a biomarker of age) of healthy mothers of healthy children and healthy mothers of chronically ill children, they found that **"Women with the highest levels of perceived stress have telomeres shorter on average by the equivalent of at least one decade of additional aging compared to low stress women."**

[Epel, Elissa, Daubenmier, Jennifer, Moskowitz, Judith T., Folkman, Susan and Blackburn, Elizabeth](#) *Can meditation slow rate of cellular aging? Cognitive stress, mindfulness, and telomeres* [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov) 2014 Following up on earlier research, Dr. Epel et al find that 12 of kirtan kriya meditation or 15 minutes of breathing meditation daily can reverse the effect of stress on telomeres

Feinberg, Lynn and Houser, Ari "Assessing Family Caregiver Needs: policy and practice considerations" *AARP Public Policy Institute* June 2012 "Family Caregivers are the backbone of long-term services and supports system" Needs assessment for caregivers helps identify the roles and challenges of caregiving and what supports the caregiver needs. While assessment is helpful in caregivers feeling heard and supported, it needs to be followed with response and action.

*Harvard Mental Health Letter* April, 2009 *Yoga for Anxiety and Depression* This article provides a review of literature and findings in the use of yoga to treat anxiety and depression. Studies found yoga modulates stress response systems, allowing for more flexibility. Some of its benefit may be related to the breathing that is used. For those same reasons, it is being seen as effective in treating PTSD.

Huffington, Arianna *The Sleep Revolution* 2016 This is a book for all readers discussing the impact of sleep deprivation and the importance of sleep, both as a behavior and as something to be valued.

Kiecolt Glaser, Janice, MD and Glaser, Ronald, MD, "Chronic stress and age-related increases in the proinflammatory cytokine IL-6." *Proceedings of the National Academy of Sciences*, June 30, 2003.

Stress of family caregiving for persons with dementia has been shown to impact a person's immune system for up to three years after their caregiving ends, thus increasing their chances of developing a chronic illness themselves.

Landro, Laura "When You Become the Nurse for a Family Member" *Wall Street Journal* July 19, 2016 This article identifies the increasing list of responsibilities family caregivers -- drops, injections, wound care -- without training or support.

Mace, Nancy L, M.A. and Rabins, Peter V., MD, MPH *The 36-Hour Day*. Johns Hopkins University Press 1999  
An excellent guide for those who are taking care of someone with Alzheimer's Disease or other dementias, but also a good guide for caregivers in general, with chapters on caring for yourself. They include chapter sub-headings including: "Take time out", "Avoid Isolation", and "Support Groups" -- all components of Nancy's House

Mallis, Melissa M. and James, Francine O. *Neuropsychiatr Dis Treat*. 2007;3(5):553-67 *The Role of Alertness Monitoring in Sustaining Cognition During Sleep Loss*. This chapter identifies the risks to 24-hour industries and businesses of cognitive deficits arising from sleep loss in workers. It proposes technologies to help workers become aware of drowsiness and ineffective work in real time. The emphasis is that sleep deprivation has negative impacts on cognitive functioning.

Mullington, JM, Haack M, Toth M, Serrador JM and Meier-Ewert HK "Cardiovascular, inflammatory, and metabolic consequences of sleep deprivation" *Progressive Cardiovascular Disease* 2009 Jan-Feb; 51(4): 294-302  
Insufficient sleep leads to poor attention and performance deficits. Associated with overall mortality and morbidity including increased blood pressure, glucose metabolism, hormonal regulation and inflammation. Insufficient sleep increases cardiovascular risks in ways known to increase cardiac morbidity (disease).

National Alliance for Caregiving, AARP and MetLife Foundation *Caregiving in America* 2009  
This is the most recent report in the on-going research on caregiving. It provides demographics and describes, in detail, all elements of caregiving and how respondents identified, giving an excellent and objective view into the lives of caregivers.

Roth DL, Perkins M, Wadley VG, Temple EM, Haley WE.  
*Qual Life Res*. 2009 Aug;18(6):679-88. doi: 10.1007/s11136-009-9482-2. Epub 2009 May 7.  
PMID: 19421895 This large study suggests the correlation between caregivers' problems and the level of strain they experience. Caregivers who had greater intensity of care responsibilities reported increased health and emotional problems. Caregivers who had little direct responsibility has few concerns.

Schulz, R. and Beach, S. R., *Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study*. *Journal of the American Medical Association*, Vol. 282, No. 23, December 15, 1999.  
Elderly spousal caregivers with a history of chronic illness themselves who are experiencing caregiving related stress have a 63% higher mortality rate than their non-caregiving peers.

Schultz, R, McGinnis, Kathleen A., Zhang, Song, Martire, Lynn M., Hebert, Randy S., Beach, Scott R., Zdaniuk, Bozena, Czaja, Sara J. and Belle, Steven H. *Dementia Patient Suffering and Caregiver Depression* author's manuscript "This is the first study to show in a large sample (1222 dementia patients) that perceived patient suffering ... contributes to family caregiver depression and medication use.

Schultz, Richard and Sherwood, Paula R. "Physical and Mental Health Effects of Family Caregiving" *American Journal of Nursing* 2008 September, 108(9 Suppl) 23-27 doi: 10 1097/01NAJ.0000336406.45248.4c  
Caregiving elements are equivalent to chronic stress; therefore chronic stress model is useful for studying health effects of caregiving. Current awareness of caregiving issues comes from 2 decades of study. Positive effects: learn new skills, feel good about self, strengthen family relationships. Negative effects: depression is common, caring for someone with dementia leads to more severe and more negative effects for caregivers, the chronic stress compromises both the physical and mental health of the caregiver.

Shapiro, D., Cook, I.A., Davydov, D.M., Ottaviano, C., Leichter, A.F. and Abrams, M. *Yoga as a Complementary Treatment of Depression: effects of traits and moods on treatment outcome*. *Evidence Based Complementary Alternative Medicine* 2007 Dec;4(4):493-502  
This study started with 27 women and 10 men who were taking antidepressants but were not getting full relief from them. 17 people completed the study. Pre/post measures showed significant reductions in depression, anger, anxiety, "neurotic symptoms" and heart rate. Those who did best were better at emotional self-regulation to begin with. Cost effectiveness and ease of implementation make yoga a viable choice for augmenting depression treatment.

Sheehy, Gail. *Passages in Caregiving: Turning chaos into confidence*. Harper Collins 2010  
A personal story of Ms. Sheehy's own caregiving experience and her research into caregiving; Sheehy highlights the importance of self-care when in the caregiving role.

Talbott, Shawn, Ph.D. *The Cortisol Connection* Hunter House, Inc. 2007  
Dr. Talbott explains the physiology of what happens when cortisol, the stress hormone, remains in the body as a result of on-going stress and inadequate ways to break it down (e.g. adequate sleep). In clear, accessible language, Dr. Talbott explains how on-going stress can lead to a suppressed immune system, developing Metabolic Syndrome X, high blood pressure, diabetes, weight gain.

<http://www.rand.org/news/press/2014/10/27.html>

Cost of Informal Caregiving for U.S. Elderly is \$522 Billion Annually