

Powerful Patient #10

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Caregiving – Part 1

The topic of Caregiving is vast. It is estimated that three out of every five people will be a Caregiver at some point in their lives. Some will do it for a short time – like helping a friend following surgery. Others will do it for a long time – like helping an aging parent through the last years of their life.

The American Association of Retired Persons and the National Alliance for Caregiving did a telephone survey in 1997 and again in 2004 to determine the make-up of caregivers in the U.S. They define caregiving as taking care of someone over 50. The Powerful Patient defines caregiving more broadly, as providing more than the “normal” role of the commonly expected role of friend, parent, or family member for someone who needs extra assistance, whatever their age.



Grayson and Margaret Smith

By the AARP definition, about one-fourth of U.S. households are caring for at least one family member. Three-quarters of caregivers are working at least part-time, and 54% reported making adjustments to their work to accommodate the caregiving requirements at home:

Go in late, leave early, time off during work	49%
Leave of absence	11%
Dropped back to part-time or less demanding job	8%
Lost job benefits	4%
Turned down promotions	3%
Chose early retirement	4%
Give up work entirely	6%

Caregiving can be divided into five “levels” of care based on the amount of time per week a caregiver spends at the job, and on the kinds of tasks they perform.

At Level 1, a caregiver spends less than 4 hours a week visiting, helping with shopping, changing lightbulbs, and helping with normal household chores.

At Level 5, a caregiver spends 40+ hours a week, and provides two or more personal services – helping with toilet, bathing, or other personal services in addition to household tasks.

About one-quarter of caregivers say that they find caregiving to be emotionally stressful. That percentage goes up considerably if

- The care recipient lives in the caregiver's home
- The time required increases
- The care recipient is disoriented or has dementia.

It is critically important to take good care of the caregiver. And that begins with the caregiver herself or himself, acknowledging the stress and taking steps to manage that stress, finding support in the family or community, and keeping a good balance in their life.

If the recipient of care is able to acknowledge the gift of care and cooperate, that goes a long way to keeping the caregiver. But unfortunately with dementia and other issues that can accompany age and disease, this is not always possible.

It helps a great deal if others in the family or around the caregiver are able to share the tasks and provide emotional support.

We will examine this topic from other angles in future programs.

1) Our Guests

Nancy Nitikman, a retired attorney from Boston, shared her story of taking care of parents who lived in Iowa and later in Tucson, Arizona. Although living far away, she became the primary manager for her parents of home health aides. She talks about her changing role with respect to her parents as they became more needful.

Margaret Smith (pictured above with her husband), a professional needlework artist from Memphis, Tennessee, talks about her role in the “sandwich generation,” balancing the continuing needs of her daughter and grandchildren on the one hand, and of three aging parents on the other. She shares the lessons she learned watching her mother and a neighbor caring for aging parents when she was a child, and how she is “passing on” the favor to her own parents and her husband's mother.

2) More About Caregiving

The AARP defines caregiving as taking care of someone age 50 or older who needs assistance.

The Powerful Patient defines “caregiving” as taking care of someone who needs extra assistance, whatever their age. Nonetheless, the data compiled by the AARP is useful in forming a basis and framework for discussion.

The 1997 AARP/NAC Survey is reported at
<http://www.aarp.org/research/housing-mobility/caregiving/aresearch-import-779-FS91.html>

A subset of women between ages 33 and 51 is reported at:
“Boomer Women Giving Care” can be found at
<http://www.caregiving.org/data/archives/babyboomer.pdf>

Based on this data, the National Alliance for Caregiving presented testimony to the U.S. Senate: <http://www.senate.gov/~finance/032701ghtest.pdf>

The survey was updated in 2004: Caregiving in the United States
<http://www.caregiving.org/data/04finalreport.pdf>

Metropolitan Life Insurance Company did an analysis based on this data to determine how much caregiving was costing American business, and what they might do to support their caregiving employees and reduce overall costs to business.
<http://www.metlife.com/WPSAssets/88881768001015600333V1F5.1.066.pdf>

Because of the publication of these analyses, there is greater recognition on the part of employers that it is more cost-effective for them to provide accommodation and emotional support for employees who are caregivers at home, to keep them at work, reduce their cost of recruiting and training a new employee, and help the employee to stay healthy. Employee Assistance Programs or Personnel Departments are usually the best place to start in looking for assistance at work.

For ideas and support, see:

AARP	http://www.aarp.org/families/caregiving/
National Alliance for Caregiving	http://caregiving.org/
WebMD	http://www.webmd.com/solutions/sc/caregiving
MedicineNet	http://www.medicinenet.com/caregiving/article.htm