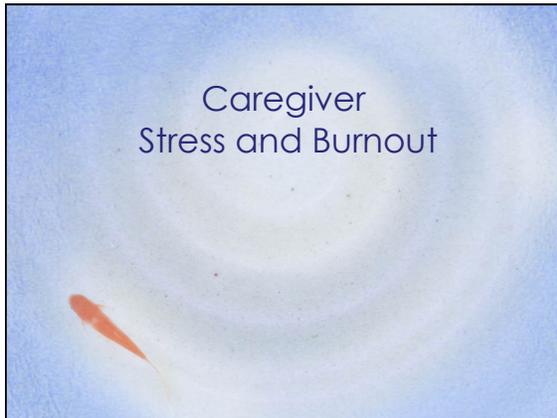


# Caregiver Stress and Burnout

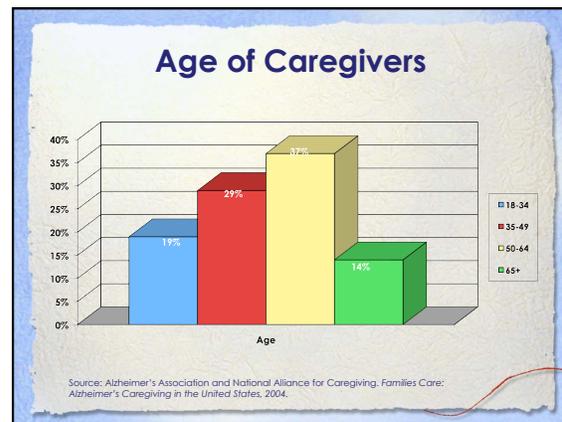


### Family Caregiving

- 10 Million Americans provide unpaid care for a person with Alzheimer's disease or other dementia.
- In 2007 they provided 8.4 billion hours of unpaid care valued at \$89 billion.

### Caregiver Tasks

- Shopping for groceries, preparing meals and providing transportation;
- Helping the person take medications correctly and follow treatment recommendations for his or her dementia and other medical conditions;
- Managing finances and legal affairs;
- Supervising the person to avoid unsafe activities, such as wandering and getting lost;
- Bathing, dressing, feeding, helping the person use the toilet or providing incontinence care;
- Making arrangements for medical care and paid in home, assisted living or nursing home care; and
- Managing behavioral symptoms.



### Impact on Caregiver's Emotional Well Being

- More than 40 percent of family and other unpaid caregivers of people with Alzheimer's and other dementias rate the emotional stress of caregiving as high or very high.
- About one-third of family caregivers of people with Alzheimer's and other dementias have symptoms of depression.
- One study of family care provided for people with dementia in the year before the person's death found that half the caregivers spent at least 46 hours a week assisting the person; 59 percent felt that they were "on duty" 24 hours a day; and many felt that caregiving in this end-of-life period was extremely stressful.
- The stress of caregiving was so great that 72 percent of the family caregivers said they experienced relief when the person died.
- Caregiver stress, especially stress related to the person's behavioral symptoms, is associated with nursing home placement.
- One study found that family caregiver stress and depression were just as high after the person was placed in a nursing home as before placement.

Source: Schulz, R.; Mendelsohn, AB; Haley, WE; Mahoney, D; Allen, RS; Zhang, S; et al. "End-of-life care and the effect of bereavement on family caregivers of persons with dementia." *New England Journal of Medicine* 2003; 349(20):1936-1942.

### Impact on Caregiver's Health

More likely than non-caregivers:

- To report that caregiving made their health worse.
- To have high levels of stress hormones, reduced immune function, slow wound healing, new hypertension, and new coronary heart disease.
- To die in the following year after their spouse passed.

Source: Christakis, NA; and Allison, PD. "Mortality after the hospitalization of a spouse." *New England Journal of Medicine* 2006; 354(7):719-730.

# Caregiver Stress and Burnout

## Caregiver Stress Test

Which of the following are seldom true, sometimes true, often true, or usually true?

- I find I can't get enough sleep.
- I don't have enough time for myself.
- I don't have time to be with other family members beside the person care for.
- I feel guilty about my situation.
- I don't get out much anymore.
- I have conflicts with the person I care for.
- I have conflicts with other family members.
- I cry often.
- I worry about having enough money to make ends meet.
- I don't feel I have enough knowledge or experience to give care as well as I'd like.
- My own health is not good.
- My care receiver needs constant supervision.
- I rarely get away from my care giving situation.

## Ten Signs of Caregiver Stress

1. **Denial** ...about the disease and its effect on the person affected.  
"I know Mom will get better. They must have made a mistake."
2. **Anger** ...at the person with dementia and others.  
"If he asks me that same question one more time I will scream."
3. **Withdrawing Socially** ...you no longer want to stay in touch with friends or participate in activities you once enjoyed.  
"I don't care about getting together with neighbors anymore."
4. **Depression** ...you feel sad and hopeless much of the time.  
"I just don't care anymore."
5. **Exhaustion** ...you barely have the energy to complete your daily tasks.  
"I don't have the energy to do anything anymore."

Source: Produced by the Alzheimer Society of Canada - Adapted from the Alzheimer's Association.

## Ten Signs of Caregiver Stress

6. **Anxiety** ...about facing another day and what the future holds.  
"I'm worried about what will happen when I can no longer provide care."
7. **Sleeplessness** ...you wake up in the middle of the night or have nightmares and stressful dreams.  
"I rarely sleep through the night, listening to hear if Dad is out of bed."
8. **Emotional reactions** ...you cry at minor upsets; you are often irritable.  
"I cried when I broke a favorite dish. Then I yelled at my Father."
9. **Lack of Concentration** ...you have trouble focusing and you find it difficult to complete complex tasks.  
"I used to do the daily crossword, now I'm lucky if I can concentrate enough to solve one quarter of it."
10. **Health Problems** ...you may lose or gain weight, get sick more often (colds, flu), you may develop chronic health problems (backaches, high blood pressure).  
"Since spring I have had a cold, I just can't seem to shake it."

Source: Produced by the Alzheimer Society of Canada - Adapted from the Alzheimer's Association.

## Identify your Stress Symptoms

- You feel constantly fatigued. Your energy reserves seem completely or increasingly drained.
- You have difficulties with sleep. Your sleep patterns change becoming irregular.
- You become increasingly irritated.
- You seem to get angry more easily.
- Your concentration is poor.
- You have short term memory problems.
- You repeat actions, chores.
- You begin to neglect your appearance.
- You neglect other family members.

## Risk Factors

- Recent studies show that 25% of American families are caring for an aging family member.
- Care giving is a risk factor for a variety of illness.
- Interleukin (IL-6) immune system molecule 4x lower in individuals caring for a spouse with dementia.
- Linked to increase risk of cardiovascular disease, osteoporosis, adult-onset diabetes.

## Risk Factors - Physical

- Feelings of exhaustion and lack of control in their lives.
- Ongoing and constant fatigue.
- Change in eating habits.
- Increased use of stimulants and alcohol.
- Effects tend to accumulate over time.

# Caregiver Stress and Burnout

## Risk Factors - Emotional

- Feelings of loneliness and depression can persist for three years after spouse passed.
- Social isolation and loss of support system.
- Emerge from care giving responsibilities with fewer social and professional contacts.
- Dealing with their own illnesses as well can contribute additional stress.

## Risk Factors - Guilt

- Feelings of guilt can be self-inflicted or imposed upon us by others.
- When guilt is warranted – spurs us to do better, if unwarranted – causes anxiety and hinders decision making ability.
- Frustration of trying to constantly “fix” things that go wrong and the fixes never seem to last.
- People are rarely prepared to accept care giving responsibilities thrust upon them from aging parents.
- Uninformed siblings sometimes only highlight primary caregiver’s shortcomings.
- Stress of care giving can expose already weak areas in a long-term relationship.

## Tips on Reducing Stress

### Stress Sources of Physical Demands

- Creating a safe physical environment, preventing falls
- Providing first aid and medical assistance as possible
- Bathing a care recipient
- Assisting with oral hygiene
- Dressing a care recipient
- Assisting with toileting needs
- Feeding or assistance with eating, nutrition needs
- Meal planning and preparation
- Lifting, turning, or transferring a care recipient
- Routine housework
- Management of behavior with care recipients who have cognitive impairment
- Other physical challenges

### Suggested Coping Tips

- Learn how to properly care for your family member. Get training so you know how to perform needed skills, which will make your work easier and safer.
- Practice healthy habits, including a balanced diet, regular exercise, sufficient sleep, and visits to the doctor.
- When needed, get help with physical tasks from other care providers, neighbors, or sources of help.
- Work to keep your care recipient as independent as possible to reduce your stress and maintain dignity.
- Utilize adaptive or assistive equipment with specific needs.

Source: Bottherson, S. and Ballal, M. Tips on reducing caregiver stress. NCDU Extension Service, Fargo, 2007

## Tips on Reducing Stress

### Stress Sources of Financial Demands

- Costs of medical care and treatment
- Costs of adaptive or assistive equipment that is needed
- Costs of hired help
- Lost income
- Reduced work hours
- Loss of employee benefits
- Management of financial concerns for care recipients
- Planning for long-term care financial needs

### Suggested Coping Tips

- Evaluate and utilize programs that assist with medical and treatment costs related to family care giving.
- Identify programs that provide assistive technology at reduced fees or on loan.
- Discuss financial needs and impacts with other family members.
- Plan ahead for projected medical costs or treatment needs.
- Work with financial planning specialists as needed.

## Tips on Reducing Stress

### Stress Sources of Emotional Demands

- Feeling alone, unaided or unappreciated
- A sense of isolation and frustration
- Insufficient time for oneself and personal activities
- Fatigue and emotional irritability
- Anger or frustration at perceived unfairness of a situation
- Discouragement or personal depression
- Loss of opportunities
- Feeling overburdened with demands from care recipient or others
- Lack of control over circumstances

### Suggested Coping Tips

- Find someone you trust and talk about your feelings or frustrations.
- Be realistic about the demands of care giving and turn to others for help.
- Set aside time for self-care and personal renewal.
- Take advantage of respite care services and get a break for a few hours or a couple of days.
- Join a caregiver support group so you can share feelings, learn about resources, and reduce stress.
- Get assistance from others.

## Tips on Reducing Stress

### Stress Sources of Relationship Challenges

- Feeling overburdened by care responsibilities so you become resentful of the care recipient
- Conflict with care recipient about care demands or plans
- Disagreement with family members about care responsibilities or plans
- Insufficient time and energy for other family relationships
- Difficulties with spouse due to care demands
- Criticism or lack of help from other family members related to care giving
- Limited communication about needs

### Suggested Coping Tips

- Focus on positive experiences with the care recipient such as sharing memories or doing a life story.
- Involve the care recipient as much as possible in discussion of guidelines for care.
- Express needs and issues clearly to other family members related to care giving responsibilities.
- Take time for other family relationships.
- Participate in a support network for caregivers and get respite care.
- Have each family member participate in care giving and express appreciation for each other.

## Solutions to Consider

- Learn to distinguish between legitimate guilt that motivates us from unwarranted guilt that leaves us dispirited.
- Resist the temptation to allow old conflicts to create guilt today. Don't be a martyr.
- Set reasonable expectations.
- Define what an emergency **is** and what it **is not**, so you can preserve personal time.
- Define what is practical and necessary... and reasonable.

## Solutions to Consider

- Write down what makes you feel guilty and examine the underlying reasons – is a solution within your power?
- Some guilt comes from thinking that you have more influence than you really do.
- Compartmentalize large problems into small ones making them more manageable.
- Tackling a few problems can give you a sense of accomplishment and build your confidence.

## Solutions to Consider

- Take care of yourself first, strive for balance.
- Consider lowering your expectations of yourself. Better to say "no" than attempt the impossible.
- Maintain personal fitness and good nutrition... protect your health, you'll need it more now than ever.
- Maintain social contacts.
- Acknowledge your emotions and find an outlet for them.
- Asking for help does not mean that you relinquish control.

## Solutions to Consider

- Try not to be disappointed when expectations are not met and gratitude is not expressed.
- When frustrated, leave the room or take a brisk walk to relieve stress.
- Talk to people, we acquire courage and support from friends who stand by us.
- Keep a positive attitude, people who become depressed are more likely to develop their own health problems.
- Breaks energize. Take time off to recharge.
- Better to be a healthy "hero" than a burned out "super-hero".

Don't allow other people to control your stress level !



## Solutions to Consider

- Pick your battles. Choose issues that concern critical health and safety.
- Try to present choices rather than ultimatums.
- Postpone confrontations, sometimes issues resolve themselves.
- Focus on the process not on a goal.
- Don't personalize.
- Learn more about the disease and its effects.

## Exercise, Exercise, Exercise

I feel like my body has gotten totally out of shape, so I got my doctor's permission to join a fitness club and start exercising. I decided to take an aerobics class for seniors. I bent, twisted, jumped up and down, and perspired for an hour. But, by the time I got my leotards on, the class was over.

## What me Exercise?



"What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?"

## Caregiver Relief

- Ask other siblings to help. Rotate tasks.
- Apply financial resources before caregiver begins to weaken.
- Apply financial resources while she can still gain benefit from a social setting.
- Once funds are exhausted Medicaid is available in most nursing homes.
- Adult Day Care.
- Respite Care & Statewide Respite Program.
- Introduces them to assisted living.

## Information Brings Control

- Geriatric Care Managers  
[www.caremanager.org](http://www.caremanager.org)
- Alzheimer's Association  
[www.alz.org](http://www.alz.org)
- Support Groups  
[www.alz.org/supportgroups.html](http://www.alz.org/supportgroups.html)
- National Family Caregivers Association  
[www.nfcacares.org](http://www.nfcacares.org)



## The Serenity Poem

*Give us the grace to accept  
with serenity the things that  
cannot be changed, courage to  
accept the things that should  
be changed, and the wisdom to  
distinguish the one from the  
other.*

- Reinhold Niebuhr

## The Senility Poem

*Grant me the senility to  
forget the people I never  
liked anyway, The good  
fortune to run into the  
ones I do and the  
eyesight to tell the  
difference.*