

Switching Caregiving Roles with an Older Relative or Parent

Handout

Presented by:
Hazel Osborn, MA



Sponsored by NIH Child Care Board & Office of Research Services/
Division of Amenities and Transportation Services

**Switching Caregiving Roles
with Your Older Relative or Parent**



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Seminar Agenda

- Caregivers today – Balancing work & life
- Roadblocks to successful communication
- How to define communication priorities
- Strategies for effective communication
- Communicating across state lines
- Working with siblings

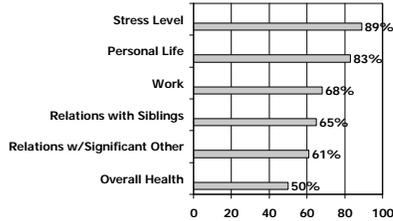
**Caregivers Today:
Who are the Caregivers?**

- Caregiving is a family affair
- Women are the primary caregivers but that is changing
- 65% of all caregivers are aged 35-64
- Shrinking pool of family caregivers
- Over 60% of caregivers are working full or part-time. More than 40% also care for children under 18.
- 47% of caregivers are employed and 71% are employed full-time.
- Caregivers dedicate on average 18 hours per week to provide care for older persons and even more when the person has multiple disabilities.

Caregivers Today: What is the Impact?

Nearly nine in ten caregivers say that their caregiving activities have affected their stress level and eight-in-ten say it has affected their personal life.

% SOMEWHAT/A GREAT DEAL CAREGIVING ACTIVITIES HAVE AFFECTED



Communication

- The most difficult subject to discuss with my older relative is...
- What makes it so hard is...
- When I discuss this topic with my older relative, I feel...
- My older relative probably feels...

Effective Communication Roadblocks

- **Ideas about Aging**
When you think of an aging person... what comes to mind?
- **Myth of Role Reversal**
Relationships will never reverse – they will redevelop!!!
- **Family Rules & Expectations**
Past "rules" are hard to break
- **Feelings**
Caregiver and older relative's feelings both need to be taken into considered

What if they don't listen to me???

Join the Club!

Did you always listen to them while growing up?!

- Be sensitive to apprehension
- Revisit the conversation on a regular basis
- Allow your elder loved one to live by his/her wishes
- Quality of life vs. risk and danger
- Your comfort level compared to their living situation when there is no imminent risk
- NOW IS THE TIME TO INITIATE OR CONTINUE ACTION PLANS

Communication Priorities: *What are Their Needs?*

Observe, Ask, Discuss Your Concerns

Without an imminent move or the start of in-home services, it is time to investigate and discuss needs.

- Social
- Nutritional
- Physical
- Emotional
- Medical

Communication Priorities

- Discuss homecare vs. housing preferences
- Identify current financial needs and potential future needs - personal and financial records
- Find out what your loved one's wishes are relating to end of life care, funeral arrangements and medical directives, e.g., advance directives, health care proxy, living will
 - BEFORE a crisis happens

**Communication Priorities:
*Safety IS the Issue***

- If your loved one is at risk and you have gained legal authority to proceed; it may be helpful to elicit the assistance of a physician, case manager, or lawyer.
- If you believe that a risk exists, but you have no legal authority to proceed and your loved one refuses to cooperate, then seek the advice of an attorney well versed in elder law and competency issues or call your Area Office on Agency.

Effective Communication

- Pay attention to content and underlying feelings
- Reflect upon and paraphrase what older relative says
- Provide verbal and non-verbal encouragement
- See yourself as the "listener" - not the "changer"

Effective Communication

- Use open-ended questions
- Use "I" statements
- Agree to disagree
- Use silence and humor, when appropriate

Managing Difficult Conversations

- Decide on purpose and goal
- Anticipate older person's response
- Do your homework; check with a professional
- Choose a mutually agreed upon time to talk
- Choose battles carefully
- Make intentions clear
- Use the techniques of effective communication
- Allow older loved one as much control as possible

Communicating from a Distance

- Know issues before talking
- Assign only a few tasks to each call
- Capitalize on relative's strengths
- Realize differences in approach and feelings
- Don't make assumptions
- Resist urge to hang up when frustrated
- Try writing letters, if appropriate

Working with Siblings

If you are the Primary Caregiver...

- Involve family members now
 - Consider holding a family meeting
- Listen to the concerns of siblings and others
- Draft a "job description" listing all the tasks that need to be performed. Let your siblings help revise it, taking on some of the responsibilities
- Keep them informed and up-to-date as the situation changes

Working with Siblings

If you are a secondary caregiver...

- Maintain or renew your relationship with your elder by visiting or calling regularly.
- Support the primary caregiver by offering to help in the ways that you can.
- Be sure to thank the primary caregiver for the work he or she is doing.
- Lend an ear to the primary caregiver. Even if you do not have answers to the day to day dilemmas, you can provide opportunity for them to talk to help reduce their stress.

Scenario – Home for the Holiday

- The possibility of relocating mom and dad closer to one of the kids
- The house and mom's personal hygiene not being what it's always been
- Dad's agitation and forgetful behavior
- Mom's being worn out and her decreased mobility

Additional Resources:

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**



NIH Employees, trainees and contractors have free, unlimited access to a Work/life Specialist, who can help you to assess your caregiving role and support you by providing a range of resources and referrals. Examples include:

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://does.ors.od.nih.gov/childcare>.

Communication Roadblocks



Ideas about Aging- *When you think of an aging person... what comes to mind?*

- Preconceived ideas about aging
 - Frail
 - Needs to be taken care of
 - Can no longer “think” for themselves
 - Confusion/dementia
 - Can not interpret the world we live in today
 - And the list goes on...



Myth of Role Reversal- *Relationships will never reverses – they will redevelop!!!*

- Often adult children do not agree with the decisions their elder loved one makes
- Reality is few of us will “buy into” something we had no part in creating
- Crucial to include loved ones in conversations regarding their future



Family Rules & Expectations

- Past “rules” are hard to break
- One person tends to emerge as the natural leader
- Roles of other siblings and loved ones
- Predetermined course of action
- Expectations



Feelings

- Caregiver’s mixed emotions
- Caregiver’s anger
- Caregiver’s guilt
- Impact of caregiver’s additional responsibilities
- Older relative’s feelings; loss of control
- Older relative’s “resistance”

Communication Tips

S - State the main point of your concern/message

I’d like to talk to you about....

H - Highlight other important relevant points

I feel it is important that I understand your preferences about...

A - Assure the receiver’s understanding

Do you understand why this is so important now?

R - React and reflect about how the receiver responds

“I understand your concern about...”

E - Emphasize / summarize your main ideas

We don’t have to make definite plans right now, but let’s contemplate the options and talk more about this next week

Identifying Your Older Relatives Needs

As our bodies age, it becomes more difficult to perform daily functions that we once took for granted. If you are concerned with a loved one's increasing difficulty with daily tasks, observation of the person's abilities can be your strongest tool. If you observe a significant number of the following issues, consider consulting a specialist.

Daily Living

- Trouble grocery shopping
- Difficulty cooking and eating
- Less frequent or poor housekeeping
- Difficulty bathing
- Poor mobility
- Trouble with dressing
- Cannot drive safely
- Cannot use public transportation safely

Physical

- Recent health problems
- Loss of vision or hearing
- Repeated falls
- Lack of hygiene
- Incontinence
- Needs "assistive" device (cane, walker)
- Memory lapses

Side Effects from Medications

- Cognitive orientation
- Impaired thinking
- Impaired communication (verbal/ written)
- Unawareness (of people, places, time)
- Inability to account for time

Financial

- Not paying bills on time
- Drastic changes in routine
- Unable to balance checkbook
- Not able to account for spending

Behaviors

- Aggressiveness
- Abusiveness
- Lethargy or apathy
- Complains about boredom
- Neglects appearance

It is always wise to take a proactive stance on safety issues. However, please keep in mind that your relative may not agree with your assessment and may continue to lead his/her life as he/she sees fit.

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

Legal Tools for Older Relatives

TOOLS	DEFINITION	COMPETENCY	WHEN TO USE	WHOM TO GO TO
Guardianship or Conservatorship	Guardian appointed by court to manage property and/or personal affairs of incompetent person. Conservator appointed by court but usually manages person's assets - not personal affairs.	Person must be found to be legally incompetent by judge	Legal tool of last resort. Necessary when incapacitated person did not sign durable power of attorney and/or decision-making is creating risk of harm to self or others.	Attorney is usually necessary because procedures can be very complicated. Laws vary state to state.
Representative Payee	Person authorized to receive Social Security payments on another's behalf. Less than restrictive legal option.	Social Security recipient must be found to be unable to manage monthly payments.	Useful when Social Security is only income. Simpler way of assisting incompetent person than going to court to obtain guardianship.	May apply directly to Social Security Administration. Attorney not needed.
Power of Attorney	Legal document that authorizes another person to act as agent for decisions or transactions that are specified in the document. Authority can be broad or limited and can be limited to a particular period of time. Only effective as long as principal (person giving authorization) is competent.	Must be competent to sign.	Legal tool used mainly for convenience so that financial matters may be handled by someone other than the principal (older relative).	Consult with attorney.
Durable Power of Attorney	Same as Power of Attorney except that it continues to be effective even if principal is no longer competent.	Must be competent to sign durable power of attorney.	Should be executed as part of making plans for potential incapacity.	Consult with attorney.

<p>Medical Power of Attorney or Health Care Proxy</p>	<p>Like Durable Power of Attorney. Governs health care decisions. Most states include this as part of their advanced directive option. Can be broad or narrow. Can give principal's agent: access to medical records, consent to or refusal of medical treatment or diagnostic procedures, right to employ or discharge medical providers.</p>	<p>Must be competent to sign. Goes into effect only if signer loses ability to give informed consent to medical treatment.</p>	<p>Should be executed as part of plans for potential incapacity.</p>	<p>No attorney needed. Use state-specific forms.</p>
<p>Living Will</p>	<p>Legal document that allows signer to state wishes about use of life-sustaining medical procedures. Most states include this as part of their advanced directive option. Applies to terminal illness and serious accidents.</p>	<p>Must be competent to sign. Goes into effect only if signer loses ability to give informed consent to medical treatment.</p>	<p>Should be executed as part of plans for potential incapacity.</p>	<p>No attorney needed. Use state-specific forms.</p>
<p>Trust</p>	<p>Legal entity that gives a trustee instructions on how to use the property in the trust for specified beneficiaries.</p>	<p>Must be competent to sign.</p>	<p>Living trusts and Testamentary trusts have different objectives and effective dates.</p>	<p>Consult with attorney to find out if either type or none is needed.</p>

Caring for the Caregiver:

Tips on Staying Healthy

Caregiving is a tremendous responsibility that can turn into a full-time job with overtime. At times being a caregiver, you may experience feelings of resentment, frustration, anger, annoyance, or discouragement. It is important to care for yourself, as well as your loved one, during this time. All too often, caregivers feel pressured to "fix" every problem whether small or large. The majority of caregivers have other responsibilities in their lives such as full-time careers, children, spouse, and other relationships/ friendships. The following are tips to stay healthy and well balanced when caring for a loved one:

- ❖ Be sure to set realistic limits for yourself and your loved one. It may be too great a challenge to provide full care twenty-four hours a day, seven days a week and remain happy and content with life. Sit down and think about all of your commitments/ responsibilities. How much time can you devote to caring for your loved one without feeling resentful? Neglecting other responsibilities is a trap that caregivers often unknowingly fall into.
- ❖ Take time for yourself. Realize that you need time to rejuvenate and recharge your battery! It may mean taking a walk in the neighborhood, getting your hair done, or going shopping. Schedule this down time for you. When you're happier, so is the loved one you are caring for.
- ❖ Participate in an area support group. This is an opportunity to meet others who may be experiencing much of the same feelings that you are. It helps to validate and normalize our own concerns when others are sharing similar ones. This is also the time to share your problems with others, and talking openly can be quite cathartic.
- ❖ Enlist the help of other family members, friends, and neighbors, or hire professionals to assist in supporting you and your loved one. It is often a good idea to have monthly family meetings (with your loved one involved also) to discuss the present schedule and future plans of care.
- ❖ Make a strong effort to exercise, to eat healthy foods and to schedule enough time for a good night's sleep.
- ❖ Be positive and gentle with yourself. Remember that you are caring for a loved one and you should be proud of your accomplishments. Your role as caregiver is promoting your loved one's quality of life with dignity.

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.

- **Alzheimer's Association**,
The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.
<http://www.alz.org/nca/>
<http://www.alz.org/maryland/>
- **Eldercare Locator**, 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/
- **National Council on the Aging**, 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
- **U.S. Administration on Aging**, www.aoa.gov/
- **American Association of Homes and Services for the Aging**, www.aahsa.org
National association of non-profit homes, housing, health-related facilities, and community service organizations.
- **Continuing Care Accreditation Commission (CCAC)**, www.ccaconline.org
The nation's only accrediting commission for non-profit and for profit continuing care retirement communities.
- **Homecare On-line**, 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
Monitors long-term care facilities and promotes "positive care planning" approach.
- **Senior Sites**, 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.

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



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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 |
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| | | Adoption information | |

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For more information visit:

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

Presenter Bio

Hazel Osborn, M.A.

Hazel Osborn holds degrees in psychology, sociology, and anthropology, and a graduate degree with a focus on research in work balance issues. Since 1991 she has worked in the DC metro area offering consulting and training seminars on a variety of workplace issues with a focus on personal and professional growth. She has provided services to over sixty corporations as well as hundreds of family care facilities. She has published several articles in professional journals, several adult training curricula and newsletters, and two books. Hazel also works with LifeWork Strategies to deliver training and parent coaching.