

# *Caring for the Caregiver: Managing the Emotional Impact of Caregiving*

Handout

Presented by:  
Kelly Collins, MA

Brought to you by:



NIH Child Care

<http://childcare.ors.nih.gov>

# Caring for the Caregiver – Managing the Emotional Impact of Caregiving

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## What We'll Cover:

- Emotions common to caregivers
- How to handle strong emotions:  
guilt, anger, depression
- Strategies for setting limits
- Taking Care of yourself
- When to ask for help
- Resources available

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## There are words for what you are going through...

- Vicarious trauma
- Empathic strain
- Cost of caring
- Compassion fatigue

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## Caregiver Emotions

- Love
- Drained
- Satisfaction
- Anger
- Pride
- Frustration
- Resentment
- Sadness/Depression
- Guilt
- Stress

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## You May Be Experiencing...

- Role Overload
- Role Reversal
- Role Confusion

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## Guilt?

- Guilt is an “alarm mechanism” within each of us that lets us know we have violated our values
- It encourages us to study our motivations and values

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## Anger?

- Can anger be constructive?
- How might we decrease anger and increase effective impact?
- What are we telling ourselves?
  - People just don't understand
  - People don't do what they are supposed to do
  - Nobody cares about me
  - Nobody wants to help me

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## Causes of Uncomfortable Feelings

- Feeling badly about your actions
- Failure to meet another's standard of behavior
- Transgressing a moral imperative
- Having empathy but not acting from empathy

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## Causes of Uncomfortable Feelings

- Dissatisfaction from our assessment of a decrease in social acceptance or contribution
- Failing to act on compassion; failing to prevent harm to an unfortunate person
- Not meeting your responsibility to others

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*Self Awareness is the enemy of  
burnout and stress.*

Activity: Resiliency Questionnaire

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### Strategies

- Identify your feelings
- Admit that the feeling exists even though it is unpleasant
- Take a step back and gain some distance from the situation
- Take time to figure out what triggers the feelings
- Talk about your feelings with someone you trust or write them down to express them
- Ask yourself, "Over **what** do I have control"?

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### Strategies - continued

- Make a plan, figure out what you can do differently when you recognize that these feelings are occurring; know specifically what you will change and how
- Remember that there **must** be a balance between your needs and those of your loved one
- Be comfortable with your limits; this means accepting what you are realistically able to do

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## Caring for Yourself

- Embrace those emotions that don't feel good
  - Use emotions as feedback
- Set time to assess and evaluate
- Set reasonable limits and enlist help
- Learn to say "NO"
- Utilize social supports
- Find opportunities for laughter
- Celebrate your efforts
- Use open and clear communication, "I" statements
- Accept apologies
- Avoid negative self-talk

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## Loehr & Schwartz

- *"Energy, not time, is the fundamental currency of high performance"*
- *"Performance, health and happiness are grounded in the skillful management of energy"*

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## Energy Maintenance

- Go to bed early and wake up early
- Go to sleep and wake up consistently at the same times
- Eat five to six small meals daily
- Eat breakfast every day
- Eat a balanced healthy diet
- Minimize simple sugars
- Drink 48 to 64 ounces of water daily
- Take breaks every ninety minutes during work
- Get some physical activity daily
- Do at least two cardiovascular interval workouts and two strength-training workouts a week

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## A Healthy Sequence

SPRINT

RECOVER

RENEW

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## Questions to Find Meaning, Purpose, and Value

- Is there anything good about this experience for me?
- How is this changing me?
- What can I learn from this?
- What is your mission statement?

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## Take Control

- What are the early warning signs
- Think creatively
- Be resilient
- Develop personal mission statements
- Make connections
- Keep it in perspective

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## Where to go for Help/Support

- Family members
- Friends
- Professional services
- Church / synagogue members
- Issue related support groups
- General support groups
- Your EAP  
<http://www.ors.od.nih.gov/sr/dohs/EAP/Pages/index.aspx>

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## Additional Support



**NIH Back-Up Care Program**

**Care When You Need It Most**  
 Children's hospitals are busy. Your children's care might be delayed. To offer NIH employees back-up care when they need to be at work and their regular child or adult care is unavailable, we offer:

- Your regular caregiver or day-at-home service is unavailable
- You are working between child or adult care appointments
- Your child's regular center or school is closed
- Your adult care provider is on medical leave or has an emergency
- Your child is unable to attend school

**Programs Available**  
 Our programs include services in the following back-up care programs:

- Center-based child care
- In-home care
- In-home visits & in-home care
- In-home adult care
- Self care

**Care Consultants**  
 Our care consultants are available to help you with the care arrangement. We will meet with you, your family, and discuss with you the options. We will help you understand the care options and the services available for your child and your family.

Register today to ensure peace of mind tomorrow.

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## Additional Support

**An Important Service for NIH Employees:**  
 If you are a caregiver, contact us for free consultation and resources to help meet your family's needs. Support is only a phone call away.  
**1-800-777-1720**

### NIH Dependent Care Resource & Referral Service



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- |                         |                          |                         |                          |
|-------------------------|--------------------------|-------------------------|--------------------------|
| Housing Options         | Home Health Aides        | Evaluating care options | Special needs resources  |
| Transportation Services | Preventing Elder Fraud   | Child care providers    | College planning         |
| Meal Services           | Long-distance caregiving | Nanny / in-home care    | Tips for paying for care |
| Adult Day Care          | Communication tips       | Back-up care resources  | And more...              |
|                         |                          | Adoption information    |                          |

This program is sponsored by the NIH Office of Research Services, Division of Amenities and Transportation Services.  
 For more information visit:  
<http://childcare.ors.nih.gov>

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## Resources

- National Alliance for Caregiving:  
[http://www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment\\_english.pdf](http://www.caregiving.org/wp-content/uploads/2010/11/caregiverselfassessment_english.pdf)
- National Family Caregivers Association  
[www.familycaregiving101.org](http://www.familycaregiving101.org)
- Medicare questions, newsletters, etc.  
<http://www.medicarerights.org/about-mrc/newsletter-signup.php>
- Communication Tips for Hospital Settings  
<http://www.familycaregiving101.org/manage/hospital.cfm>

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## Thank You

- Please take a moment to complete the evaluation form provided, your input is appreciated

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## Difficult Conversations

The most difficult subject to discuss with my older relative is...

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What makes it so hard is...

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When I discuss this topic with my older relative, I feel...

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My older relative probably feels...

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## How Resilient Are You?

Disagree Strongly	Disagree	Neutral	Agree	Agree Strongly	
1	2	3	4	5	In a crisis or chaotic situation, I calm myself and focus on taking useful actions.
1	2	3	4	5	I'm usually optimistic. I see difficulties as temporary and expect to overcome them.
1	2	3	4	5	I can tolerate high levels of ambiguity and uncertainty about situations.
1	2	3	4	5	I adapt quickly to new developments. I'm good at bouncing back from difficulties.
1	2	3	4	5	I'm playful. I find the humor in rough situations, and can laugh at myself.
1	2	3	4	5	I'm able to recover emotionally from losses and setbacks. I have friends I can talk with. I can express my feelings to others and ask for help. Feelings of anger, loss and discouragement don't last long.
1	2	3	4	5	I feel self-confident, appreciate myself and have a healthy concept of who I am.
1	2	3	4	5	I'm curious. I ask questions. I want to know how things work. I like to try new ways of doing things.
1	2	3	4	5	I learn valuable lessons from my experiences and from the experiences of others.
1	2	3	4	5	I'm good at solving problems. I can use analytical logic, be creative, or use practical common sense.
1	2	3	4	5	I'm good at making things work well. I'm often asked to lead groups and projects.
1	2	3	4	5	I'm very flexible. I feel comfortable with my paradoxical complexity. I'm optimistic and pessimistic, trusting and cautious, unselfish and selfish, and so forth.
1	2	3	4	5	I'm always myself, but I've noticed that I'm different in different situations.
1	2	3	4	5	I prefer to work without a written job description. I'm more effective when I'm free to do what I think is best in each situation.
1	2	3	4	5	I "read" people well and trust my intuition.
1	2	3	4	5	I'm a good listener. I have good empathy skills.
1	2	3	4	5	I'm non-judgmental about others and adapt to people's different personality styles.
1	2	3	4	5	I'm very durable. I hold up well during tough times. I have an independent spirit underneath my cooperative way of working with others.
1	2	3	4	5	I've been made stronger and better by difficult experiences.
1	2	3	4	5	I've converted misfortune into good luck and found benefits in bad experiences.

Total Score: \_\_\_\_\_

### Interpretation

80 or higher very resilient!

65-80 better than most

50-65 slow, but adequate

40-50 you're struggling

40 or under seek help

By Al Siebert, PhD, author of *The Resiliency Advantage*. See [www.resiliencycenter.com/resiliencyquiz.shtml](http://www.resiliencycenter.com/resiliencyquiz.shtml)

## 10 Ways to Build Resilience

1. **Make connections.** Good relationships with close family members, friends, or others are important. Accepting help and support from those who care about you and will listen to you strengthens resilience. Some people find that being active in civic groups, faith-based organizations, or other local groups provides social support and can help with reclaiming hope. Assisting others in their time of need also can benefit the helper.
2. **Avoid seeing crises as insurmountable problems.** You can't change the fact that highly stressful events happen, but you can change how you interpret and respond to these events. Try looking beyond the present to how future circumstances may be a little better. Note any subtle ways in which you might already feel somewhat better as you deal with difficult situations.
3. **Accept that change is a part of living.** Certain goals may no longer be attainable as a result of adverse situations. Accepting circumstances that cannot be changed can help you focus on circumstances that you can alter.
4. **Move toward your goals.** Develop some realistic goals. Do something regularly -- even if it seems like a small accomplishment -- that enables you to move toward your goals. Instead of focusing on tasks that seem unachievable, ask yourself, "What's one thing I know I can accomplish today that helps me move in the direction I want to go?"
5. **Take decisive actions.** Act on adverse situations as much as you can. Take decisive actions, rather than detaching completely from problems and stresses and wishing they would just go away.
6. **Look for opportunities for self-discovery.** People often learn something about themselves and may find that they have grown in some respect as a result of their struggle with loss. Many people who have experienced tragedies and hardship have reported better relationships, greater sense of strength even while feeling vulnerable, increased sense of self-worth, a more developed spirituality, and heightened appreciation for life.
7. **Nurture a positive view of yourself.** Developing confidence in your ability to solve problems and trusting your instincts helps build resilience.
8. **Keep things in perspective.** Even when facing very painful events, try to consider the stressful situation in a broader context and keep a long-term perspective. Avoid blowing the event out of proportion.
9. **Maintain a hopeful outlook.** An optimistic outlook enables you to expect that good things will happen in your life. Try visualizing what you want, rather than worrying about what you fear.
10. **Take care of yourself.** Pay attention to your own needs and feelings. Engage in activities that you enjoy and find relaxing. Exercise regularly. Taking care of yourself helps to keep your mind and body primed to deal with situations that require resilience.

**Additional ways of strengthening resilience may be helpful.** For example, some people write about their deepest thoughts and feelings related to trauma or other stressful events in their life. Meditation and spiritual practices help some people build connections and restore hope.

*If you see ten troubles coming down the road, you can be sure that nine will run into the ditch before they reach you.* Calvin Coolidge

*I have become my own version of an optimist. If I can't make it through one door, I'll go through another door - or I'll make a door. Something terrific will come no matter how dark the present.* Rabindranath Tagore

Source: American Psychological Association

## Qualities of Highly Resilient People

- 1. Playful, childlike curiosity.** Ask lots of questions, want to know how things work. Play with new developments. Enjoy themselves as children do. Have a good time almost anywhere. Wonder about things, experiment, make mistakes, get hurt, laugh. Ask: "What is different now? What if I did this? Who can answer my questions? What is funny about this?"
- 2. Constantly learn from experience.** Rapidly assimilate new or unexpected experiences and facilitate being changed by them. Ask "What is the lesson here? What early clues did I ignore? The next time that happens I will...."
- 3. Adapt quickly.** Very mentally and emotionally flexible. Comfortable with contradictory personality qualities. Can be *both* strong and gentle, sensitive and tough, logical and intuitive, calm and emotional, serious and playful, and so forth. The more the better. Can think in negative ways to reach positive outcomes. "What could go wrong, so it can be avoided?"
- 4. Have solid self-esteem and self-confidence.** Self-esteem is how you feel about yourself. It determines how much you learn after something goes wrong. It allows you to receive praise and compliments. It acts as a buffer against hurtful statements while being receptive to constructive criticism. "I like, appreciate, and love myself...."
- 5. Self-confidence is your reputation with yourself.** It allows you to take risks without waiting for approval or reassurance from others. You expect to handle new situations well because on your past successes. "These are my reliable strengths...."
- 6. Have good friendships, loving relationships.** Research shows that people in toxic working conditions are more stress resistant and are less likely to get sick when they have a loving family and good friendships. Loners are more vulnerable to distressing conditions. Talking with friends and family diminishes the impact of difficulties and increases feelings of self-worth and self-confidence.
- 7. Express feelings honestly.** Experience and can express anger, love, dislike, appreciation, grief--the entire range of human emotions honestly and openly. Can also choose to suppress their feelings when they believe it would be best to do so.
- 8. Expect things to work out well.** Deep optimism guided by internal values and standards. High tolerance for ambiguity and uncertainty. Can work without a job description, is a good role model of professionalism. Has a synergistic effect, brings stability to crises and chaos. Ask "How can I interact with this so that things turn out well for all of us?"
- 9. Read others with empathy.** See things through the perspectives of others, even antagonists. Win/win/win attitude in conflicts. Ask "What do others think and feel? What is it like to be them? How do they experience me? What is legitimate about what they feel, say, and do?"
- 10. Use intuition, creative hunches.** Accept subliminal perception and intuition as valid, useful sources of information. Ask "What is my body telling me? Did that daydream mean anything? Why don't I believe what I'm being told? What if I did this?"
- 11. Defend self well.** Avoid and block attacks, fight back. See through and side-step cons, "games," and manipulations that others attempt. Find allies, resources, and support.
- 12. Have a talent for serendipity.** Learning lessons in the school of life is the antidote to feeling victimized. They can convert a situation that is emotionally toxic for others into something emotionally nutritious for them. They thrive in situations distressing to others because they learn good lessons from bad experiences. They convert misfortune into good luck and gain strength from adversity. A good indicator of exceptional mental health is when a person talking about a rough experience says "I would never willingly go through anything like that again, but it was the one of best things that ever happened to me." Ask "How can I turn this around? Why is it good that this happened? What is the gift?"
- 13. Get better and better every decade.** Become increasingly life competent, resilient, durable, playful, and free. Spend less time surviving than others and survive major adversities better. Enjoy life more and more.

## What Services Are Available When Your Loved One Needs Additional Support?

Each community has services that are available to their aging residents. The services vary depending on the community. The following is a list of programs that may be available:

- **Senior Centers**- these community centers provide a variety of activities to seniors; may include arts and crafts, meals, pool playing, socialization, etc. Usually free.
- **Adult Day Program**- programs providing socialization, meals, therapies, and health care; these programs typically provide transportation and the cost is usually on a sliding scale. The cost might be thirty dollars a day; some are government subsidized.
- **Transportation Services**- cars, wheelchair accessible vans, buses, etc. can provide transport to and from doctor appointments, grocery shopping, church, etc. Free or minimal charge.
- **Meal Programs**- Group dining at a community center or meals delivered to home. Home-delivered meals, usually through the Meals on Wheels program provide warm, nutritional meals to homebound residents; the cost is minimum and waived at times.
- **Friendly Visitors/Companions**- this service may be volunteer-based, fee for service, or via private agency; non-medical individuals visit to provide socialization and assistance with chores; they may also be willing to provide telephone check-ins. \$5 - \$15 per hour, some free through state-funded programs.
- **In-Home Personal Care Agencies**- these agencies provide home health aides to assist with light housekeeping, light meal preparation, and assistance with personal hygiene (bathing, dressing, toileting, etc.) \$8 - \$30 per hour, although some areas offer free or sliding scale homemaker services.
- **Telephone Reassurance and Visitors**- Phone calls or brief visits to check on your parent's well-being. Free or minimal charge.
- **Emergency Response Systems**- older adults can be monitored 24 hours a day by wearing a pendant with an emergency button; when activated a call will be made to ascertain the client's needs; 911 will be called if help is needed or if there is no response.

## Home Care Services & Providers

- **Home health aides**- Personal care (bathing, feeding, etc.), some medical care and light housekeeping. Helps person with Activities of Daily Living (ADL's), will notify doctors if problems arise as needs change. \$50 per visit (usually anywhere from 2 to 4 hours), or \$10-\$15 per hour may be covered by Medicare.
- **Home therapists**- Training in communication, physical movement or doing daily tasks. \$85 per visit (from a half-hour to 2 hours), may be covered by Medicare.
- **Skilled Nurses**- Skilled nurses coordinate health care with doctors, agencies, and individuals who are involved. They can teach patients how to care for themselves or teach family members how to care for the older person. \$90 per visit (from a half-hour to 2 hours), may be covered by Medicare.
- **Geriatric care managers**- Management of some or all of your parent's care. Coordinates health care services when other doctors, agencies, or other individuals are involved; teaches elderly how to care for themselves; teaches family members to care for elderly; plans for further care based on changing needs. \$30 - \$150 per hour.
- **Respite care**- A break for caregivers, from a few hours to a few weeks. Cost varies; some are subsidized and some use volunteers.
- **Occupational therapist**- assessment of physical and mental limitations; makes recommendations of adaptations to current living environment.
- **Physical therapist**- provides therapy to help older persons recover their mobility after an illness, stroke, or accident.
- **Speech therapist**- A speech therapist provides therapy to help a person regain or improve speech.
- **Nutritionist**- Nutritionists provide counseling services that may include instruction for preparing meals or special diets.
- **Social Worker**- Social workers offer assistance with the emotional aspects of illness.

*Medicare coverage of home care services is time limited and must be prescribed by treating physician.*

## How to Say It: Words That Work

The following are examples of effective ways to express your thoughts and feelings to your older relative:

### ■ Phrases that show acceptance

I can understand if such and such makes you angry.

I hear your point of view.

I know that you're trying to do all that you can to manage, and I respect you for that.

I know you thought things would work out differently.

### ■ Phrases that show reassurance

We'll try to help as much as we can.

We know that this is difficult for you to do.

Hopefully, you'll feel more like yourself in a few weeks.

The doctor says that you will be able to do (such and such) within time.

### ■ Phrases that show respect

I can understand why you'd feel that way.

Your opinions show that you've thought this through carefully.

Your opinions are important, and your wishes are what we're striving for.

I hadn't looked at it that way before now.

I accept your opinion because I love and respect you, but I see it differently.

Would you like to try it yourself, or would you like some help?

The following are phrases to avoid saying since they serve as barriers to effective communication:

### ■ Being patronizing

It's time to take 'our' medicine.

Dearie, let me help you get dressed.

Mom, it's like I'm the mother now, and you're the child.

### ■ Making decisions for the older relative

You need to do (such and such).

You cannot drive any more.

We know what's best for you.

- **Making the older relative feel guilty**

After everything I do for you, this is the thanks that I get.

I'll help you, Mom, but that means I have to take a whole day off from work.

Dad, you know that I have too much to do, but I'll take care of that for you anyway.

You think that you have problems, well you haven't heard about so and so.

Are you doing everything that the doctor said you should?

That's no big deal.

Why don't you ever want to do what I suggest?

- **Being judgmental and critical**

Of course you should sell your house and move into a small apartment.

Don't you think that you ought to keep your home cleaner?

Aren't you trying to act like you are twenty?

You're not as neat as you used to be.

- **Withholding important information**

Mom doesn't need to know this.

What she doesn't know won't hurt her.

We don't have to tell Dad what the doctor said.

- **Giving false reassurance**

Of course you'll never have to live in a nursing home.

I promise I'll never put you in a nursing home.

You'll be up and about in no time at all.

Everything will be just perfect. Don't worry.

That's nothing to be depressed about.

## Elder Care Resources

The following are resources that may assist caregivers in locating the appropriate information and services to provide loved ones with the highest quality of care.

- **Eldercare Locator**, [www.eldercare.gov](http://www.eldercare.gov), 1.800.677.1116 - Assistance with accessing an extensive network of organizations serving older people at state and local community levels.
- **National Institute on Aging (NIA)**, [www.nia.nih.gov/](http://www.nia.nih.gov/)
- **National Council on the Aging**, [www.ncoa.org/](http://www.ncoa.org/), 202.479.1200  
Offers resources, programs and services designed for professionals and caregivers who work with older adults.
- **FirstGov for Seniors**, [www.firstgov.gov/Topics/Seniors.shtml](http://www.firstgov.gov/Topics/Seniors.shtml)
- **U.S. Administration on Aging**, [www.aoa.gov/](http://www.aoa.gov/)
- **American Association of Homes and Services for the Aging**, [www.aahsa.org](http://www.aahsa.org)  
National association of non-profit homes, housing, health-related facilities, and community service organizations.
- **Continuing Care Accreditation Commission (CCAC)**, [www.ccaonline.org](http://www.ccaonline.org)  
The nation's only accrediting commission for non-profit and for profit continuing care retirement communities.
- **Homecare On-line**, [www.nahc.org](http://www.nahc.org)  
Provides information on home and hospice care; helpful in locating agencies.
- **National Citizen's Coalition for Nursing Home Reform**, [www.nccnhr.org](http://www.nccnhr.org)  
Monitors long-term care facilities and promotes "positive care planning" approach.
- **Senior Sites**, [www.seniorsites.com](http://www.seniorsites.com)  
Provides listings of non-profit senior housing, assisted living facilities, and retirement communities that are members of the American Association of Homes and Services for the Aging.
- **The American Geriatrics Society**, 212.308.1414 - Offers a partial list of geriatric centers around the country. If service is needed in Maryland, call Aging Services at 410.767.6767. They will conduct an evaluation to identify services available to help older adults remain independent.
- **National Academy of Elder Law Attorneys**, 520.881.4005  
Organization of attorneys who specialize in areas such as estate planning, long-term care and admissions into continuing care retirement communities, health law, and management of trusts and estates.
- **National Family Caregivers Association**, 301.942.6430  
Non-profit corporation that publishes the newsletter, TAKE CARE! and informational resources.
- **American Association of Retired Persons**, 202.434.2277 - Includes health information brochures, discount pharmacy, supplemental group insurance, financial investment programs, and lodging and care-rental discounts.
- **Veteran's Benefit Information**, 1.800.827.1000 - Can provide answers to questions regarding health care benefits/programs.
- **Medicare Hotline**, 1.800.MEDICARE  
Can provide answers to questions regarding Medicare information, telephone numbers, and updated information.

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*If you are a caregiver, contact us for free consultation and resources to help meet your family's needs. Support is only a phone call away.*

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**This program is sponsored by the NIH Office of Research Services,  
Division of Amenities and Transportation Services.**

**For more information visit:  
<http://childcare.ors.nih.gov>**

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An affiliate of Adventist HealthCare, Inc

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Kelly Collins holds a Master's degree in Counseling Psychology from Marymount University and B.S. degree in Business from Virginia Tech. For over 15 years, Kelly has worked with both public and private sector organizations to educate, counsel, and support employees and their families regarding personal and professional development issues. She has worked in several Department of Defense facilities in addition to working for several years at Potomac Ridge Psychiatric Hospital.

For the past ten years, Kelly has worked with corporate employee assistance programs to meet the work/family and mental health needs of employees and their families. Her responsibilities have included program development, training, and project management.

Kelly delivers seminars on a range of topics from stress management to personal development to effective communication. She draws from her professional education and training, and her personal experience as a mother of two and a resident of Montgomery County, MD.

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