

Section 2

Caregiving and Family Relations



10 Warning Signs Your Older Family Member May Need Help

Changes in physical and mental abilities that may occur with age can be difficult to detect—for older adults and their family members, friends, and caregivers too. To help in determining when an older adult may need assistance in the home, the Eldercare Locator has compiled a list of 10 warning signs. Any one of the following behaviors may indicate the need to take action. It is also important to inform the older adult's physician of these physical or psychological behavior changes.

Has your loved one:

- Changed eating habits, resulting in losing weight, having no appetite, or missing meals?
- Neglected personal hygiene, including wearing dirty clothes and having body odor, bad breath, neglected nails and teeth, or sores on the skin?
- Neglected their home, with a noticeable change in cleanliness and sanitation?
- Exhibited inappropriate behavior, such as being unusually loud, quiet, paranoid, or agitated, or making phone calls at all hours?
- Changed relationship patterns, causing friends and neighbors to express concerns?
- Had physical problems, such as burns or injury marks, which may result from general weakness, forgetfulness, or misuse of alcohol or prescribed medications?
- Decreased or stopped participating in activities that were once important to them, such as bridge or a book club, dining with friends, or attending religious services?
- Exhibited forgetfulness, resulting in unopened mail, piling of newspapers, not filling their prescriptions, or missing appointments?
- Mishandled finances, such as not paying bills, losing money, paying bills twice or more, or hiding money?
- Made unusual purchases, such as buying more than one subscription to the same magazine, entering an unusually large number of contests, or increasing purchases from television advertisements

Through the Eldercare Locator, older adults and their loved ones can get connected with information on local aging resources that offer assistance for aging in place, enabling older adults to continue living independently in their homes and communities.

For additional information on programs and services for older adults and their caregivers in your area, contact the Eldercare Locator at 800-677-1116 or www.eldercare.gov.

Source: Eldercare Locator, a public service of the Department of Health and Human Services, 4/27/2012

Informed Care Planning

Helping older relatives or friends plan and make informed decisions about future care.

As a family caregiver, you willingly offer comfort, support, and assistance to maximize a relative's well-being. In this role, it is important to identify problems that may exist, assess what is needed, and gather the most relevant information so that together you and your relative can make the best possible decisions regarding current and future care needs.

For assistance in making care planning choices or for information on the resources and options available for caregivers in Pima County, call Pima Council on Aging (PCOA) and ask for a referral to a Caregiver Specialist.

Frequently Asked Questions about How to Make Good Care Planning Decisions

I feel overwhelmed and at a loss. I think my relative needs care beyond what I am able to provide as a family caregiver. How do I begin? What are my options?

If you have been tending to all of your relative's caregiving needs, it may be time to take a step back and evaluate what you can and cannot realistically continue to provide. Call PCOA at (520) 790-7262 for a referral to a Caregiver Specialist who can discuss your particular caregiving situation and provide you with resources and options that may help.

My relative and I are ready to sit down and develop short- and long-term care plans. Where do we start?

Before developing a care plan, it may help to ask yourself and your relative the following questions and use the answers to guide you in the care planning process.

- What are my relative's wishes and preferences regarding future care?
- Is my relative willing to accept assistance from others (friends, family members and/or paid help)? If not, how can I address his or her concerns while also helping my relative understand I can't do everything on my own?
- Who among family members and friends will be able and willing to help?
- What type of contributions can others make to the care of my relative?
- Who among family members and friends is my relative most likely to trust?
- How much money is available to put toward the care needed?
- Is my relative eligible for publicly-funded long-term care services?

Talk over important problems with persons you trust. If you and your relative feel unable to pinpoint what you really need, try asking a friend, another family member and/or seek professional advice.

What areas should I consider when helping my relative plan for care?

The following is a list of resources and options that you may want to consider when planning care for a relative. If you would like to talk in depth about any or all of the following options and how they can help you in your caregiving role, call PCOA at (520) 790-7262 and ask for a referral to a Caregiver Specialist.

- **Advance Directives:** Do you know what your relative would want if he or she became unable to communicate? Talk to your relative about completing advance directives such as a living will, health care and financial powers of attorney, and pre-hospital medical directives. These documents allow your relative to state what kind of medical care he or she would want in certain situations and grant decision-making abilities to another person who can ensure that your relative's wishes are followed. Call PCOA at (520) 790-7262 for a list of elder law attorneys who can help, or visit the Arizona Attorney General's website for more information and advance directive forms: www.azag.gov/seniors/life-care-planning.
- **Home Health Services:** Home health services, such as bathing assistance, housekeeping, and companion care, are available through a number of agencies for costs ranging from about \$17 to \$26 per hour depending on the specific tasks requested, skill level required, number of hours per week, agency standards, etc. Most agencies require a 2 to 4 hour minimum for each visit but some will offer a shorter visit at a higher rate. Live-in care is usually \$250/day or more and the caregiver must be able to sleep 8 hours/night. Medicare only pays for limited homecare when a person is homebound and is receiving skilled services ordered by a physician and provided by a Medicare certified agency. Medicare does not pay for custodial care (see p.156 for definition). Other payors for home health care are: Long Term Care Insurance, the Veterans Administration, the Arizona Long Term Care System (ALTCSS) or the Community Services System (CSS) if eligibility criteria are met. For a fee, Home Health Placement Agencies can provide screened, private caregivers who may charge a lower hourly rate than an agency, but the older adult or family is responsible for supervision, payroll, scheduling, taxes, workman's comp, etc. To find an agency or placement service, look in the phone book or do an online search for "Home Health" or call PCOA.
- **Housing:** Is it possible your relative's care needs could best be met in an assisted living facility? In addition to providing 24/7 care by a trained staff, assisted living placement also offers increased opportunities to socialize. For information on assisted living, the criteria to use when looking for assisted living, and lists of other housing options in Pima County, call PCOA at (520) 790-7262 or visit www.pcoa.org.
- **Meal Services:** Home delivered meals and socialization and nutrition services are available throughout Tucson and parts of Pima County. Call PCOA for nutrition program locations or to determine which agency delivers home delivered meals in your area. A \$2 donation is suggested for home delivered meals; donations are also requested at socialization and nutrition sites. Mobile Meals of Tucson provides meals for people with special dietary needs or circumstances in Tucson and Green Valley. Call (520) 622-1600. The Mobile Meals program of Interfaith Community Services (520) 297-6049 serves the Northwest area of Tucson. Both programs offer a sliding scale fee based on income. For a list of private pay home delivered meal options, call PCOA at (520) 790-7262 or go to www.pcoa.org.

- **Transportation:** Contact PCOA or go to www.pcoa.org for a list of transportation options in Pima County. Cost depends on distance, so remember to ask for estimates. Some home care agencies may include transportation in their services. Volunteers provide transportation in some areas through PCOA's Neighbors Care Alliance. Call PCOA at (520) 790-7262. Handicar and Sun Van provide door-to-door transportation for those meeting American Disabilities Act (ADA) criteria. Call (520) 791-5409 for more information or to request an ADA application.
- **Respite:** Do you get so wrapped up caring for your relative that you neglect to take care of yourself? It's important to take a break from caregiving responsibilities from time to time to avoid caregiver burn-out. Arranging respite care for your relative by a friend, family member, home health agency, or other program might provide you with the breathing space you need. It's also a good idea to think about who can provide care to your relative if you become unavailable due to an emergency. Would a family member be able to step in? Would you need to hire a home health agency or arrange temporary placement at an assisted living facility? For information about respite options call PCOA (520)790-7262.
- **Adult Day Health Care:** PCOA maintains a list of adult day health care options. Prices and minimum time requirements vary. Contact Handmaker's Jewish Services for the Aging in Tucson at (520) 547-6037 or Casa Community Services in Green Valley at (520) 625-2273. Funding may be available through ALTCS, CSS, or the VA if eligibility criteria are met. Some Assisted Living facilities also offer day care. Handmaker's offers "The Adventure Bus"—a program of cultural events and field trips for persons with early stage memory loss.
- **Durable Medical Supplies:** Some medical equipment may be covered by Medicare or other insurance providers. Equipment loans are available on a sliding scale basis through One Stop Home Medical Equipment (520) 624-3367 or at no cost through New Spirit Lutheran Church (520) 296-2461. For other options, look in the phone book or do an online search for "Medical Equipment" or "Home Health Care Equipment."
- **Emergency Response Systems:** The average monthly monitoring cost for an emergency response system is about \$39/month and up. This does not include installation fees. Some companies may offer sliding scale fees based on income or offer discounts on installation. Compare monitoring companies for differences in the technical capabilities of their equipment, availability of tech support, monthly monitoring fees, installation fees, and length of contract. For a list of emergency response system providers, contact PCOA at (520) 790-7262 or visit www.pcoa.org.
- **Home Repairs and Adaptation:** Pima Council on Aging maintains a list of reliable contractors and handymen that can provide quality home repairs or accessibility modifications, such as walk-in showers and wheelchair ramps. Resources are also available for low-income home owners. Call PCOA's Helpline at (520) 790-7262 or visit www.pcoa.org.
- **Veteran Services:** If you are a veteran or the caregiver of one, check to see if any assistance is available through the Southern Arizona VA Health Care System (520) 792-1450. For veterans and surviving spouses who require assistance with the activities of daily living, contact the Arizona Department of Veteran's Services at (520) 207-4960 for information and eligibility requirements for the Aid and Attendance Pension Program.

- **Friendly Visitors/Telephone Reassurance:** Friendly visitors or phone reassurance calls are available in some neighborhoods through PCOA's Neighbors Care Alliance. Call PCOA at (520) 790-7262 to see if one of these volunteer programs is available in your area. TMC's Seniors Helping Seniors (520) 324-1960 may be able to provide a friendly visitor. Interfaith Community Services (520) 297-6049 may be able to provide telephone reassurance and/or friendly visitors.
- **Hospice:** Hospice is a philosophy of care focused on providing a peaceful death at home with a minimum amount of pain. Support is provided to both the patient and family. Hospice care is available to anyone determined by a physician to be within 6 months of death regardless of age. Hospice care is covered by Medicare and/or insurance. Most hospices will provide care for people who are not insured. Some hospices also offer palliative care (consultations in comfort care) for persons who do not yet meet hospice eligibility criteria. Look in the phone book or do an online search for "Hospices."

What if my family can't agree on a plan to care for my relative?

When there are disagreements among family members it can be helpful to bring in an objective third party such as an eldercare mediator or geriatric care manager. Our Family Services has an Eldercare Mediation Program that can help your family create a care plan in the best interests of your relative. For more information call Our Family Services at (520) 323-1708 or go to www.ourfamilyservices.org. Geriatric care managers are skilled professionals who can also be very helpful by assessing your relative's needs, providing recommendations, coordinating services, etc. Call PCOA for a list of geriatric care managers or visit the website of the National Association of Professional Geriatric Care Managers at www.caremanager.org.

What if something unexpected happens?

Even if you and your relative have made good plans, there is simply no way one can be prepared for all contingencies. However, discussing your relative's wishes and preferences in advance may go a long way in guiding you if you and your relative find yourselves in a crisis situation.

Try to keep your care plan current. If your relative's abilities have declined significantly since the care plan was first drawn up, an honest assessment of the situation and corresponding adjustments to the care plan might forestall a crisis situation from developing. You and your relative may want to review the care plan periodically and evaluate what works, what hasn't been working well, and what, if anything, has changed.

Keep your relative's pertinent information at hand so that you can have it at a moment's notice in event of emergency. This information includes your relative's date of birth, social security number, Medicare number, health insurance policy numbers, health conditions and allergies, names and dosages of current medications, names and telephone numbers of all treating physicians and copies of advance directives, if any. If you find yourself in a crisis situation, having this information readily available will help reduce your stress and allow you to focus on what needs to be done.

Although it is not always possible, try to avoid getting into situations where you are expected to make important decisions while you are upset or under stress. If you feel pressured to make a decision in this type of situation, take a moment to ask yourself if a decision really needs to be made immediately or if it can wait until you have time to consider all the facts.

Effective Communication Skills

*By: Julie Bubul, MSW
Caregiver Consortium*

The most common barriers to being a good listener are distractions, misinterpretations, being judgmental, being too quick to offer solutions and attachment to our own opinions.

What Is Active Listening and Why Is It Important?

- Active listening is a communication tool that involves using specific techniques and skills to portray empathy, understanding and respect for the speaker. It is important because it assures the speaker that nothing is being misinterpreted or “misheard” and nothing is being assumed by the listener. This leads to better understanding, reduced conflicts and better identification of what the speaker needs.
- Active listening means you don’t talk very much.

Active Listening Skills

- Body Language
- Leaning in towards person or assuming similar posture
- Eye Contact
- Tone of voice

Questions

- Open-ended: can’t be answered by “Yes” or “No” but do elicit a lot of information:
 - Use words and phrases like “Tell me about...” “How?” “What?” “When?”
- Closed - when you want specific information:
 - Can often be answered by “Yes” or “No”
 - Short answers

Minimal Encouragements

- Sounds made, especially on the phone, to let one person know the other is there and listening. Such as, “Oh?” “When?” and “Really?”
- They do not interfere with the flow of conversation, but do let the speaker know you are there and listening. They help build rapport and encourage the subject to continue talking.

Paraphrasing or Clarifying is the skill of summarizing part of a conversation and repeating it back to the speaker, using different words.

- Shows the speaker that you are really paying attention.
- Allows the speaker to confirm that you have understood correctly or to correct your interpretation and elaborate.

Parroting

- Involves repeating a word or short phrase that the speaker has said to clarify or validate that you have understood the speaker.
- Helps focus the conversation and encourages elaboration.

Reflecting

- Involves identifying the underlying emotion indicated by the speaker's words and/or body language.
- Validates the emotion and creates a more in-depth relationship between the speaker and listener.

Silence

- Allows a person time to gather their thoughts and process the conversation or information.
- Prevents the speaker from jumping in with a quick solution.

Communication Blockers

- “Why” questions: They tend to make people defensive.
- Quick reassurance, saying things like, “Don’t worry about that.”
- Advising: “I think the best thing for you is to move to assisted living.”
- Digging for information and forcing someone to talk about something they would rather not talk about.
- Patronizing: “You poor thing, I know just how you feel.”
- Preaching: “You should. . .” Or, “You shouldn’t. . .”
- Interrupting: Shows you aren’t interested in what someone is saying.

Effective Communication Examples

Skill		Example
Asking	<p>Open-Ended: Elicits more information</p> <p>Close-Ended: Short answers with little detail</p>	<p>“What have you been doing for transportation?”</p> <p>“Do you have a pet?”</p>
Minimal Encouragement	<p>Sounds or body language that lets the speaker know you are listening, such as nodding or responding with “Oh?” “Really?” “Uh-huh”</p>	<p>Speaker: I’m just not sure how to take care of my elderly father.</p> <p>Listener: Hmmm.</p> <p>Speaker: He really shouldn’t be living alone and he won’t even talk about other living situations.</p>
Paraphrasing	<p>Restating what the speaker says using different words but keeping the same meaning</p>	<p>Speaker: “I really didn’t like it when she made fun of my work. It made me feel humiliated.”</p> <p>Listener: “So when she criticized your job, you felt embarrassed.”</p>
Parroting	<p>Repeating the last few words a person says to clarify and to encourage the person to talk more</p>	<p>Speaker: “Well, sometimes I wish it was easier.”</p> <p>Listener: “Easier?”</p> <p>Speaker: “I just wish I could be more patient with my husband when he keeps asking the same thing over and over.”</p>
Reflecting	<p>Identifying the feelings underlying what the speaker has been saying to test the validity of how you are interpreting what the speaker is really saying</p>	<p>Speaker: “I just don’t know what to do about my parents. They can’t cook very much anymore but won’t accept any help.”</p> <p>Listener: “It sounds like you’re really worried about your parents and aren’t quite sure what to do.”</p>
Silence	<p>Many people are uncomfortable with silence but it can lead to a deeper understanding of what they are trying to convey</p>	

Resolving Conflicts Related to Family Caregiving

Introduction

As most families know “Conflict Happens.” Families involved with making decisions about the care of an adult family member know how stressful conflict can be for the care provider, care receiver and other family members. Conflict is not always a bad thing. However, those unprepared for conflict are not typically able to resolve it in a positive way. This fact sheet provides an overview of areas of potential conflict that arise in family caregiving and includes tips for resolving conflict when it occurs.

Areas of Potential Conflict

The easiest way to avoid caregiving conflict is for a potential care receiver to plan in advance for the following issues, including, but not limited to:

Healthcare decisions:

- Who should provide care?
- What care is needed?
- Who should make medical decisions?

Financial decisions:

- How should money be spent?
- How should investments be handled?
- How will concerns over “unwise spending,” etc. be handled?

Living arrangements:

- Where?
- With whom?
- Who decides?
- How much independence / supervision is needed?

Communication issues:

- What information is needed or missing?
- Who has legal authority to access information?
- How will information be shared with those who need it?

Family relationship issues:

- How should the family deal with sibling rivalries, new spouse or companion, death of a spouse/caregiver, other changes in the relationship?

Decision – making:

- Who should have authority to make decisions?
- What input (if any) should others have?
- How can decision makers obtain input from the care receiver?

Household care and maintenance:

- What options are available for ongoing services?
- What services are needed and how frequently?

Safety / risk taking / autonomy:

- What safety issues are identified?
- Is the level of risk understood and acceptable?
- What safety issues are identified?

Respite care and support for caregiver:

- What services are needed to support the caregiver?
- What services are available locally?
- What resources are available or can be used to pay for services?

Needs of other family members / caregivers:

- Are there competing needs of other care receivers such as dependent children or grandchildren?

Resolving Conflict

Sometimes it is hard to see another person's point of view, particularly in family situations where strong emotions are at play. The following tips can help address conflict in a positive way and stop it from escalating.

Plan a time to talk things over and set an agenda:

- Focus agenda on the issues that are causing conflict.
- Keep the agenda focused. Don't discuss too much in one meeting.
- Set additional meeting for other issues if necessary.

Practice good communication skills:

- Clearly say what is important to you and why you feel that way. Use "I" statements to explain how you feel and why.
- Speak for yourself and let others raise issues of importance to them.
- Separate the person from the problem. Look at the problem objectively and try to avoid assigned blame.
- Focus on interests (why someone feels, believes, or wants a certain thing) rather than positions (what someone feels, believes, or wants).
- Focus on how things might work in the future. Don't dwell on past problems.
- Try to respond to one another in a way that is not defensive and hostile. (This can be hard!)

Practice “active listening” techniques:

- Let everyone speak without interruption.
- Listen to what they are saying; it is important to them.
- Repeat back what you thought was said to be sure you understand how others are feeling.

Try role reversal:

- Ask family members to pretend they are another family member who has the opposite view. Then ask them what their interests are and why they feel as they do.

Gather needed information:

- Is more information or resources needed to make a decision?
- Figure out where and how to get the information.
- Who will get it and how will it be shared?
- Schedule an additional “meeting” if necessary, after everyone has reviewed the new information.

Involve a Mediator

When families are unable to resolve caregiving problems on their own, it may be useful to involve a trained, neutral third party such as a mediator. A mediator can provide a confidential, private setting in which everyone’s concerns can be heard and addressed. Mediators use a process that is fair and unbiased, and allow the participants to make decisions about the outcome.

*Source: U.S. Department of Health and Human Services
Administration on Aging
National Family Caregiver Support Program Resources*

Information provided in this fact sheet was adopted from materials submitted by the Center of Social Gerontology, Ann Arbor, MI. For more information, visit their website at www.tcsg.org.

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept. of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 357-3560; Email: aoain-fo@aoa.gov; or contact our website at www.aoa.gov.

Caregiving and Sibling Relationships: Challenges and Opportunities

Your mother has been diagnosed with dementia and it is clear that she can no longer live alone. You feel an assisted living facility is the best care option, but your brother disagrees. Every conversation you have with him seems to lead to confrontation and hurt feelings....

Providing care for an aging or ill parent can bring out the best and the worst in sibling relationships. Ideally, the experience of caregiving is a time for siblings to come together and provide mutual support to one another. However, as a stressful transition, the pressure can also lead to strained connections and painful conflict.

One major source of sibling friction is the legacy of family dynamics. Invariably, the demands of caregiving bring out old patterns and unresolved tensions. Past wounds are reopened and childhood rivalries reemerge. It is not unusual for adult children to find themselves replaying their historical roles in the family, recreating old dynamics of competition and resentment as they vie for mom's attention and affection.

Another conflict can arise when one sibling is in denial over a parent's condition. Adult children who seem unable to accept the reality of a parent's illness and refuse involvement may be protecting themselves from facing a parent's eventual death and their own loss. More active siblings may react with bitterness and anger.

Most often though, discord surfaces from the unequal division of caregiving duties. Generally, one sibling takes on the primary role of caring for a loved one. This may be because he or she lives closest to a parent, is perceived as having less work or fewer family obligations, or is considered the "favorite" child. Regardless of the reasons, this situation can lead the overburdened caregiver to feel frustrated and resentful and other siblings to feel uninformed and left out.

Resolving these conflicts can be challenging. But ignoring the difficulties in a caregiving situation can create greater challenges. Ultimately, strained family relationships can impede a family's capacity to provide the greatest quality of care to a parent. How can families come together in caregiving?

Here are some suggestions:

- Express your feelings honestly and directly. Let your siblings know their help is both wanted and needed.
- Keep family members informed regarding a parent's condition.

- Be realistic in your expectations. Allow siblings to help in ways they are able and divide tasks according to individual abilities, current life pressures and personal freedoms. Assistance with errands, finances, legal work or other indirect care may be the best option for some family members.
- Express appreciation to your family for help they are able to provide.
- Accept siblings for who they are and expect differences of opinion.
- Try to respect other's perceptions and find opportunities to compromise.
- If communication is particularly contentious, arrange a family meeting that includes an outside facilitator, such as your FCA Family Consultant, social worker, counselor, religious leader or friend. A trusted outside party can ensure that everyone's voice is heard.
- If siblings are unable to help with care, seek other assistance to provide a respite for yourself. Call your local Caregiver Resource Center, Area Agency on Aging, Senior Center or other community resource to locate help.

Try to forgive family members who continue to refuse to get involved in a loved one's care. The only thing we have control over in a situation is our reaction. Attempt to work through your negative emotions to take care of yourself and move forward.

For more information, call Family Caregiver Alliance at (800) 445-8106 or www.caregiver.org/caregiver

Source: Family Caregiver Alliance



Setting Limits: Just How Much Should We Do for Our Parents?

A noted family psychologist tells how to strike the right balance between doing too much for your parents-and not doing enough.

DO Separate Needs From Wants

There's a chasm of difference between a crucial need parents may have (food, clothing, shelter, and basic kindness) and something they want (two-hour visits every day, your kids to be quiet at the table, a bigger condo in Boca Raton). One of my clients developed a stock answer when her father called from the nursing home to tell her he "needed" expensive cigars and single-malt scotch. "Dad, do you have any requests that don't require me to bring things that are bad for you?"

DO Face Your Fears

Parent's demands can trigger elemental fears - the looming specter of their mortality, the scary knowledge that a parent's decline brings us a step closer to our own old age. But only by facing fears can we defuse them and put ourselves back in control.

A client's mother was a well-known academic reaching 80 and blind. The client found herself shutting down emotionally. One night she simply came out with it: "Mom, the truth is that I'm accustomed to you being the rock in my life and I get scared that you aren't that right now." Her mother was relieved. Now she knew why her daughter had been so cold. Best of all, the admission helped the mother regain some sense of independence and personal value.

DO Pack Your "Baggage"

Often parents demands create extreme feelings of guilt about the times we've hurt them - and resentment about the times they've returned the favor.

Jeremy, a photographer, resented the nightly calls from his father, a retired stockbroker in his late 70s who wanted his son to know all the moves he had made that day in his own small investment portfolio.

Jeremy angrily interpreted this as distrust because he had been irresponsible until he turned 30. But as the family's therapist, I discovered that the reason the father called was simply to connect with his son. When the son realized he had misinterpreted his father's intentions, he was able to enjoy the calls.

DO Say No, but Gently

It's not easy, especially when we're faced with a request we're not prepared to argue against. It can even take practice: Enlist a spouse or friend to act out a scenario in which your parents make an unreasonable demand. Write dialogue out in advance, supplying your helper with a list of your parents' usual defenses. Formulate responses to all their potential harangues. Example: "Dad, I know how much your freedom and mobility mean to you, and I'll try to be as available as possible to take you places, but I cannot allow you to drive anymore."

DO Make Fun a Priority

Many people mistake quantity for quality when it comes to spending time with their parents. I would argue that it's better to spend less time with them and make sure those hours are truly satisfying. Plan activities that will bring you together as human beings. If possible, hire caregivers for routine chores; save your own time and energy for more meaningful interactions. Join a book club with your mom, escort your father to an exhibit of Civil War memorabilia. If they are not able to get up and about, find audio books that you can listen to together.

DON'T Settle Old Scores

No matter how neglectful or cruel your parents were when you were a child, their dotage is not the time for payback. Showing them compassion and respect, whether or not you feel they deserve it, is a mark of adulthood and depth of character. Example: "Dad, I still find you frustratingly unable to show me the love you say you have for me, but I'm going to hug you when I see you because you mean a lot to me, regardless."

DON'T Let Others Set the Agenda

If your friend cocks an eyebrow at the news that you're bringing Mom home (or moving her out), try this mantra. "No one else's judgment matters." Trust your instincts. Only you know how much you can take—and give. If the busybodies don't come around, maybe you should find more empathetic friends.

DON'T Treat Them Like Babies

Too many people believe the cliché that parent-child roles are automatically reversed as our parent's age. I strongly disagree. Caregiving should not be confused with parenting; preserving your parents' independence and dignity is perhaps the most important job you will have at this stage in their lives. A great way to break this cycle is to figure out something they can do for others - it could be as simple as helping your kids do their homework - and thus give new purpose to their lives.

DON'T Shirk Your Share of the Work

Family dynamics tend to build to a fever pitch when the care of an aging parent is involved. While it's true that some siblings may be more suited to the task than you, don't assume they are okay with the situation. Ask them periodically how they feel about it. And remember, there is plenty you can do from afar; researching a medical procedure on the Internet, subsidizing home care, and sending care packages.

DON'T Mistake Money for Caring

People who confuse the two often come from families in which money was a defining issue. Nobody is too old to change, and it is likely that even those parents who seemingly valued money above all else will appreciate outward expressions of love. One man thought he was caring for his mom by having his assistant figure her taxes. But what she really needed, more than tax expertise, was personal contact with her son.

Psychologist Dale Atkins is the author of *I'm OK, You're My Parents* (Henry Holt and Company, 2004), www.aarpmagazine.org/family/caregiving

Source: Dale Atkins, May & June 2005

Changing Places: Should Your Parents Move in with You?

Lisa's mother, Ruth, has been living alone since Lisa's father died five years ago. Ruth has been active at church and eats lunch at the local senior center a couple of times a week. Lisa does the food shopping, takes Ruth to doctors' appointments and has her over to her house for dinner, usually once a week.

Lisa has begun to notice, however, that when she is at her mother's house, it is not as clean as it used to be. Several times lately she's noticed a pile of dishes and a burned saucepan in the sink-something her mother would never have done before. The other day she saw a bright green envelope on the dining room table, which was a notice that the utility bill had not been paid.

Slowly, Lisa has begun to think that her mother may have problems with her memory, and may not be able to live safely at home alone any more. Having always been close to her mother, she had assumed that her mother would eventually come live with her. But now Lisa has to think about what that would mean.

Making the decision to move a parent into your home is not necessarily as clear-cut as it would seem. A number of situations and questions arise that need addressing. FCA's Family Consultants suggest that it is helpful to consider these issues before the move is made:

Relationships

- How will I talk to my mother about moving?
- How do my spouse and children feel about moving mother into our home and how will it change our lives together?
- What things will be easy for us to negotiate in living together and what things will be hard?
- What are the limits of my ability to care for mother at home and what if I have to put her in a nursing home?
- How will my siblings feel and how much help will they give me in caring for mother?
- Will her friends come to visit her at my house or will she be dependent on me for all her socializing?
- What are my needs for privacy and alone time?

Adapting Your Home

- Where will mother sleep-in my daughter's room, convert the den, build an addition?
- What assistive devices do I need-grab bars in the bathroom, raised toilet seat, ramps, etc.?
- Does mother smoke or drink and will that be a problem for me?
- Does mother have a pet that will be coming with her and how will I cope with caring for it?

- What will the financial arrangement be? Should I charge rent? Will I have expenses for her to cover?
- How will my siblings feel about the financial arrangement?
- Will my work situation have to change, and if so, how will I cover the bills?

Time

- Will mother need care during the day, and if so, how will it be provided?
- How will I juggle my job, childcare responsibilities, marriage and taking care of mother?
- When in my day will I be able to make the phone calls needed to make arrangements for mother?
- When will I have time for myself?

Personal Care

- How comfortable am I with helping mother bathe or changing an adult's diaper?
- Do I know what to expect over time as mother's condition changes?
- How is my health and will I be able to take care of myself as well as my mother?
- Am I willing to accept respite care to get a break?

Every family situation is different. If you are facing these questions, a Family Consultation with one of FCA's professional staff can help you sort out the pros and cons of such a move and provide information and resources to make things easier for you and your family. Call us at (800) 445-8106.

Source: © Family Caregiver Alliance, Winter 2001



Long Distance Caregiving FAQs

Helping long distance caregivers to prepare for the current and future care of older care recipients.

Frequently Asked Questions about Long Distance Caregiving

Caregiving is considered long distance if it requires travel of at least one hour to reach your care recipient. If you are a long distance caregiver, you are not alone. Nearly 7 million Americans manage care for an older care recipient or friend who lives at a distance. The following information offers suggestions on how to evaluate, plan and organize your resources and time to maximize your ability to provide support from a distance.

Shortly after my father's medical diagnosis, I went home to visit. He assured me he can take care of himself, but I am not convinced. How can I help?

Keep in mind that a person may be willing to give up a great deal in order to continue living independently in his or her own home. Talk with your care recipient about your concerns. Your care recipient's perception of the situation may be very different from yours. For example, you may think your loved one is no longer capable of performing certain tasks when, in fact, all that is needed is more time for your care recipient to complete those tasks.

If your care recipient is willing to accept help, you can contact PCOA at (520) 790-7262 for options, such as Emergency Alert providers, home modification resources, transportation options, home delivered meals, etc.

Remember to be sensitive and caring and treat your care recipient with respect. Ask yourself how you would feel if a care recipient were getting involved in your personal life.

What is involved in creating a plan of care that provides the help and support my loved one needs and is willing to accept?

If your care recipient is willing to accept help, identify the type(s) of help your caregiver thinks is needed and who he or she would prefer to receive help from—a home health agency, a caregiver, a neighbor, etc. Together you can create a care plan that may include help from more than one source. Other family members, for example, may already be (or want to be) involved in the care of your care recipient. If multiple caregivers are willing to contribute to the care plan, set up a meeting so everyone can decide how to effectively work together as a team.

You may also want to identify friends, neighbors and members of faith groups, associations and societies to which your care recipient may belong and who may be available to provide assistance. Try not to overwhelm people when asking for help, but be direct in explaining what types of help are needed so that others can accurately determine how much help they are able to provide, if any.

Introduce yourself to everyone who will be helping your care recipient if you do not already know them. Keep a list of each person's phone number and address. Let them know they can call you if they are worried about your loved one. Develop ways to show appreciation and recognition of the help they are giving (such as friendly phone calls, thank you notes, cards etc.).

There are many agencies in Pima County that offer home health services. For a list of questions to use when determining if a particular home health agency will serve your care recipient's needs, call PCOA at (520) 790-7262 or visit the Resources tab on our website: www.pcoa.org.

Other possible sources of help include public and private agencies that offer professional health and social services for the elderly. Educate yourself about resources and services that are available in your care recipient's community. For services available in Pima County, contact the Pima Council on Aging at (520) 790-7262 or www.pcoa.org. For services available elsewhere in the United States, contact the Eldercare Locator at (800) 677-1116 or www.eldercare.gov.

What do I need to do for myself in order to prepare for what may lie ahead as a long distance caregiver?

As a long distance caregiver, you must come to terms with what you can and cannot do. You will need to determine how much assistance you are willing and able to provide and you should follow a course that fits your personal strengths, resources and lifestyle.

Before visiting your care recipient, plan in advance what you would like to accomplish during the visit, such as: gathering medical, financial and legal information, calling local social service agencies, visiting assisted living facilities, socializing with your care recipient and other family members, etc.

You will need to be prepared for emergencies and, if necessary, be ready to travel at a moment's notice. If this might be a financial hardship for you, ask your care recipient or other family members if they would be willing to help cover the costs.

Caregiving from a distance can be very challenging and you may want to consider hiring a geriatric care manager. A geriatric care manager is a professional – usually a nurse or a social worker – who can assess your care recipient's needs, provide recommendations, arrange and coordinate services, attend doctor's appointments, and be your eyes and ears so you don't have to wonder what's really going on. Also, sometimes an older adult might not want to listen to the advice of a grown child, but he or she will listen to the advice of an objective third party. For a list of local geriatric care managers contact PCOA at (520) 790-7262 or visit the website of the National Association of Professional Geriatric Care Managers at www.caremanager.org.

Periodically assess your caregiving responsibilities and weigh them against your other obligations. You may need to talk to your employer, for example, about taking personal days or formal leave to care for your care recipient. The Family Medical Leave Act (FMLA) of 1993 grants employees of firms with more than fifty employees the right to take up to twelve weeks of unpaid leave to care for a child, spouse, or parent with a serious medical condition. Talk to your manager or Human Resources Department for more information.

Sometimes I am not sure if my concerns about my loved one are significant problems or not. How do I know when the situation is serious enough to require immediate action?

Crisis situations that demand your immediate attention might include a serious fall or accident, a sudden decline in your care recipient's mental status, or the unexpected loss of a live-in caregiver. In those situations you may be most effective handling the situation in person. However, before you make the trip, you may want to ask yourself the following questions:

- If your care recipient has local sources of support, such neighbors, friends, a case manager, or other caregivers, what do they think about the situation? What does your care recipient's primary physician recommend?
- What is your care recipient's style? For example, does your care recipient have a tendency to underestimate or exaggerate the seriousness of a situation?
- What is your style? Do you tend to panic or overreact? Is there someone you trust who can help you think it through before deciding on a course of action?

More practical considerations include:

- Can you afford the trip right now?
- Is work a consideration? Do you have accrued vacation and/or sick time? Are you eligible for Family Medical Leave?
- Do you need to make arrangements to meet your responsibilities to your spouse, children and other household members?

I've been thinking about either relocating to be closer to my care recipient, having my care recipient move to a location within my community, or perhaps having my care recipient live with me and my family. What should I consider before making a final decision?

It is best to talk with your care recipient about these alternatives in advance, before a crisis situation occurs. Factors to consider before moving or relocating an older care recipient include:

- Does your care recipient want to live in your city or within your household? What are your care recipient's needs for independence and familiarity with friends and community? It may be difficult to leave old friends and make new friends in a different city.
- Would your care recipient be willing to relocate to assisted living or some other supportive living environment within your community? Many times older persons do not want to live in the same household as their adult children.
- What housing options are available for your care recipient in your city? How will housing be paid for?
- What publicly funded community resources are available and accessible to help your care recipient, if needed? States differ in what services are available as well as eligibility criteria for participation in services and programs.
- Be realistic about what it would take to live again with your parent(s).
- Would this be the best situation for both of you? Consider having your care recipient for a visit in order to evaluate whether living together in the same household is a possible alternative.
- What is your emotional and physical capability to deal with your care recipient's care needs?

- What is your past relationship with your care recipient? Are there any unresolved conflicts with your care recipient? If so, consider if resolution is possible before moving in with your care recipient.
- What safety, privacy and space modifications would have to be made to your home to accommodate your care recipient's needs?
- What are your needs, your care recipient's needs and the needs of other household members? What lifestyle differences exist?
- How long do you expect the arrangement to last?

Resources

Pima Council on Aging: (520) 790-7262 or www.pcoa.org.

Caregiver Consortium: www.caregiverconsortium.org.

Tips for Long Distance Caregivers

- Be observant when you visit your care recipient. Do you notice anything new or unusual in your care recipient's health and functional status?
- Discuss your concerns with other family members. Call a family meeting if possible.
- Encourage your care recipient to complete Advance Directives. Often health care providers will be reluctant to provide you with detailed medical information over the phone unless you are a Health Care Power of Attorney.
- Allow yourself time to search the Internet and other information sources about medical concerns, resources for services and caregiving information.
- Establish a routine. Stay in regular contact, either by telephone, e-mail or letters. Your emotional support is important and your advice in helping them make decisions is a form of caregiving.
- Set up a list of contact information for care recipients and friends and keep them informed.
- Take notes. Write down dates, times and pertinent information gathered during conversations with your care recipient's health professionals and personal helpers.
- Create a log or a journal to keep track of important information, such as: notes and observations on your care recipient's health status, names and contact information for helpers, travel information, legal, financial and insurance information, etc.
- Assess housing features that may need modification to prevent falls or promote safe bathing and other activities.
- Learn about helpful products and assistive devices, such as a personal emergency response systems, lift chairs, and other aids to daily living.
- Be aware of hidden demands and expectations placed on caregivers by society and culture that may contribute to feelings of guilt and isolation.
- Don't feel you have to stick with one solution if it isn't working out. Be flexible.
- Trust your feelings and intuition. Sometimes the ones we love hold back information because they don't want us to worry.

