Section 2
Caregiving and Family Relations
Signs & Symptoms a Senior Family Member May Need Help

By Eldercare.gov

One question that can be difficult to answer is when do I need to intervene on behalf of someone I care about when I am not sure what might be needed. Eldercare Locator and Pima Council on Aging have noted some changes that can occur in senior family members related to physical, mental, and psychosocial health. Some of these changes are harder to detect than others. Some signs and symptoms below that may alert you to the fact of a need for assistance and taking some action is needed. These signs and symptoms may also warrant notifying the physician of the senior adult of these changes.

- Urinary Tract Infections (UTI) are quite common in seniors 65 and over and even more so after age 80. The classic symptoms of a UTI are burning pain and frequent urination...However, in senior adults, especially those with dementia, they may experience increased behavioral symptoms such as confusion. UTI can be mistaken for early dementia or Alzheimer’s disease.

- One change that commonly shows up early on in cognitive changes is not taking medication as directed. 7 day pill box organizers, when filled by family allow them to see if medications are being taken appropriately. This is harder to keep track of with pill bottles where daily counting of pills would be needed to check on errors.

- Changing eating habits, other than medically directed, resulting in weight loss, appetite loss, or missed meals.

- Neglecting personal hygiene, such as clothing, body odor, oral health, nails, and skin.

- Neglecting the home, with a noticeable change in tidiness and/or sanitation.

- Increased dings/scratches on cars, auto accidents, or an increase in getting lost.

- Exhibiting inappropriate behavior, such as being unusually loud, quiet, paranoid, or agitated, or making phone calls at unusual hours.

- Changing relationship patterns, causing friends and neighbors to express concern.

- Showing physical injuries, such as burns, which may have resulted from general weakness, forgetfulness, or misuse of alcohol or medication.

- Decreasing or stopping participation in activities that were once enjoyable, such as a bridge or book club, dining with friends, or attending religious services.

- Exhibiting forgetfulness, resulting in unopened mail, newspaper piles, unfilled prescriptions, or missed appointments.

- Mishandling finances, such as not paying bills or paying them more than once and losing or hiding money.

- Making unusual purchases, such as more than one subscription to the same magazine, entering an unusually large number of contests, or increasing purchases from television advertisements.

Source: Signs and Symptoms a Senior Family Member May Need Help, www.eldercare.gov.
When Your Relative Refuses Help

It can be frustrating when you know your family member has difficulty functioning independently yet refuses necessary services. Although you cannot force your relative to accept help, you need to understand the reasons behind the resistance if you are going to have any success overcoming the reluctance. Ask yourself:

- Is my family member concerned about the cost of the service and its impact on his or her savings?
- Does my relative feel he or she does not have a problem?
- Does he or she view agency assistance as “welfare,” “charity,” or “going on the dole”?
- Is my family member fearful about having a stranger in the house or having possessions stolen?
- Does my relative feel the task(s) I want to hire someone to do are ones that he or she can do? Or, that family should do?
- Does he or she view accepting outside help as a loss of control and independence?
- Are the requirements of community agencies—financial disclosure, application process, interviews—overwhelming to my relative?

It’s important to deal with your relative’s perceptions and feelings. For example, if your mother feels she does not have any problems, be as objective and specific as you can in describing your observations. Indicate that you know it must be hard to experience changes. If your father views federal or state supported services as “welfare,” emphasize that he has paid for the services in past years through taxes.

Try to approach your family member in such a way that he or she does not feel helpless. Many of us, regardless of age, do not find it easy to ask for or to accept help. It is best to present the need for assistance in a positive way, emphasizing how it will enable the person to live more independently. Try not to emphasize what he or she cannot do. For example, avoid statements such as “you can’t do that anymore.” Pushing a person too hard or focusing only on limitations often increases resistance.

It usually helps to suggest only one change or service at a time and if possible, begin with a small change. People generally need time to think about and accept changes. Introducing ideas slowly rather than pushing for immediate action increases the chances for acceptance. The more your relative feels a sense of control in planning and making arrangements, the better off you’ll both be.

Sometimes suggesting a trial period—trying the service for a month—will help. Some people are more willing to accept a service when they initially see it as a short-term, rather than a long-term, commitment. Some families have found that giving a service as a gift works. Examples include giving spring cleaning as a Mother’s Day gift, a Christmas gift of hair appointments for a woman who has difficulty brushing her hair because of arthritic shoulders and hands, and home-delivered meals as a get-well gift after surgery.
Some individuals are more willing to accept assistance from someone they know than from a “stranger.” Could a neighbor be hired to prepare a daily meal for your relative? Is there a responsible teenager in the neighborhood who could be hired to do grocery shopping or yardwork or provide transportation? Sometimes this person will have more success in getting your relative to accept an “outside service” for a short time when he or she cannot do it.

If your family member persists in asserting, “I’m okay,” “I don’t need help,” try focusing on your own needs rather than those of your family member. For example, saying “I would feel better if…” or “I care about you and I worry about…Will you consider doing this for me so I will worry less?” sometimes makes it easier for a person to try a service. Having a service suggested by someone your relative respects may also be an effective approach.

Be careful about how much assistance you volunteer to provide. Be realistic about what you can do, and communicate your limits to your relative. For example, if you volunteer to prepare your mother’s meals, do your father’s laundry and grocery shopping, or clean your grandmother’s house weekly, are you really willing to do the task for as long as the person needs it? The need that appears to be for only a few weeks may turn out to be for several months or years. Family members sometimes find that once they take on a task the encounter even greater resistance from their relative when they try to hire an agency or person to do the task.

*Source: Public Domain*
Informed Care Planning

By Family Caregiver Alliance

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 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 care for 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 relatives feel unable to pinpoint what you really need, try asking a friend, another family member and/or seek professional advice.

Caregiving with Your Siblings

By Family Caregiver Alliance

Introduction
Providing care for your parents can be complicated. When your brothers and sisters are also involved, caregiving can become even more complex. While your siblings can be enormously helpful and your best support, they can also be a source of stress.

In this fact sheet, you will learn how to identify the family dynamics that can impact caregiving, ways your siblings can help, how to increase your chances of getting that help, and how to deal with emotions that arise.

Why Sibling Tensions Can Erupt as Parents Need Care
Today’s adult children and their parents are going through a new kind of family transition. Because parents are living longer—but with chronic illnesses—their adult children are now caring for them for up to a decade or more. Siblings—or in some cases step-siblings—might not have a model for how to work together to handle caregiving and the many practical, emotional, and financial issues that go with it. There is no clear path guiding who should do what, no roadmap for how siblings should interact as mature adults. While some families are able to work out differences, many others struggle.

Siblings are also going through a major emotional passage that stirs up feelings from childhood. Watching our parents age and die is one of the hardest things in life, and everyone in the family will handle it differently.

It’s normal to feel a wide range of emotions. You may find that needs arise for love, approval, or being seen as important or competent as a sibling. You may not even be conscious of these feelings, but they affect the way you deal with your parents and with each other. So without realizing it, you may all be competing with each other as you did when you were kids. Now, however, the fights are over caregiving: who does or doesn’t do it; how much; and who is in charge.

This is a hard time, so have compassion for yourself, and try to have compassion for your siblings. You don’t have to excuse negative behavior, but try to imagine the fear, pain, or need that is causing your siblings to react as they do. That kind of understanding can defuse a lot of family conflict.

As a Family, Carefully Consider—or Reconsider—the Caregiving Responsibilities
Families often don’t think through who becomes the primary caregiver and what supporting roles other family members will play. Caregiving may start when the sibling who lives nearby or has a close relationship to the parent helps out with small things. You may not even identify yourself as a caregiver at first, but then find yourself overwhelmed and feeling resentful of your siblings as your parent requires more help. It’s easy for families to fall into common traps, assuming, for example, that the son will handle finances while the daughter will take care of emotional or physical care needs.
In another common trap, one sibling may become Mom’s caregiver because he or she doesn’t have a job or needs a place to stay, and family members think this arrangement will solve a lot of problems. But it can be a recipe for trouble. The family needs to spell out clearly what that person will be expected to do, whether there will be financial compensation, and how that will work. In addition, the sibling(s) should be clear about what support tasks each will provide.

You need to re-examine all these assumptions as a family. The best way to do this is to call a family meeting as early (and, later, as often) as possible. A family meeting can provide a place to discuss the parent’s needs and to ask what each person can contribute in time or money. If needed, a trusted person outside the family can facilitate.

**Think About Family Roles When You Were Growing Up, and How You Can Change Them for Caregiving**

Whenever we get together with family, most of us tend to slip into our old roles, even though we behave differently when we are with other people. But these roles may not work anymore. Parents may not be able to play the parts they did when the family was young, like making the decisions, providing emotional support, or smoothing tensions between family members.

Maybe you were expected to be the responsible one; maybe your brother was seen as someone who needed taking care of. Maybe your other sister was groomed to go off and become the achiever while family chores were left to others. Perhaps you were identified as the "caring" one while your sister was labeled “selfish” or “cold.” So ask yourself: am I being pulled into being the big sister or the helpless little kid even though we’re all adults now?

Also, it’s helpful now to take a fresh look at your siblings. Parents create labels and roles for each child, and everyone in the family adopts them and assumes they are true. They may be based on some reality, but parents may also assign these labels for all kinds of reasons: who was born first or last, which kid reminds Mom of her older sister (whom she resented), which kid is most like Dad in personality—and how Mom feels about Dad!

Whatever the reasons for these roles, we need to re-examine them now. If you were the “responsible” one, it does not mean that you should accept doing everything because you always did—even though your siblings may expect you to take on that role. You may need to help them see that you can all adapt your roles to new times and who you are today. Also, if you assume a brother or sister is less capable or helpful because that’s the way you saw them as kids, you are less likely to get help from them. If you approach them differently, they may prove to be more helpful than you think possible.

**Siblings May Have Different Ideas About What Parents Need**

The idea that you may soon lose Mom or Dad, or that they need more care, can be really scary. Some adult children still need their Mom to be the parent. Some get over-anxious and think the parent is in bigger trouble than they are. Some just can’t accept that the parents need as much help as they do. These differences are common. Here are some ways to handle this:
• If there’s no emergency, allow some time to get everyone on the same page. It’s natural for siblings to take in the situation at different times and in different ways. This can happen regardless of whether they’re far away or close.
• Share information. Get a professional assessment of your parent’s condition by a doctor, social worker, or geriatric care manager and send the report to all your siblings. Try using email, online care sharing tools, and/or in-person family meetings to help keep everyone abreast of care issues and information.
• Keep in mind that parents often tell their kids different things about how they’re doing. This is a good reason to keep communication lines open with each other and to try to pool your information about your parent’s health.

Try to Separate Your Parent’s Needs from Your Own—and Yesterday’s Battles from Today’s Decisions

It’s natural to take pride in being able to help your parent, or feel satisfaction that you are doing something important and valuable. When these basic needs are satisfied, caregivers feel good about what they’re doing and feel less burdened.

But you may also have other less conscious, emotional needs that can actually make things harder for you. For example, if you feel you must make your Mom happy—when she’s never been a happy person or has suffered painful losses—you may be setting yourself up for an impossible task. You can make sure your parents are well cared for, but it isn’t your job—nor is it always possible—to make them happy.

So try to focus on the essential things your parent needs for good care. For example, if you insist on doing all Mom’s shopping because only you know what she likes, you may exhaust yourself. And it’s hardly a tragedy if your sister buys her a different brand of tuna.

When those old needs to be loved and approved of get stirred up, it can fire up sibling rivalry. After all, you’re not the only child who needs to feel important to Mom or Dad. So when you’re discussing whether Dad needs a more expensive wheelchair or Mom is still safe at home, try to keep the discussion on the concrete issue at hand, not on which of you cares the most or knows what is best.

Clues That You Are Acting out of Emotional Needs or Fighting Old Battles
• Your level of emotion is out of proportion to the specific thing being discussed right now. For example: getting into a heated argument about which of you should go to the doctor with Dad next week.
• You or your siblings criticize the way you think another person is being, for example: selfish, bossy, uncaring, irresponsible, or worse.
• You feel that none of your siblings understands what Mom needs the way you do and you are the only one who can do certain things.
• You or your siblings generalize a discussion, saying, for example, “You always do this!”
• You or your siblings criticize the way one another feels, for example, “You don’t care anything about Mom.”

When you become furious or terribly hurt in a dispute with your sibling, try to step back, calm down, and focus just on the issue at hand, e.g. getting Dad to his doctor appointment.

Tips for Winning More Support from Your Siblings

1. **Try to accept your siblings—and your parents—as they really are, not who you wish they were.** Families are complicated and never perfect. There are no “shoulds” about how people feel. They are not bad people or bad children if they don’t feel the same as you do. If you can accept this, you are likelier to get more support from them, or, at least, less conflict.

2. **Do not over-simplify.** It’s easy to assume that you are completely right and your siblings are all wrong—or lazy, irresponsible, uncaring, etc. Each person has a different relationship with your parent, and each person’s outlook is bound to be different.

3. **Ask yourself what you really want from your siblings.** Before you can ask for what you want, you need to figure this out, and that’s not always as simple as it seems. First of all, ask yourself whether you really, deep down, want help. Many caregivers say they do but actually discourage help. So think hard. Do you want them to do certain tasks regularly? Do you want them to give you time off once in a while? Or do you feel you have everything under control but you’d like them to contribute money for services or respite?

4. **Or—and this is a big one for many caregivers—do you really not want them to do anything but you’d like more emotional support?** Many caregivers feel lonely, isolated, and unappreciated. If you’d like your siblings to check in on you more, ask them to call once a week. And tell them it would really help if they would say “thanks” or tell you you’re doing a good job. They are more likely to do this if you don’t criticize them for what they are not doing.
   - Ask for help clearly and effectively.
   - Asking is the first step. You might ask for help by saying: “Can you stay with Mom every Thursday? I have to get the shopping done for the week and it gives me some time to myself.” Don’t fall into the common trap of thinking, “I shouldn’t have to ask.” Your siblings may assume that you have everything covered so they don’t recognize the added responsibilities and “burden.” They are involved with their own lives and struggles and not so attuned to yours that they can read your mind. Also, if you’re not exactly sure what you want from them, you may be giving them mixed messages.
   - Ask directly and be specific. Many caregivers hint or complain or send magazine articles about the hardships of eldercare. But these strategies do not work well.
o Ask for what’s realistic. People get more when they don’t ask for the impossible. So consider the relationship your sibling has with Mom or Dad and ask for what that person can really give. If your sister can’t spend ten minutes with Mom without screaming at her, don’t ask her to spend time; ask for something that’s easier for her, like doing paperwork or bringing groceries.

5. **Watch how you ask for help—and steer clear of the cycle of guilt and anger.**

o Avoid making your siblings feel guilty. Yes, really. Guilt makes people uncomfortable and defensive. They might get angry, minimize or criticize what you are doing, or avoid you. That is likely to make you angry, and then you will try harder to make them feel guilty. They will attack back or withdraw even more. And round and round you go.

o Sometimes your siblings will criticize you because they are genuinely concerned about your parents. Try to listen to these concerns without judgment and consider whether it is useful feedback. At the same time, be bold by asking for appreciation for all that you are doing—and remember to say thanks back when someone is helpful.

o Be careful of your tone and language when you request something. It’s not always easy to hear the way we sound to others. You might think you are asking for help in a nice way, but if you’re angry, that’s the tone your siblings will hear. And they’re likely to react in unhelpful ways.

6. **Get help from a professional outside the family.** Families have long, complicated histories, and during this very emotional passage, it is often hard to communicate with each other without overreacting, misinterpreting, or fighting old battles. Even the healthiest families can sometimes use the help of an objective professional. People like family therapists, social workers, geriatric care managers, physicians, or clergy can help siblings establish what is real about a parent’s health and needs in order to help distribute responsibilities more equitably. In family meetings, they can help you stay focused on the topic at hand and help you avoid bringing up old arguments.

7. **Steer clear of power struggles over your parent’s assignment of legal powers.** Whether or not you have been given your parent’s legal powers over finances or health, you need to remember that it is your parent who has made these decisions. If you have your Mom’s or Dad’s power of attorney, be sure to keep detailed records and send your siblings statements about how you have spent Mom’s money. This may seem like a lot of extra work, but record keeping is required by law, and being open will reduce distrust or distortion—and lawsuits. If a sibling has been given legal power, try to accept your parent’s decision and don’t take it as a personal attack on you. Do your best to work with the sibling who has the authority by presenting expenses and bills in black and white. If the sibling who has the purse strings doesn’t cooperate, then bring in a professional to explain your
parent’s needs and to mediate. If you are concerned about manipulation, a changed will, or undue influence, contact your local Adult Protective Services.

8. **Don’t let inheritance disputes tear your family apart.** If you feel wronged by the way your parents have divided their money and property, it’s natural to be upset, especially when you are grieving. You may feel that you deserve more because you have cared for your parents. If that’s what you feel, you need to discuss this with your parents while they are alive and can make these decisions. If you suspect foul play by another sibling, then this is the time to consult an attorney or Adult Protective Services.

Yet, research shows that most parents feel a need to leave their estates equally as a sign of their equal love for all their children. When they divide things unequally, it’s often because they are worried that a particular child will be in greater need. Whatever their reasons, remember that it was your parents, not your siblings, who decided this. Think hard before you take your anger or disappointment out on your siblings. They are what remains of your original family, and for most people, this relationship becomes more important after parents die.

**Summary**

Dealing with your siblings over parent care can be difficult, complex, and emotional. It is important to understand your own emotions at this challenging time and to try to have sympathy for your siblings’ feelings as well, even if you disagree. Ask for what you need from them directly and specifically without guilt or anger. If you cannot, or there is conflict anyway, bring in an objective professional to help your family solve the problems that need solving. Family dynamics were present prior to your caring for your parent(s), and you may not be able to resolve existing conflicts now to your satisfaction. The important thing is to be sure to get support for yourself so that you can find peace during your caregiving journey, and once it is completed.

Home Away from Home: Relocating Your Parents

By Family Caregiver Alliance

As you’ve watched your parents get older, perhaps you have struggled with situations such as these:

• You’ve travelled to visit your mother for the holidays, and found her refrigerator nearly empty, her bills unpaid and her house in disarray.
• A neighbor has called you to report that your father was wandering in the street, unable to find the home he’s lived in for 30 years.
• Your mother has neglected to take her diabetes medications, severely compromising her health.
• Your very independent father fell and broke his hip, making it impossible to navigate the stairs in his home.

If there is a decline in cognitive abilities as a result of Alzheimer’s disease or a related dementia, or a shift in a medical condition that requires increased care, there is clear cause to be concerned about your parent’s welfare. It may be time to consider a move to a safer environment.

But where should he or she live? Often your first inclination is to move Mom or Dad into your home—but this major life change deserves thoughtful examination, and there are many alternatives to explore. This Fact Sheet offers advice and summarizes the issues to consider before making the important and challenging decisions regarding relocating your parent.

First Step: Open Discussions

Open and honest discussion with your parent and other family members becomes an essential first step when you are trying to decide if moving your parent to a new living situation is the right thing to do. Family meetings with your parent, spouse, children, siblings and other key people will help everyone share their views and will help you decide how best to proceed. Active communication among all family members is the building block to a strong support system for an older parent and all family members involved.

Although some of these discussions may be very difficult and emotional, several topics require attention. Together, the family—including your parent—will need to talk about:

• All possible residential options
• The type of care needed
• Finances
• Each person’s role in the transition
• Changes in lifestyle
• The location of the new home
Expectations must be defined and clear to everyone involved. The following can help guide your discussions.

**The Level of Care Needed**
As your parent gets older, his/her care needs will change, and in most cases become more challenging. It’s essential to develop a strategy for providing care, and this requires both practicality and planning. Consulting with a Geriatric Care Manager or social worker may be beneficial as you consider your options and what you will and will not be able to do for your parent.

- Evaluate whether your parent needs constant supervision or assistance throughout the day and how this might be provided.
- Determine which activities of daily living (such as eating, bathing, toileting) your parent can do independently.
- Determine your comfort level for providing personal care such as bathing or changing an adult incontinence pad.
- Evaluate your own health and physical abilities to help decide if you are able to provide care for your parent.
- Explore the availability of services such as in-home care, adult day services, meal delivery, a friendly visitor program,
- Investigate long-term arrangements and options if living with your parent will not work or is not your choice.
- Determine the type of medical care that will be needed by your parent, and whether appropriate physicians and services—including transportation services—are available in your community.
- As time goes by, expect changes in your parent’s medical or cognitive condition.

**Family Dynamics**
Families are rich in historical experiences, and many of your positive and negative feelings about your parents and other family members will play a role in your decision to relocate or live with a parent. Be honest with yourself and do not allow unresolved conflicts or feelings of guilt or obligation pressure you into taking on more than you can manage.

- Be realistic about the significant life changes that relocating your parent will mean for you, your parent, your siblings, your spouse and children.
- Try to come to terms with past disagreements between you and your parent.
- When deciding whether to relocate or move your parent into your home, consider the opinions of your spouse, children, siblings and other family members.
- Come to an agreement with your siblings regarding how much and what kind of help you can expect to receive from them.
- Recognize that, despite possible cognitive or physical limitations, that your parent is an adult, is entitled to maintain as much autonomy and dignity as possible, and should be at the center of any decision-making.
Living Arrangements and Housing Options
Moving your parent into your home is certainly one option, but you and your family should take some time to consider other living arrangements as well. The type of housing you choose will largely depend on three important factors: your parent's care needs, finances, and the service and supportive options available in your parent's or your community.

When deciding where a parent should live, family members need to discuss, understand and accept the benefits and drawbacks of living close to one relative versus another. Often, the choice of location can cause conflict between family members because those living near the parent often bear most of the responsibility for the parent's care, and may feel that those living further away do not help enough. On the other hand, family members who live far away can feel frustrated that they do not have the opportunity to participate more in providing care. An open dialogue and an agreement on how to share local and long-distance caregiving are essential.

Many residential communities for seniors are owned and operated by faith-based or other organizations with which your parent may feel an affiliation or interest. Ask your parent if they know of any friends who have moved to these new communities, and find out if your parent would be interested in being in the same community. Before any decision is made, visit more than one community with your parent, ask to join the community for lunch and get a facility tour, view the activities schedule and menu, and take particular note of how the staff interacts with the residents. Ask the community employees how they might accommodate your parent's interests, hobbies and transportation needs. If the community under consideration is a category of licensed facility, ask to view the facility’s compliance history with minimum standards, and the number and types of complaints that may have been filed against the facility.

The following list outlines different types of living arrangements that may be appropriate for your parent. Each community offers different choices. Remember, Medicare does not usually cover these expenses.

Other options . . .

- **Living Independently:** Most people prefer to remain in their own homes if possible. Sometimes resources in the community such as meal delivery service, "friendly visitors," housekeeping, transportation or other in-home assistance provide enough support so your parent can remain at home, in familiar surroundings. Keep in mind, though, that it can be a hard sell for your parent to accept this kind of help if he or she feels you are meddling and the assistance is unneeded. These issues must be addressed in a family meeting. A small apartment, condominium or one-story house in their community or close to you might also be feasible, with help and check-ins from family. Sharing an apartment or house with a friend or relative could be another possibility. There are agencies in some cities that help arrange shared living situations. A newer option, called Naturally Occurring Retirement Communities (NORCs) or Villages, offers members—generally a group of older people whose homes are in
close proximity—vetted services such as home repair, transportation and social/educational activities. There is a fee to join and the organization is directed by volunteers and/or paid staff. This is a growing movement across the country, and for some people, this is enough support to allow them to remain in their homes.

- **Retirement Community:** Independent retirement communities usually offer individual apartments in a multi-unit setting, with group meals, transportation, housekeeping services and numerous organized social and enrichment activities. Residents are free to come and go as they please and still retain their privacy, yet have the benefits of a larger group setting. Amenities and prices vary from place to place. Some offer access to a nurse or nurse practitioner. As care needs increase, additional services (e.g., help with dressing) often can be added for a fee. Some communities require that new residents be ambulatory (not in a wheelchair) at admission. Some places offer subsidized housing for low-income individuals, with stringent limitations.

- **Residential Care Facility (RCF):** These facilities are small group homes (sometimes called board and care homes or adult foster home) that provide supervision, meals and care for people who cannot be left alone but do not require skilled nursing care. Residential care facilities provide assistance with bathing, grooming, eating, using the toilet, and walking, and they also provide socialization and recreational activities. Rooms may be private or shared.

- **Assisted Living Facility (ALF):** Individuals who are somewhat independent but require daily oversight and assistance with housekeeping, medication management and personal care will want to consider an assisted living facility. Assisted living facilities offer rooms or apartment-style accommodations and, often, social activities. Meals are provided in a shared dining room. Staff is available to assist with care needs such as bathing, grooming, eating or using the toilet, and care is arranged as needed by the individual. Medical staff may be on-site or on call. The monthly charge for assisted living is determined by how much care a person requires and varies widely throughout the US. Some assisted living facilities are dedicated to—or include a separate wing for—those with Alzheimer's disease or other memory impairments. These "dementia care" or "memory care" units offer a special security-protected environment, and social and other activities designed for the abilities of the residents.

- **Intermediate Care Facility (ICF):** This type of facility provides 'round-the-clock care for those who require help with bathing, grooming, going to the toilet and walking. Individuals in these facilities cannot live independently and require nursing care, although the nursing care is not offered 24 hours a day. Residents generally require a lower level of care than is offered in skilled nursing facilities.

- **Skilled Nursing Facility (SNF):** Commonly called nursing homes, these facilities provide nursing services 24 hours a day and are designed to provide high levels of personal and medical care, such as administration of injections, monitoring of blood pressure, managing ventilators and intravenous feedings to individuals who cannot function independently. People living in skilled nursing facilities
usually require help with the majority of their self-care needs; it would be very difficult to provide this level of care in a home environment. Medicaid (Medi-Cal in California) may help cover the costs if residents meet specific financial and medical requirements. Medicare may pay for a time-limited stay after hospital discharge, on a doctor's orders.

- **The Eden (or Greenhouse) Alternative** is a program in certain nursing facilities around the country to make the environment more elder-centered and less institutional. These are set up to encourage as much independence and interaction as possible for the residents, and to be more home-like. Contact with plants, animals and children is encouraged.

- **The Program for All Inclusive Care (PACE)** is designed for people 55 years or older certified by the state where they reside to be nursing-home-eligible, but who can remain at home with a complement of health and supportive services. Sometimes referred to as a "nursing home without walls" this growing care option is available in many, but not all, parts of the country. Most participants are Medicaid-eligible.

- **Continuing Care Retirement Communities (CCRCs)** (sometimes called "Life Care") offer independent, assisted and skilled nursing facilities all in one location. If a person's health deteriorates, a disruptive move to a new community is not necessary. These communities often can be quite large and generally require a substantial entrance fee.

- **Veteran's Communities** may be available in your state, and offer multiple levels of care. From independent living with supportive health and social services, to skilled nursing facilities, these communities permit a veteran (or their spouse) to live in the same community.

Regardless of the type of facility you choose, be sure to visit each one. Don't be shy about asking a lot of questions. A preliminary visit should reveal a facility that is clean, smells pleasant, has staff actively but gently interacting with residents, and in which the residents are satisfied with their "home."

**When Your Parent Moves in with You**

**Change of Family Roles.** If you and your parent decide the best place for your parent is in your home, understand that living with a parent most likely will lead to a shift in family roles. A once-authoritative parent may become more dependent—you may become the guardian who gives direction and controls many aspects of your parent's life, while trying to preserve as much autonomy as possible for your parent. You may have less time for your spouse and for yourself. You may need your children to help with more household responsibilities including care of their grandparent. These role changes can be hard adjustments for everyone.

- Determine your ease with becoming the decision-maker and the person with authority.
- Be prepared for resistance from your parent if they feel that they can no longer set the rules, control their situation or fear losing independence, but make sure
your parent is involved in the decision-making process and that their perspectives and preferences are heard.

- When possible, allow for negotiation in decision-making activities offering a greater chance for a win-win situation.
- Consider how your parent can contribute to the household, such as babysitting, doing light chores or making financial contributions.
- Think about your spouse’s and children’s readiness to help with caregiving, and their comfort level with having a grandparent in the home—particularly if he or she suffers from dementia.
- Think about ways in which your parent’s traditional interests, routines and food preferences can be accommodated, without unnecessarily disrupting your own lives.
- Agree upon financial arrangements up front. Given available resources, will your parent be able to contribute towards food and utilities?
- If you have siblings or other family members with whom your parent is comfortable, can you agree in advance that they can stay with your parent, or accommodate your parent temporarily in their home so you are able to get a break from caregiving or take a vacation?

**Lifestyle Changes.** You and your parent probably have very different lifestyles. Sleeping cycles, eating patterns and preferences, social calendars, interests, and daily activities may need adjustments in order to guarantee a smooth transition.

- Talk about and plan how to accommodate bedtimes, nap schedules and sleeping habits of all family members in the house.
- Discuss what types of food you eat, when meals are prepared, and if special diets are required and how they will be accommodated.
- Assess whether smoking/nonsmoking or drinking/nondrinking practices are compatible.
- Consider how you can support your parent’s continued participation in social networks such as visiting friends and attending a place of worship and how transportation to these and other activities will be managed.
- Encourage your parent to keep enjoyable and safe hobbies.
- Consider whether your parent will be fully integrated into your family’s activities or whether he/she will maintain an independent social life.
- Consider how the household noise level and general activity pattern will affect your parent.

**The Loss of Your Time.** Caregiving requires a significant amount of time and is very likely to impact your work, family time, personal time and sleep.

- Determine the amount of time you can devote to your parent’s care needs. When will you make phone calls for appointments or to set up needed services? When will you be able to take your parent to medical appointments?
• Evaluate whether you will need to make adjustments to your current work schedule and if your employer is willing to accommodate those adjustments.
• If you will reduce your work hours, determine the implications for your financial picture, career advancement, health insurance and Social Security and retirement benefits.
• Consider whether you will have time for your spouse, children and friends.
• If your parent requires full-time supervision, who will provide it while you are at work or attending your children’s activities?
• Consider the reduced private time you will have to pursue your own friendships, hobbies or exercise, and your need for some time alone on a daily basis.
• Expect that you will, at times, feel your energy is spent and will need to find a way to rest.
• Investigate how to arrange for some time off from caregiving duties (“respite”) and enlist the help of your family members, friends, a paid aide or a home care agency.

Your Home. Physical living arrangements must be adequate if your parent is to move in. There must be enough room and a layout that is adaptable to an older adult who may have mobility or vision problems. A home may require special adaptations to make it safe. Many of these changes are inexpensive but need time and planning to implement. Some families consider an addition to their home or the use of an "accessory apartment" (or "accessory dwelling unit")—a fully equipped modular unit that may be temporarily or permanently set up in the yard or elsewhere on a lot. Home health agencies and/or area agencies on aging may have the resources to do a home assessment in terms of home modifications, and safe lift/transfer techniques that are recommended to better assist your parent.

• Evaluate the amount of available space and whether there is enough privacy.
• Think about where your parent will sleep. How will a child feel if he or she has to give up a room for a grandparent?
• If possible, locate your parent on the first floor in order to avoid stairs.
• Consider major changes that may be needed in order to accommodate any disabilities or mobility problems, for example wheelchair-accessible bathroom and shower, different door handles, lower light switches.
• Determine what assistive devices may be needed such as grab bars in the bathroom, raised toilet seats, handrails and a ramp.
• If your parent wanders and is at risk for becoming lost, consider special locks, door chimes and other devices that will help keep doors and windows safely secured.
• Look through your home for hazards such as dangling cords, toxins, slippery surfaces, unsteady chairs, throw rugs. Consider installing a stove-top shut-off device.
• Install bright non-glare lights above all walkways, and low-cost adhesive strips on steps and other potentially slippery areas such as bathrooms and showers.
• Adjust temperature controls so that the house is not too hot or too cold. Be aware that older people often like their environment warmer and this may affect both your comfort and your utility bills.
• Discuss how you might incorporate your parent’s furniture into your home.
• Review how existing or new pets will be integrated into the new home situation.
• Think about having a system or alarm set up so you can be alerted when your parent needs help.

Financial Arrangements

Individual financial information may not typically be shared among your family members. However, if you are caring for a parent it may become necessary for you to become more involved in his/her personal finances, including paying bills, monitoring accounts and managing retirement accounts or investments. This can create problems with your parent or siblings who may question your access to and how you are handling your parent’s money.

• Agree upon how much, if any, financial payment your parent will provide towards their living expenses. Will they pay for rent, food and other costs?
• Your siblings may be resentful of any money you might receive. Openly discuss financial arrangements with siblings to keep them updated on new expenditures and apprised of accounts.
• Come to an agreement between your parent and siblings regarding out-of-pocket expenses.
• Consider preparing a formal legal document called a Personal Care Agreement describing any payment to you from your parent for accommodations or your caregiving services.
• To save time, investigate the option of automatic payment of recurring bills.
• Look into free or low-cost services that assist with Medicare paperwork for older adults.
• Be sure such legal documents are in place such as Durable Power of Attorney, Representative Payee, Advanced Directives, (See Resources section for the Fact Sheet Legal Planning for Incapacity.)

Managing the Move

It is likely that your parent has lived in his or her current home for many years and has developed strong ties to community, family, friends, healthcare providers, social life and daily routine. Packing and moving out of a house is a significant chore for anybody, but for the older adult who has decades’ worth of memories and possessions, moving can represent a tremendous emotional challenge. Moving away from this familiar and comfortable setting is difficult and can cause great sadness. Furthermore, leaving one’s own house represents a decrease in independence and signals a new life stage. Often the
thought of packing and sorting decades of history, memories and possessions is daunting enough to delay even considering the difficult decision to relocate. But there are some resources to help.

In some communities, there are specialized companies that will, for a fee, help organize a senior’s move to a new location and arrange to sell or give away unneeded furniture and possessions. They will also help pack and unpack. Regardless of services used, in most families the adult children still play key roles in this task. Open communication will help ease the way through these challenges.

While you help your parent pack, talk through the difficult feelings, acknowledge the loss that your parent is experiencing and reassure him/her that you are all making the best decision possible. Allow time and opportunity to reminisce. Reassure your parent that you will still be involved in their life regardless of their living arrangements—even in a new community you will want to ensure that the quality of care are services meet your parent’s needs.

If your parent owns the home, consider renting it to tenants. The rental income can help defray extra costs that the family may incur, or help pay for the care provided in other community settings, and offer certain tax benefits. In addition, renting the home, rather than selling, can also give your parent a longer transitional period to adjust to new living arrangements. Selling a long-time residence can seem very final, and can add an extra dimension of anxiety to the transition.

Your parent will need time to adjust to his/her new living environment and role with your family. Your patience and support will help make this transition smoother. An outside counselor may also be helpful.

Rewards
Despite the challenges, many adult children find that providing support and care for their parents is one of the most rewarding experiences they have ever had. Parents can contribute to the family through sharing their past and become an integral part of your household. Grandchildren have the unique opportunity to learn and absorb family history. Caregiving carries with it the extraordinary opportunity to give back what your parent once provided to you.

Recommended Reading

_Elder Care Made Easier_. Somers, M., 2006, Addicus Books.


Holding a Family Meeting

By Family Caregiver Alliance

When taking care of an elderly parent or another relative, family members need to work cooperatively. The more people participating in care, the less alone a caregiver feels in his/her role. Books and articles about caregiving often mention the family meeting as a way to facilitate this process. But how does one go about having such a meeting?

Who Should Attend?

Each family is different. In some families, only a husband/wife and their children are considered “family.” In other families, aunts, uncles, cousins, current and ex-in laws, and close friends may be included in the definition of family. When planning a family meeting, it is important to include everyone who is or will be part of the caregiving team, and this may include a family friend, neighbor, or paid caregiver.

It is also sometimes helpful to engage the help of an outside facilitator, such as a social worker or minister, to help the family communicate about difficult subjects during the meeting. (This is discussed in more detail below.)

A decision must also be made about whether or not to include the ill family member in the meeting. Family members usually do not want to be excluded from family events, and their preferences for care must be considered. However, if someone has dementia or another condition where he/she might misunderstand the purpose of the meeting, it might be appropriate to hold at least the first meeting without him/her present. Also, other family members may need to share with each other thoughts or feelings that would be painful for the ill person to hear. Consider holding one meeting to focus on those matters, and holding a second meeting with the ill person present.

How Should We Begin?

Communication is the key to working successfully with a group of people. If it’s difficult for some family members to travel to the location of the meeting, technology can help: a conference call or the use of a speaker phone can make it easier for them to participate. A videotape or an audiotape of the meeting can also be sent out to all family members who are unable to attend. With the use of email, even those who are not nearby can also be kept up to date on how things are going.

Prior to a meeting, you’ll find it helpful to prepare an agenda. Someone in the family will generally introduce the idea of a meeting and arrange the date and location. That person can also create an agenda for the meeting and send it out to all the family members ahead of time. Family members can then share their ideas and suggest other items to include.
An agenda might include topics such as:

- The latest report from the physician
- Sharing of feelings about the illness/caregiving
  - Fears:
    - About death and dying
    - About being overwhelmed
    - About what will happen to family members after the death
  - Sadness, confusion, anger, guilt, shame
  - What does the person who is ill want and need?
- Daily caregiving needs:
  - Should the sick person move in with us?
  - Does she/he need to be in an assisted living facility or nursing home?
  - How much time does each family member have to visit?
  - Other ways each person can help? What other help might be available?
- Financial concerns in caregiving:
  - How much will it cost?
  - How much work can family members afford to miss?
  - What financial help might be available from outside?
- Who will make decisions (e.g., financial, medical, hiring a caregiver, etc.) and how will they be made?
- What support role does each person want to play?
- What sort of support does the primary caregiver need?
  - Need for respite (a break from caregiving)
  - Help with meals, shopping, cleaning, laundry, etc.
  - Emotional support by telephone or email
  - Help with chores—i.e., taking the care recipient to doctor’s appointments
- How will the caregiving and support needs change as the illness progresses?
- Problem solving
  - List of tasks that need doing
- Summary of meeting and schedule for next meeting
  - Written summary of what each person has agreed to
  - Email or telephone tree for regular updates

It will probably be difficult to cover all these issues in one meeting, so additional meetings will be helpful. Each ensuing meeting should have a clear timetable and a definite beginning and ending time. Be sure to stick to the time table; if meetings get to be too long, fatigue sets in, minds will wander, and people may resist coming to future meetings.
The Meeting
As with all high-level negotiations, deciding where to hold the meeting is as potentially controversial as the meeting itself. Whether you hold it in an office, a restaurant, or someone's home, keep in mind that you want a setting that the majority of the participants will find comfortable and convenient and that presents as few distractions as possible (e.g., noise, small children who need attention, etc.).

A successful family meeting gives everyone a chance to be heard. All feelings are appropriate and need to be expressed and acknowledged. People will be more willing to talk about their feelings regarding the situation if they feel safe. For example, the brother who is never present may reveal that he is unable to stand seeing someone sick, and the sister who is doing all the work may not realize how she pushes others away when they offer to help. Another sibling may be having marital problems that he or she has not yet shared with the family, and yet another sibling might be worried about losing a job. Each person needs to balance his/her own fears, concern, love, and desire to help with available time, strengths, weaknesses, and hopes.

Until the depth and breadth of the issues concerning the ill family member are explored, it is important to not try to solve the problems. Recording the problems in a list as they are shared, however, will be useful during the problem-solving portion of the meeting.

It is important for each family member to learn to use “I” messages, as well to say “I need...” rather than “You should...” Even when disagreeing, try to find the part of what is said that you can agree with. The goal of the meeting is to work as a team in caring for the person who is ill, even if there is conflict among family members in other areas.

At the conclusion of the meeting, make sure everyone has a clear understanding of the issues and considerations discussed. When the solutions to issues have been established, make sure that each person understands what he/she has agreed to do.

The most important thing for family members to remember is that the meeting is not a one-time event. Family meetings need to take place regularly. It is helpful to schedule them at a given time, perhaps at the same time each month. However, if this is not possible, they at least need to take place when the caregiving situation or other situations in family members' lives change. Holding regular meetings puts less pressure on family members to get everything resolved in just one meeting, and allows more time for processing of information and decision-making. When a family member is unable to attend a meeting, keep in touch with them by phone, mail, or email.

Potential Challenges
Families come with history: a history of how each person relates to the others, a history of what role each person has played and currently plays within the family, a history of how each person feels toward the person who is sick, and a history of how each person deals with illness and adversity. And in each family there are rules about what can and cannot be said, what emotions are okay and not okay to express. These factors can make family meetings difficult. This is why a third party facilitator can be helpful.
Family members play roles based on position in the family, relationship to the person who is ill, special talents, etc. The person who is the caregiver may be different from the one who handles the money, who may be different from the person who is the information gatherer, who is different from the one who is the decision maker or the one who has some medical background. One person might play several roles. Also, often someone is the “blamer,” and someone else the “blamed.” One person may try to make peace, and another may try to sabotage the process. There will be secrets, old family rivalries, guilt, unequal burdens, differing investments, values, and interests. Some will worry about past promises and about someone else not pulling his/her own weight. Everyone will need attention, power, love, control, and appreciation. It can help to acknowledge that there is probably no fair distribution of work and trying to make it even will fail.

A narrow focus for each meeting can help alleviate some of the pitfalls. Still, you will have to deal with some of the difficult issues when they get in the way of cooperation. Remember that you can't resolve long-standing family issues with one such meeting. The task is not to “fix” the family, but rather to have everyone on the same team, as much as possible, in caring for someone who is ill.

If alcohol will detract from the main focus of the meeting or will lead to conflict, it is better not to offer it. However, each family has different ways of communicating, and in some families a drink may make everyone more comfortable and more able to talk. In any case, overconsumption should be avoided.

Win/Win Situations
Consensus: Not all the issues inherent in caregiving and decision-making can be solved; sometimes it is important to accept approximations of a good solution. Try to work toward consensus building. Change happens slowly, but when families meet regularly, the seeds that are planted can grow into more productive solutions. Often things do not change until there is a crisis, but the work that has been done during the family meeting will make decision-making easier when the crisis does come. Agreements can be made on a time-limited basis to see if the agreed-upon action will work. Future meetings can be used to evaluate these trials and revise them as necessary.

Respecting each person's individuality and situation helps to create an atmosphere of acceptance and allows for creative solutions to problems. For example, Carol finds it difficult to be around sick people, so when her brother got lung cancer, she knew she couldn't take care of him. However, she was more than willing to make the pastas of their native Italy and take them to him to comfort him during his illness. Jesse lives a thousand miles away, but can get time off from work to be with her mother while her brother and his family take a vacation. When Ed's mother had surgery, Ed arranged to take care of his father with Alzheimer's, while his sister worked full time and helped with the expenses. Gina takes her parents to medical appointments while her sister makes sure they get their medicines properly every night.

Compromise: In order for these solutions to work, people have to learn to compromise. By being open to alternatives, you might get part—although maybe not all—of what you want or need. We often hold out for only one solution to a problem, we don't consider
other possibilities that could assist us. Asking for help is one of the hardest things to do. Learning to graciously receive help offered can also be a struggle, not only for the person who is sick, but also for the person who is the primary caregiver. Being appreciative is the best reward you can give someone who is trying to help you, even if the type of help he/she is offering isn’t exactly what you wanted. When you make someone feel good about helping, he/she will want to help again. “Thank you” will take you a long way in working together. In creating the caregiving team, think about how each person should be acknowledged.

Put it in writing: A written agreement capturing the decisions and agreements made at the end of the meeting can be a helpful reminder for family members. Distributing a calendar with different days marked with responsibilities and commitments can also help each person honor the agreements made.

When Do You Need Outside Help? Where Can You Get It?

Although family meetings can be powerful and effective ways to connect and work with family members, they cannot magically solve all the problems of caring for an ill family member. When families have trouble working together or coming to agreements or when the family is divided on a big issue, it often helps to invite a neutral outside facilitator to attend. Sometimes a crisis precipitates the need for a meeting—perhaps someone is in the hospital and major life and death decisions need to be made. Time can be of the essence. Whatever work you have done together earlier will help you at these times of extreme stress.

Social workers from local caregiver organizations (such as Caregiver Resource Centers in California), as well as ministers, private case managers, social workers in home health or hospice, physicians, and discharge planners in hospitals and nursing homes can help facilitate a family meeting or refer you to someone who can. Psychotherapists in private practice are trained in family counseling. If you find yourself in a difficult position, you might also want to see a psychotherapist privately. Don’t forget the support you can find with friends, colleagues, and support groups. Sharing experiences with other caregivers can help ease the feelings and frustrations often involved in being a caregiver.

Identify and Resolve 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 it can be for the family caregiver, 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 section provides an overview of areas of potential conflict and methods for resolving conflict when it occurs.

Identifying Common Areas of Potential Conflict:

- **Health Care Decisions**: Who should provide care and what care is needed? Who should make medical decisions?
- **Financial Decisions**: How should money be spent? Who should have oversight of finances? How will concerns over “unwise spending,” etc. be handled?
- **Living Arrangements**: Where? With whom? Who decides? How much independence/supervision is needed? What about costs?
- **Communication Issues**: What information is needed or missing? Where are the important papers? Who has legal authority to access information? How will information be shared with those who need it?
- **Family Relation Issues**: How should the family deal with sibling rivalries, new spouse or companion, death of a spouse/caregiver, other changes in the relationship?
- **Legal Decision-Making**: Who should have authority to make decisions — one person or joint decision making? What input should others have? Does care receiver have the mental capacity to contribute in decision making and how can that input be obtained?
- **Household Care and Maintenance**: What services/assistance is needed and how frequently? What options are available for ongoing assistance and how much does it cost? Is there money available or is public assistance needed?
- **Safety/risk taking/autonomy**: What safety issues or concerns are identified? Is the level of risk understood and acceptable? If not, what action is needed and by whom?
- **Respite Care and Support for Family Caregiver**: What services are needed and available to support the family caregiver? Can family members and friends be involved to contribute? What resources are available to pay for services?
- **Needs of Other Family Members/Care Receivers**: Are there other care receivers such as dependent children, grandchildren or live-in siblings that rely on family caregiver?
Resolving Conflict
Sometimes it is hard to see another’s point of view, particularly in family situations where strong emotions are in play such as family caregiving. The following tips and techniques can assist to address conflict in a positive way and minimize or reduce stress.

Negotiation: Negotiation is the most basic means to resolve conflict. It is back and forth communications between parties of conflict with the goal of working toward finding a solution. Key elements include:

- Allowing each one to verbalize without interrupting and affirm you hear what they are saying.
- Repeating back to them what you think you hear them saying to make sure you understand their position.
- Focus your agenda on the issues that need to be resolved for care. Don’t discuss too much in one meeting. Set additional meeting for other issues, if necessary.
- Keep the agenda focused and bring conversation back when it goes into destructive conversation.
- Separate the person from the problem. Look at the problem objectively and if blaming starts, refocus to affirm what problem you are there to resolve.
- Keep focused on planning for future and leave past problems out of it.
- Role reversal can be useful to see problems from a different point of view, asking the person pretending to be someone else, what is of importance to them and what makes them feel as they do.
- Gathering more information and/or resources can sometimes be useful when making a decision. Figure out how to get the information, who will get it and how will it be shared.

Mediation: Mediation is a voluntary process in which an impartial person (the mediator) helps with communication and promotes reconciliation between the parties which will allow them to reach a mutually acceptable agreement. Mediation is often the next step if negotiation proves unsuccessful.

- In mediation, the mediator manages the process and helps facilitate negotiation between the parties. A mediator does not make a decision nor force an agreement. The parties directly participate and are responsible for negotiating their own agreement.
- At the beginning of the mediation session, the mediator will describe the process and ground rules. They use a process that is fair and unbiased. Mediation helps each side to better understand the other’s point of view. Most people uphold a mediated agreement because they were part of the making of it.
• For help mediation in Pima County, Our Family Services (520) 323-1708 ext. 504 offers an Eldercare Mediation service. Each family member is given the opportunity to be heard and, if possible, a care plan will be created. There is a fee for this service. The Pima Council on Aging Family Caregiver Support Program (520) 790-7262 offers informal support to family members who may not be in agreement, and need assistance prioritizing needs and making plans. There is no fee but donations are gratefully accepted.

Source: Public Domain
It’s important to take a break from caregiving responsibilities from time to time to avoid caregiver burn-out. Respite is defined as a period of temporary rest or short-term relief from caregiving. Respite care can be provided by a friend, family member, home health agency, or day respite program to provide you with the breathing space you need.

Benefits of Respite:

- Reduce caregiver stress
- Improve physical and emotional health
- Improve ability to continue being a caregiver
- Helps caregivers maintain own identity and not get lost in their caregiving
- Might prevent or delay out of home placement of care receiver
- Many care receivers are comforted knowing the burden of caregiving is lessened some with breaks.

In-Home Respite

Some families have a number of family members who can give a few hours here and there to stay with the person cared for while the caregiver takes a break. However, commonly that is not the case. If family and/or friends are not available to provide periodic breaks, Family Caregiver Support Programs in every state offer in-home respite for low or no cost and some programs use a sliding scale. First, an assessment is done of the caregiver and care receiver to make sure they meet qualifications. Once qualified, respite care is usually provided by an in-home care agency for a few hours, perhaps a few times per week.

To see if you qualify, call Pima Council on Aging, Family Caregiver Support Program (520) 790-7262. Outside of Pima County, another respite program available statewide in Arizona is through Arizona Caregiver Coalition. Their number is: (888) 737-7494. To explore respite care anywhere in the U.S., call the ElderCare Locator at (800) 677-1116 or visit www.eldercare.gov.

Adult Day Care Respite

Adult day respite services provide participants a safe and stimulating environment, while offering respite and support to family caregivers. Caregivers can drop off their loved one at a day respite center and then pick them up later in the day. Most day respite services offer a free day and lunch to try out the program and make sure it fits with what you and your loved one needs. Most locations offer a variety of activities to promote socialization, as well as healthy living programs. Cost can vary from free to sliding scale. To see if you qualify, call Pima Council on Aging, Family Caregiver Support Program (520) 790-7262 for a free assessment and list of day respite facilities. The Veterans Administration also provides respite services. Contact them at: (520) 792-1450. Outside of Pima County, another respite program available statewide in Arizona is through Arizona Caregiver
Coalition. Their number is: (888) 737-7494. To explore respite care anywhere in the U.S., call the ElderCare Locator at (800) 677-1116 or visit www.eldercare.gov.

It’s also a good idea to think about who can provide care to your loved one 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? Family caregiver specialists at PCOA can assist you in exploring options and provide useful information as well as support. You are not alone. Call PCOA at (520) 790-7262.