FAMILY CAREGIVERS AND CAREGIVER STRESS

Objectives/Goals:
• Outline the various factors that contribute to caregiver stress and the ways that caregiver stress affects both caregiver and care recipient.
• Encourage physician awareness and assessment of issues of caregiver stress.
• Familiarize physicians with resources available to support and assist family caregivers.

Family Caregivers:
• Most people (70-80%) who need long term care supportive services live at home or in community settings, not in institutions.¹
• Over 78% of adults who receive LTC at home get all their care from unpaid family & friends.¹
• Changes in the health care system, including shorter hospital stays and insurance company restrictions on coverage of care, require family members to provide more extensive care in the home.
• Of those caring for someone aged 65+, the average age of caregivers is 63 y/o with one third of these caregivers in fair to poor health. The person most likely to be providing care to an older person is an adult child. (For all caregivers caring for a 65+ y/o: 41% are adult children, 23% are spouses, 27% are other relatives, 8% are non-relatives.)²
• As the older adult population grows, so will the demand for family caregiving. Caring for the caregiver will become an ever more important part of maintaining the health and safety of older patients in the community.

Caregiver Stress:
• Physical _ Physical demands of caregiving
  o Caregivers are less likely to engage in preventative health measures.³ Caregivers are at increased risk for illness due to the physiological and emotional strain of caregiving and lack of self-care.
  o Being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers.³
• Social _ Lost friendships, social isolation as a result of caregiving role, role adjustment
• Economic _ Lost professional/income opportunities, cost of paying for care over long-term
• Emotional _ Grief re. losses (personal losses and witnessing losses experienced by loved one), anticipatory grief re. future decline and death of loved one, guilt, conflict with care recipient.
  o Caregivers report higher levels of depressive symptoms and mental health problems than do their non-caregiving peers -- 20% to 50% report depressive disorders or symptoms.¹
  o Risk of abuse (by and to care recipient, although most often the latter.)
• Stress with accessing supportive resources _ Complex and disjointed systems of services, embarrassment or feeling of “failure” for needing assistance in caregiving, fear of having
strangers in home delivering services, services themselves can be inadequate and disappointing.

• There may also be positive feelings associated with caregiving that mitigate some of the stress and burden the caregiver experiences. Satisfaction of helping family member, development of new closeness to care recipient, developing new skills and competencies, improved family relationships.

Physician’s role in assisting the caregiver
When the caregiver is not the doctor’s identified patient, what role does the MD have in assessing and assisting the caregiver? Why assess an individual who isn’t your patient?

• The American Medical Association encourages physicians to routinely screen adult patients about their caregiving responsibilities and assess for health risks arising from these caregiving responsibilities. The Administration on Aging (AoA), in an effort to address this gap of support for caregivers, has launched a campaign entitled, Making the Link, to promote the concept within the medical community that the needs of caregivers is a major public health issue. After screening and assessing caregiver needs, the AoA advises physicians to refer caregivers to local Area Agencies on Aging so they can receive information about social services available in their communities.

• Physicians are in a unique position to identify caregivers at risk. Simply asking: “Are you overwhelmed or feeling stressed by your caregiving responsibilities?” opens the door for further assessment and intervention.

• Caregiver stress screens: AMA Caregiver Self-Assessment Questionnaire, Modified Caregiver Strain Index (CSI), Psychosocial Screening Tool (PSST) (not yet validated instrument), among others.

• Studies show that caregivers want concrete, practical advice from physicians and referrals or information on how to access community agencies. They additionally want emotional support and attention.

Due to time constraints in the primary care setting, intervention can be brief. Dispensing written materials and referrals to ISWC social worker or community agencies are useful.

1. Support/validate caregiver’s experience.
   • “You are not alone in this experience and there are supports for you.”
   • “Caregiving can be very stressful. There are physical and emotional symptoms that can result from caregiver stress.”

2. Educate caregiver about the illness and disease process.
   • Clinical symptoms and the progression of the illness.
   • Safety concerns (falls, wandering prevention).
   • Need for legal and financial planning.

3. Encourage caregiver’s respite/support. Suggest that the caregiver:
   • Use his or her social network for support and/or join a support groups.
   • Find sources to help with caregiver tasks, ie. family, friends, neighbors, church/synagogue, community agencies.
   • Preserve personal time and engage in leisure activities. Maintain health and keep doctor appointments, eat well, exercise.
   • Watch out for symptoms of depression.

4. Provide referral to ISWC Social Worker and/or Community Resources
   • Home care services – private hire or Medicaid-covered care, respite home care
   • Adult Day Care Programs  [www.alznyco.org/_resourcedb/res/main.asp]
• Residential Respite Care (ALF or SNF) – private pay, M’caid (some circumstances)
• Geriatric Care Manager or Home Care  [www.caremanager.org](http://www.caremanager.org)
• Caregiver support group  [www.alznyc.org/_menu.supp/ch_prog/supp_group_loc.asp](http://www.alznyc.org/_menu.supp/ch_prog/supp_group_loc.asp) (in-person and phone groups available), support groups for non-dementia illnesses often listed on related websites
• Individual or family psychotherapist
• Educational meetings at the Alzheimer’s Association
• Caregiver magazines and newsletters

**What variables are looked at during a more comprehensive caregiver assessment?**

• Relationship of the caregiver to the care recipient (eg. spouse, parent, sibling, child, non-spouse partner)
  o Adult daughters are the most common caregivers. Several spheres of the caregiver’s life will be impacted, including marriage/family/social relationships, employment, finances.
  o Spouses of older adults may themselves have medical illness that requires care or impairs their ability to provide care. May also be grieving the loss of his/her primary companion, including the possible loss of the sexual aspect of the relationship.
• Illness(es) of care recipient (dementing vs nondementing)
  o Caregivers to older adults with dementia report higher levels of burden and depression than caregivers to individuals without dementia.
• Tasks involved in caregiving – eg., is the caregiver accompanying person to doctors appts vs. assisting with bathing and other ADLs?
• Financial resources
• Gender of the caregiver
  o More women then men are caregivers. A number of studies have found that female caregivers are more likely than males to suffer from anxiety and depression.
• Culture and ethnicity of the care recipient and caregiver - different expectations in different cultural/ethnic groups.
• Distance btwn caregiver and care recipient – living together, nearby or long-distance?
• Caregiver’s social, financial and emotional resources. Perceived obligations and willingness to provide care as well as caregiver’s subjective experience of burden.
• Quality of baseline relationship prior to onset of caregiving role.
• Care recipient’s preferences regarding and reaction to care provision.

**Conclusion:**
Caregiver strain can affect the quality of life for caregivers and those for whom they care. Assessing caregivers at risk and linking them to supports that decrease stress and burden helps ensure that caregivers provide safe and appropriate care. High caregiver burden hinders the caregiver’s ability to provide care, which leads to higher health care costs and increases risk of need to place family member in a long-term care facility. Therefore, assessing and addressing family caregiver needs helps to sustain caregivers in their ability to provide the necessary care to patients.

For additional information and/or printed materials, see:
• Alzheimer’s Association:  [www.alznyc.org](http://www.alznyc.org)  1-800-272-3900
• Family CaregiverAlliance:  [caregiver.org](http://caregiver.org)  1-800-445-8106
• National Family Caregivers Association and the National Alliance for Caregiving  [www.familycaregiving101.org](http://www.familycaregiving101.org)
• US Administration on Aging – Caregiving Resources  
  www.aoa.dhhs.gov/prof/aoaprog/caregiver/overview/overview_caregiver.asp  
• Eldercare at Home – online guide  www.healthinaging.org/public_education/eldercare  
• AARP  www.aarp.org/families/caregiving  
• CornellCARES  www.cornellcares.com  
• NYP/Cornell Environmental Geriatrics  
  www.environmentalgeriatrics.com/home_mod/alz_friendly_home.html  
• New York City Department for the Aging, 2 Lafayette Street, NYC 10007  
  Dial 311

REFERENCES


