

Caregiver Issues: Care for the Caregiver

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Dr. Needham practices full-service family medicine, providing care from "conception to resurrection." In 2013, he received the Florida Academy of Family Physicians Exemplary Full-Time Educator award. Previous awards include the Georgia Academy of Family Physicians Teacher of the Year award in 2007 and the AAFP Foundation's Parke-Davis Teacher Development Award in 1997. It is his joy and passion to teach students of medicine the wonders of the human body and spirit.

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Learning Objectives

1. Counsel, educate, and refer patients at risk for caregiver strain.
2. Adopt an assessment tool to identify patients at risk for caregiver strain.
3. Assist in the development of contingency plans in the event of caregiver illness or other life event.
4. Provide caregivers with evidence-based decision making tools to assist in advanced care planning.

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Audience Engagement System

The image displays three sequential screenshots of a mobile application interface for an audience engagement system.
Step 1: A dashboard with a grid of icons representing various CME activities.
Step 2: A list of CME events with columns for title, date, time, and status. One event is highlighted with a red arrow.
Step 3: A detailed view of a selected event, including its title, location, date, and duration. A red arrow points to a section titled 'Audience Engagement System' within the event details.

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The importance of caregivers

- Mr. Smith and his wife come for an appt. Both in their early 70's
- Mrs. Smith is pleasant but has obvious dementia.
- Thrice during 15 minutes she asks the exact same question about her health.
- You can almost see Mr. Smith break down to cry, but he holds it in.

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Caregiver statistics

1. A family caregiver is defined as a friend or relative who provides unpaid assistance to a person with a chronic or disabling condition.
2. In 2009, 66 million Americans reported at least one person providing care as an unpaid family caregiver (3 in 10 U.S. households)
3. Approximately 10 million Americans need long term care.
4. 80% of adults requiring long-term care reside at home or in the community, and 80-90% of this care is provided by unpaid family caregivers.

CDC statistics at: www.cdc.gov/aging/caregiving/assuring.htm
Collins L, Swartz K. Caregiver Care. Am Fam Physician. 2011 Jun 1;83(11):1309-1317.

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The screenshot shows the Family Caregiver Alliance website. The main navigation bar includes 'About FCA', 'Caregiver Education', 'Policy & Advocacy', 'Caregiver Connect', 'Press', and 'Contact Us'. Below the navigation is a banner image of two men, one of whom is being cared for. To the right of the image is a 'Get Involved' section with a list of options: 'Subscribe to Newsletter', 'Join an Online Caregiver Group', 'Share Your Caregiving Experience', and 'Become a Foster Caregiver'. Below this is a 'FAMILY CARE NAVIGATOR - Pick an Your State' section.

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The screenshot shows the Family Caregiver Alliance website. The main navigation bar is the same as in the previous screenshot. Below it is a 'Support Groups' section with a large image of people sitting around a table outdoors. To the right of the image is a 'Get Involved' section with a list of options: 'Get Help Area Services', 'Family Care Navigator', 'Research Registry', 'Support Groups', 'Caregiver Stories', 'Caregiving Newsletter', and 'Caregiving Products & Tools/Care'. Below this is a 'Get Involved' button.

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The screenshot shows the Family Caregiver Alliance website. The main navigation bar is the same as in the previous screenshots. Below it is a 'Resources by Health Issue or Condition' section with a large image of an elderly woman being cared for. To the right of the image is a 'Get Involved' section with a list of options: 'Health Conditions', 'Caregiving Issues and Strategies', 'Fact and Tip Sheets', 'Classes & Events', 'Calendar', 'Webinars', 'Webinars', 'Advanced Search', and 'Public Opinion Online Polls'. Below this is a 'Get Involved' button.

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Increasing Caregiver need

- Shorter hospital stays
- Changes in insurance reimbursement
- Limited hospital discharge planning
- Increase in home health care technology
- Aging U.S. population

Barriers to Practice

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The caregiver

- Mr. Hall and his wife
 - Mr. Hall – 67 yo with stable COPD and attempting to stay fit
 - Mrs. Hall – 52 yo with no chronic medical problems but anxious personality type
- Mr. Hall's 91 yo mother with Alzheimer's dementia stays at home with them
- Who is the caregiver? How many care recipients?
 - Overt and covert care recipients

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Demographics - Care recipients

- Typically female with an average age of 69.
 - They usually need help with at least one ADL
 - Bathing, dressing, eating
 - Need help with four or more Instrumental ADLs
 - Shopping, taking meds, managing finances

Collins L, Swartz K. Caregiver Care, Am Fam Physician. 2011 Jun 1;83(11):1309-1317.

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Demographics – Caregivers

- Typically female
 - Daughter or spouse of care recipient
- Average age = 49
- One third have provided care for > 5 years
- Majority provide unpaid care for 20-40 hours per week

Collins L, Swartz K. Caregiver Care, Am Fam Physician. 2011 Jun 1;83(11):1309-1317.

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Caregiver Burden

- Caring for loved ones has benefits, to include:
 - Personal fulfillment, family functioning as family
 - Satisfaction from helping to relieve another's suffering
- Burdens
 - Health
 - Finances
 - Little to no preparation for role

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Caregiver burden - Health

- Higher rates of insomnia and depression
- Less likely to engage in preventive health measures
- One-half of caregivers have at least one chronic health problem
- Spousal caregivers with high levels of strain have a 23 percent higher stroke risk as well as increase in all cause mortality. (refs)

Halley WE, Roth DL, Howard G, Safford MM. Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: differential effects by race and sex. *Stroke*. 2010;41(2):333-336.
Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*. 1999;282(23):2215-2219.

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Caregiver burden - Finances

- Work schedules adjusted
- Leaves of absence (FMLA)
- Reduce work hours
- Loss of salary and promotional activities
- Reduction in retirement savings and Social Security benefits
- Female caregivers who care for parents are 2.5x more likely to live below the poverty level

Family Caregiver Alliance. Family caregiving: state of the art, future trends. Report from a national conference. San Francisco, Calif.: Family Caregiver Alliance; 2007.

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Caregiver burden – inadequate preparation

- 80 percent of caregivers feel inadequately trained to perform the required skills
- Top unmet needs include:
 - Keeping care recipients safe at home
 - Managing emotional and physical stress
 - Finding easy activities to do with the care recipient
 - Time for themselves

Family Caregiver Alliance. Family caregiving: state of the art, future trends. Report from a national conference. San Francisco, Calif.: Family Caregiver Alliance; 2007.

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Caregiver Assessment



- Systematic process for gathering information about a caregiving situation
- Identify needs, strengths, and resources for the family caregiver.
- It can be performed by the caregiver's physician, social worker, or case manager.

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AES Question



<https://commons.wikimedia.org/wiki/File:Crisis-question-blue.png#/media/File:Crisis-question-blue.png>

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Please answer true or false:

I have ready access to a social worker in my office

- A. True
- B. False

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Caregiver Assessment

- Context in which the caregiver provides care
- Caregiver's perception of recipient's health and functional status
- Caregiver's values and preferences
- Caregiver's perception of their own well-being
- Challenges and benefits of caregiving
- Confidence in abilities to provide care

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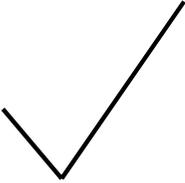
Caregiver Assessment

- Do you feel that you don't have enough time to yourself because of the time you spend with the person for whom you are providing care?
- Do you feel stressed between caring for this person and trying to meet other responsibilities (work, family)?
- Do you feel angry when you are around this person?
- Do you feel that this person currently affects your relationships with family members or friends in a negative way?
- Do you feel your health has suffered because of your involvement with this person?
- Do you feel that you have lost control of your life since this person's illness began?

Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. *Gerontologist*. 2001;41(5):652-657.

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Reality



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Caregiver Assessment – Residency version

- Do you feel that you don't have enough time to yourself because of the time you spend with ~~the person- residency for whom you are providing care?~~ **residency**?
- Do you feel stressed between caring for ~~this person~~ **residency** and trying to meet other responsibilities (work, family)?
- Do you feel angry when you are around ~~this person~~ **residency**?
- Do you feel that ~~this person~~ **residency** currently affects your relationships with family members or friends in a negative way?
- Do you feel your health has suffered because of your involvement with ~~this person~~ **residency**?
- Do you feel that you have lost control of your life since ~~this person's illness~~ **residency** began?

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Caregiver Assessment



- May be triggered by a medical condition
 - Dementia, heart failure, cancer, stroke
- Change in functional status of caregiver or care recipient
- Care transition
- Family Caregiver Alliance resources (slides 34-38)

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Supporting caregivers

Encourage care providers to care for themselves

- Take breaks
- Take care of their own health
- Eat a healthy diet
- Exercise
- Pursue preventive care
- Join a support group
- Locate respite care ("Help!")
- Prayer
- Talking with family and friends
- Obtaining information

AMERICAN ACADEMY OF FAMILY PHYSICIANS

Caregiver interventions and innovations

- Outcomes for both care recipient and caregivers are improved when they are treated as a dyad
 - (Almost sounds like Family Medicine 101)
- Automatic medication dispensers
- Vibrating alarm watches
- Scooters
- Lifting systems

Schulz R, O'Brien A, Czaja S, et al. Dementia caregiver intervention research: in search of clinical significance. *Gerontologist*. 2002;42(5):589-602.

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Tim Tebow Foundation

Prom night event for special needs children and their caregivers/parents to celebrate

By Clemmed - Own work, CC BY-SA 3.0, <https://commons.wikimedia.org/w/index.php?curid=18158946>

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Night to Shine



Screen shot from: <https://www.timtebowfoundation.org/index.php/stand-with-night-to-shine/>

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Nathaniel's Hope – Buddy Break



Screen shot from: <http://www.nathanielshope.org/events-programs/buddy-break/>

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Buddy Break



Screen shot from: <http://www.nathanielshope.org/events-programs/buddy-break/>

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Caregiver scenario - dementia

- 25% or more of caregivers care for someone with cognitive impairment.
- High levels of strain due to:
 - Behavioral disturbances
 - Intense physical needs
 - Constant vigilance
- High caregiver strain is a predictor of institutionalization
 - Identify early and provide support
 - Family Caregiver Alliance (slides 34 – 38)

Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist*. 1995;35(6):771-791.
Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*. 2002;287(16):2090-2097.

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The caregiver

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 - Mr. Hall – 67 yo with stable COPD and attempting to stay fit
 - Mrs. Hall – 52 yo with no chronic medical problems but anxious personality type
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Caregiver scenario - dementia

- 2006 meta-analysis of 127 RCTs demonstrated a small to medium benefit in:
 - Caregiver burden
 - Depression
 - Well-being
 - Coping skills
- Psychoeducation interventions with active participation of caregivers yielded the highest benefit

Pinquart M, Sörensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr*. 2006;18(4):577-595.

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Caregiver scenario - cancer

- Much of cancer care is now provided at home
- Caregivers receive little formal training to provide care
- 2006 RCT of 354 family caregivers of advanced cancer patients, coping skills intervention improved quality of life and decreased caregiver burden (ref 1)
- 2010 meta-analysis of 29 RCT's with therapeutic interventions showed small to medium effects in decreasing cancer burden and increasing coping skills, self-efficacy, and quality of life (ref 2)
- More data needed

1. McMillan SC, Small BJ, Weitzner M, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer*. 2006;106(1):214-222.
2. Northouse LL, Katsipodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin*. 2010;60(5):317-339

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Caregiver scenario – heart failure

- Patients often have frequent exacerbations with attendant hospitalizations → increased caregiver strain
- Burdens
 - Enforcing dietary restrictions and adherence
 - Monitoring for signs/symptoms of heart failure
- Telemonitoring and multidisciplinary teams may be helpful but not yet widely available.

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Caregiver scenario - stroke

- Improved stroke care is decreasing stroke disability, enabling more patients to live at home.
- Assistance with ADLs and IADLs
- Caregiver burden and emotional distress with:
 - Assistance with toileting
 - Mood disturbances
 - Memory deficits

Haley WE, Allen JV, Grant JS, Clay OJ, Perkins M, Roth DL. Problems and benefits reported by stroke family caregivers: results from a prospective epidemiological study. *Stroke*. 2009;40(6):2129-2133.

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Resource table for caregivers Advanced Care Planning

- <http://www.aafp.org/afp/2011/0601/p1309.htm#afp20110601p1309-t3>

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Transitions in care

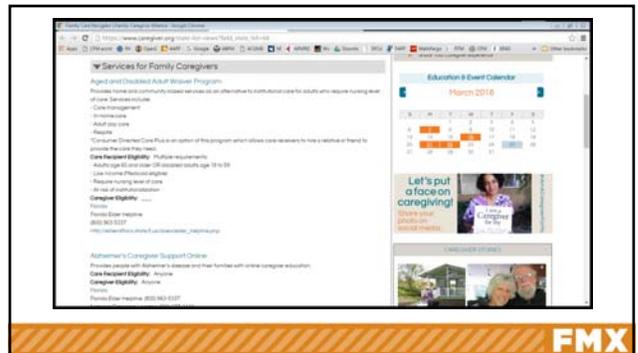
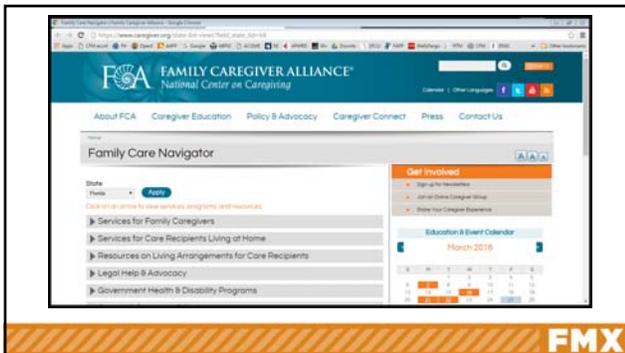
- Many caregivers experience a decrease in depressive symptoms after the death of a care recipient.
 - End of care recipient's suffering, perhaps
- Placement in a long-term care facility is not associated with positive effects
 - May increase caregiver anxiety
- Provide:
 - Anticipatory guidance, advance care planning, resources for respite, long-term, and end-of-life care

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The screenshot shows the homepage of the Family Caregiver Alliance (FCA), National Center on Caregiving. The website has a blue header with the FCA logo and name. Below the header, there are navigation links: About FCA, Caregiver Education, Policy & Advocacy, Caregiver Connect, Press, and Contact Us. A main content area features a photograph of two men, one of whom is being supported by the other. To the right of the photo, there is a section titled 'Get Involved' with a list of options: Subscribe to Newsletter, Join an Online Caregiver Group, Watch for Caregiving Events, and Become a Partner with Us. At the bottom of the page, there is a search bar with the text 'Searching for Caregiving Information? Find Your Caregiving Situation' and a 'FAMILY CARE NAVIGATOR' section with the text 'Click on Your State'.

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Best Practice Recommendations

1. Identify caregivers at risk of fatigue and strain, and screen them using an assessment tool. <http://www.aafp.org/afp/2011/0601/p1309.html>
2. Use community and web-based resources to educate, train, and support caregivers in their efforts. <https://www.caregiver.org/>
3. Use evidence-based decision tools for advanced care planning: <http://www.aafp.org/afp/2011/0601/p1309.html#afp20110601p1309-13>

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Questions

CLICK HERE

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